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LONG-TERM CARE AFTER OLMSTEAD: AGING AND DISABILITY GROUPS SEEK COMMON GROUND

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BEFORE THE

SPECIAL COMMITTEE ON AGING
UNITED STATES SENATE

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LONG-TERM CARE AFTER OLMSTEAD: AGING AND DISABILITY GROUPS SEEK COMMON GROUND

MONDAY, SEPTEMBER 24, 2001

U.S. SENATE,
SPECIAL COMMITTEE ON AGING,
Washington, DC.

The committee met, pursuant to notice, at 1:02 p.m., in room SD–192, Dirksen Senate Office Building, Hon. John B. Breaux (Chairman of the Committee) presiding.

Present: Senators Breaux and Craig.

OPENING STATEMENT OF SENATOR JOHN B. BREAUX, CHAIRMAN

The CHAIRMAN. The Committee on Aging will please come to order.

I want to thank all of our guests who are here with us today for what I consider to be a most important hearing, and our ranking colleague, Senator Craig, for being with us as well.

The events of the past 2 weeks have given all of us reason to think about what we believe in and what our country stands for. As Americans, we of course believe in personal liberty and freedom, but we also recognize the rule of law. As individuals, we are very proud of our independence and our self-reliance, but we are also very grateful for the comfort and support of our families and friends.

As a society, of course, we also believe in the value of private enterprise, but we also know that Government plays a very important role in protecting our liberties and also safeguarding and helping to improve the quality of our lives. These traditional American values have carried us through very difficult times before and will do so again.

But today we also continue the business of Congress and the work of this Aging Committee. These traditional values are especially relevant to the issues that are before the committee this afternoon.

This is the third of a series of hearings that this committee has held in which we continue to examine the need for reform of our long-term care system in this country. In one sense, the witnesses who appear here today will help us to do that by interpreting law, by analyzing statistics, and by providing us with recommendations based on their professional as well as personal experiences.

But in a deeper sense, the message that they bring us also reflects traditional American values. Older Americans in every part of our country want to prolong their independence and also their freedom. They want to live in familiar communities and surroundings and in the company of family and friends.

To help them achieve those goals, we need to build new partnerships that combine the resources of private enterprise and of Government; and we need to remember that the functional limitations associated with aging are a form of disability and that we can draw upon the independent living skills learned by individuals who have developed disabilities caused by chronic or catastrophic illness or even mental illness.

I would like to recognize Senator Larry Craig for any comments that he might have.

OPENING STATEMENT OF SENATOR LARRY E. CRAIG

Senator CRAIG. Mr. Chairman, again let me thank you for calling this third hearing in our series on long-term care.

I would also like to thank the witnesses from whom we are about to hear for being here today to testify on long-term care after Olmstead, aging and disability groups seeking the kind of common ground that I think the chairman has just spoken to.

Over the past months, we have examined many aspects of long-term care. I think we have gained an understanding of the immense challenges facing our system in the coming years. We have discovered innovative ways that States are preparing their systems. With this last hearing, we hope to learn from the experiences of the disability community so we can build a foundation for working together.

People with disabilities have been receiving services in the home and community setting for many years. It is appropriate for older Americans to look to this group for guidance for effective ways to deliver quality care to individuals.

One of the ways the disability community has been receiving these services is through private-public partnerships, and I am especially excited to hear about these types of approaches.

Through this series of hearings, we have learned invaluable information about our Nation's long-term care services, and the chairman and I will now be working together to evaluate this information and looking to construct legislation to make long-term care systems more adaptable to a changing society. That certainly is our goal, and to ensure accountability and high-quality care while doing this.

Again I want to thank the witnesses and the chairman for this hearing.

Thank you, Mr. Chairman.

The CHAIRMAN. Thank you, Senator.

We would like to welcome our panel this afternoon. We would like to welcome Ms. Kathryn Allen, who is Director of Health Care, Medicaid and Private Health Insurance Issues, with the General Accounting Office; Ms. Sara Rosenbaum, who is Director of the George Washington University Center for Health Services Research and Policy here in Washington; Dr. Jane Isaacs Lowe, who is Senior Program Office at the Robert Wood Johnson Foundation at

Princeton; and, from my State of Louisiana, the Director of the Louisiana Governor's Office of Disability Affairs, Ms. Laura Brackin. Thank you, Laura, particularly for coming up; I know that we have all had to rearrange things because of the circumstances in the country. And to all of you, we deeply appreciate your being with us and look forward to your testimony.

Ms. Allen, thanks for the good work that GAO has done. I note that you have an over-20-page document that you have presented to us. I would encourage all organizations to take the opportunity and time to review it; it is an excellent summary of what has happened since Olmstead. We would ask you to summarize it, and please begin.

STATEMENT OF KATHRYN G. ALLEN, DIRECTOR, HEALTH CARE, MEDICAID AND PRIVATE HEALTH INSURANCE ISSUES, U.S. GENERAL ACCOUNTING OFFICE, WASHINGTON, DC

Ms. ALLEN. Thank you, Mr. Chairman and Senator Craig.

It is a pleasure to be here today as you continue this series of hearings on long-term care, and with today's focus particularly exploring implications of the Supreme Court Olmstead decision in addition to other issues.

What I would like to do is focus my remarks on three brief points—highlights of the decision itself in terms of the Olmstead case; an overview of current and future demand and financing of long-term care services in which the Olmstead decision will have some effect; and finally, implications of the decision for State long-term care programs.

The 1999 Olmstead decision has been widely interpreted as actually going far beyond the specific circumstances of the case that was heard. This particular case involved two women with developmental disabilities and mental illness who were inpatients in a State psychiatric hospital and whose physicians had determined that a community-based setting would be appropriate for their needs.

The Supreme Court concluded that in order to avoid violating Title II of the Americans with Disabilities Act, ADA, States would be required to provide community-based treatment for persons with mental disabilities when three conditions are present—that treatment professionals determine that such placement is appropriate; that the affected persons do not oppose such treatment; and that the treatment can be reasonably accommodated taking into account the resources available to the State and the needs of others with mental disabilities.

Beyond the specific circumstances of this case, the Olmstead decision is being interpreted to extend to persons with physical as well as mental disabilities, to those in nursing homes and other institutional settings in addition to psychiatric hospitals, and to those who already live in the community but are at risk of institutionalization.

As such, it carries broader implications for the provision of long-term care, not just for persons with disabilities who currently need services, but also for the expected changes that loom on our horizon.

Without question, the approaching tidal wave of aging baby boomers will generate new demand for long-term care services that will increasingly tax our capacity, that of public and private resources. Although a chronic physical and mental disability can and does strike at any age, whether child, young adult or senior, the risk of developing a disability increases as a person ages. As a result, the number of disabled elderly individuals who will need care by the year 2040 is projected to be two to four times the current number.

There are scores of Federal programs that support persons with disabilities. We counted about 70. But implications are most profound for Medicaid, with its open-ended commitment to serve eligible persons. Medicaid is now the primary public payer for long-term care. It paid about 44 percent of the $134 billion spent nationwide on long-term care in 1999 for both institutional and home and community-based services. How Medicaid serves individuals with disabilities, however, varies widely from State to State.

States have considerable flexibility to decide within broad Federal guidelines who and what services they will cover and in what settings. While historically, Medicaid programs have been viewed as being slanted toward institutional care, spending for home and community-based services has increased more than fourfold over the past decade, from $4 billion to over $18 billion last year.

But these are still optional services that are not federally required, so States can and do vary widely in terms of the degree to which they choose to cover these services.

With the continuing shift to greater provision of community care and the reduced reliance on institutions that actually predated Olmstead, we need to look beyond the implications for Federal programs and public programs. Individuals and their families will also certainly be impacted. Private resources that include out-of-pocket spending and insurance already make up the second-largest share of long-term care spending, about 40 percent. But this does not include the unspecified but high cost of care provided by family members and other informal caregivers.

An estimated 60 percent of disabled elderly individuals living in their own homes and communities rely exclusively on their families and other unpaid sources for their care. While the shift from institutional to in-home and community care offers many benefits and advantages for persons with disabilities, formal or paid services most often satisfy only a portion of these individuals' needs, with the balance falling to family and other informal caregivers.

My third and final point is that the implications of the Olmstead decision are still unfolding for States and their long-term care programs. Although the Supreme Court ruled that under certain circumstances, institutionally based services may violate the ADA, the Court also acknowledged that the community may not be the most appropriate setting for many individuals. It further recognized that States' responsibilities are not boundless. There are limits to what States can do given available resources and the obligation to provide a range of services for persons with disabilities.

The ADA does not require States to fundamentally alter their existing programs as they make so-called reasonable modifications to avoid discrimination. The Olmstead decision therefore leaves open

many questions for States and lower courts to resolve in determining States' obligations as to the nature and scope of their programs.

To date, most States' responses to Olmstead have focused on preparing plans that lay out goals and actions. Because most of these are still works-in-progress, it is too soon to tell how and when they will be implemented. State programs will no doubt also be influenced over time by the resolution of the many pending lawsuits and complaints that have been filed seeking access to appropriate services.

In conclusion, Mr. Chairman, we face a growing need to anticipate and plan for the inevitable increase in demand for long-term care in settings that offer both varying options and choices. This increased demand will emanate not just from the Olmstead decision but also from the needs and preferences of the baby boom generation. Finding ways to develop and finance additional service capacity that meets needs, allows choice, and leverages limited public and private resources will be the ongoing challenge for this generation, families, and Federal, State, and local governments.

Mr. Chairman, this concludes my prepared remarks.

The CHAIRMAN. Thank you very much, Ms. Allen.

Ms. Rosenbaum.

[The prepared statement of Ms. Allen follows:]

United States General Accounting Office

GAO

Testimony

Before the Special Committee on Aging, U.S. Senate

For Release on Delivery
Expected at 1:00 p.m.
Monday, September 24, 2001

LONG-TERM CARE

Implications of Supreme Court's *Olmstead* Decision Are Still Unfolding

Statement of Kathryn G. Allen
Director, Health Care—Medicaid
and Private Health Insurance Issues

GAO-01-1167T

Mr. Chairman and Members of the Committee:

I am pleased to be here today as you address challenges in providing for long-term care, in view of the Supreme Court's 1999 decision, known as *Olmstead*, that addressed issues pertaining to the setting in which a person with disabilities receives care.[1] Long-term care includes many types of services that a person with a physical or mental disability may need, and encompasses a wide array of care settings. Such care can be provided in institutional settings such as nursing homes or state psychiatric facilities, or in community settings such as assisted living facilities, adult foster homes, and people's own homes. About 80 percent of the estimated 5.2 million elderly individuals who require assistance with daily activities[2] live at home or in community-based settings, while about 20 percent live in nursing homes or in other institutions. Many people with disabilities who live outside of institutions rely on home and community-based services such as home health care or nursing services, assistance with meals or medication management, and personal care services. Many people with disabilities are elderly adults, but children and adults of all ages have diverse types of disabilities that may require long-term care services.

In *Olmstead*, the Supreme Court decided that states may be violating title II of the Americans With Disabilities Act of 1990 (ADA)[3] if they provide care to people with disabilities in institutional settings when they could be appropriately served in a home or community-based setting. While the *Olmstead* decision involved two women with developmental disabilities and mental illness who were residents of a psychiatric hospital, it has been interpreted to extend beyond these specific circumstances. This includes applicability to people with physical as well as mental disabilities, to those in nursing homes and other institutional settings in addition to psychiatric hospitals, and to those who live in the community and are at risk of institutionalization. As a result, the decision has generated considerable discussion about its implications for the provision of long-term care services—not only for people with disabilities who currently need services, but also for the growing numbers of aging baby boomers who

[1] *Olmstead v. L.C.*, 527 U.S. 581 (1999).

[2] Individuals needing long-term care may have difficulty performing some activities of daily living (ADL) without assistance, such as bathing, dressing, toileting, eating, and moving from one location to another; or instrumental activities of daily living (IADL) such as preparing food, doing housekeeping, and handling finances; or both.

[3] See 42 U.S.C. §§12131-12165.

will need care in the coming decades. In responding to these current and future long-term care service needs, much attention has been focused on Medicaid, the joint federal-state health financing program for certain low-income individuals, including the elderly and persons with disabilities. Flexibility built into the Medicaid program allows states to make many of their own decisions, within broad federal guidelines, about whom and what long-term care services to cover, and in what settings.

As part of your ongoing series of hearings on long-term care, you asked us to address the implications of the *Olmstead* decision in this larger context. My remarks today, which are based on our current and previous work[4] and on the research of others, will focus on (1) an overview of the demand for and financing of long-term care, in view of the *Olmstead* decision and the growing numbers of baby boomers, and (2) implications of the decision for state-administered long-term care programs.

In summary, the extent to which the *Olmstead* decision will dictate major shifts in long-term care services from institutional to home and community-based settings—and for whom—is uncertain. What is more certain, however, is that responses to the decision will take place in the larger context of preparing for the tidal wave of aging baby boomers who will increasingly tax the current capacity of public and private resources. This aging generation, with the associated expected increase in the numbers of people with disabilities, could increase the number of disabled elderly people who will need care to between 2 and 4 times the current number. While many public programs support people with disabilities, Medicaid is the dominant public program supporting long-term care institutional and home and community-based services, accounting for about 44 percent of the $134 billion spent for these services nationwide in 1999. Historically, Medicaid has financed long-term care primarily in nursing homes or other institutions. While Medicaid spending for home and community-based services is growing, these are largely optional benefits that states may or may not choose to offer, and states vary widely in the degree to which they cover them as part of their Medicaid programs. Consequently, the ability of Medicaid-eligible people with disabilities to access care in home and community-based settings also varies widely from state to state and even from community to community. Private resources—which include out-of-pocket spending and private health and long-term-care insurance—make up the second largest source of long-term

[4]A list of related GAO products is at the end of this statement.

care financing, comprising about 40 percent of total spending. This public and private spending, however, does not quantify the total costs of long-term care. Families play a major role in supplying services. For example, an estimated 60 percent of disabled elderly individuals living in communities rely exclusively on their families and other unpaid sources for their care.

Implications of the *Olmstead* decision—in terms of the scope and nature of states' obligation to provide home and community-based long-term care services—are still unfolding. While the Supreme Court ruled that, under certain circumstances, providing care in institutional settings may violate the ADA, it also recognized that there are limits to what states can do, given available resources and the obligation to provide a range of services for people with disabilities. The ADA does not require states to "fundamentally alter" their existing programs. The decision thus left many open questions for states and lower courts to resolve. To date, most states' responses to *Olmstead* have focused on preparing plans that lay out goals and actions for expanding home and community services for people with disabilities. The Supreme Court had indicated that such plans were a way for states to demonstrate they were making reasonable progress in changing their long-term care programs. Because most of these plans are works in progress, it is too soon to tell how and when they will be implemented. State programs also may be influenced over time as dozens of lawsuits and hundreds of formal complaints seeking access to appropriate services are resolved.

Background

The plaintiffs in the *Olmstead* case were two women with developmental disabilities and mental illness who claimed that Georgia was violating title II of the ADA, which prohibits discrimination against people with disabilities in the provision of public services. Both women were being treated as inpatients in a state psychiatric hospital. The women and their treating physicians agreed that a community-based setting would be appropriate for their needs. The Supreme Court held that it was discriminatory for the plaintiffs to remain institutionalized when a qualified state professional had approved community placement, the women were not opposed to such a placement, and the state could

reasonably accommodate the placement, taking into account its resources and the needs of other state residents with mental disabilities.[5]

The *Olmstead* decision is an interpretation of public entities' obligations under title II of the ADA. As one of several federal civil rights statutes, the ADA provides broad nondiscrimination protection for individuals with disabilities in employment, public services, public accommodations, transportation, and telecommunications. Specifically, title II of the ADA applies to public services furnished by governmental agencies and provides in part that "no qualified individual with a disability shall, by reason of such disability, be excluded from participation in or be denied the benefits of the services, programs, or activities of a public entity, or be subjected to discrimination by any such entity."[6]

Two ADA implementing regulations were key in the Supreme Court's ruling in *Olmstead*. The first requires that public entities make "reasonable modifications" when necessary to avoid discrimination on the basis of disability, unless the entity can demonstrate that the modification would "fundamentally alter the nature of the service, program or activity."[7] The second requires public entities to provide services in "the most integrated setting appropriate to the needs of qualified individuals with disabilities."[8] That setting could be in the community, such as a person's home, or in an institution, depending on the needs of the individual. For example, professionals might agree that a nursing home is the most integrated setting appropriate for an institutionalized person's needs. In *Olmstead*, physicians at the state hospital had determined that services in a community-based setting were appropriate for the plaintiffs. The Supreme Court recognized, however, that the appropriate setting for services is

[5]527 U.S. 581, 607 (1999). The Supreme Court remanded the case to the United States District Court for the Northern District of Georgia for further consideration of whether changes would "fundamentally alter" the nature of the services, programs, or activities of the state of Georgia. On July 11, 2000, the parties settled. Under the settlement agreement, the state agreed to provide both plaintiffs with community-based residential placements; individual service plans; and, in the event of institutionalization, a return to community-based treatment within 30 days of a determination that a return to residential or community-based treatment is appropriate.

[6]The ADA defines a public entity as including (1) a state or local government or (2) a department, agency, special purpose district, or other instrumentality of a state, states, or local government. 42 U.S.C. §12131(1).

[7]28 C.F.R. §35.130(b)(7).

[8]28 C.F.R. §35.130(d).

determined on a case-by-case basis and that the state must continue to provide a range of services for people with different types of disabilities.

The ADA has a broad scope in that it applies to individuals of all disabilities and ages. The definition of disability under the ADA is a physical or mental impairment that is serious enough to limit a major life activity, such as caring for oneself, walking, seeing, hearing, speaking, breathing, working, performing manual tasks, or learning.[9] The breadth of this definition thus covers people with very diverse disabilities and needs for assistance. For some individuals with disabilities, assistance from another person is necessary—direct, "hands-on" assistance or supervision to ensure that everyday activities are performed in a safe, consistent, and appropriate manner. For others, special equipment or training may enable them to continue to function independently. Disability may be present from an early age, as is the case for individuals with mental retardation or developmental disabilities; occur as the result of a disease or traumatic injury; or manifest itself as a part of a natural aging process. Moreover, the assistance needed depends on the type of disability. For example, individuals with physical disabilities often require significant help with daily activities of self-care. In contrast, individuals with Alzheimer's disease or chronic mental illness may be able to perform everyday tasks and may need supervision rather than hands-on assistance. To be a "qualified" individual with a disability under title II of the ADA, the person must meet the eligibility requirements for receipt of services from a public entity or for participation in a public program, activity, or service—such as the income and asset limitations established for eligibility in the Medicaid program.[10]

[9]Specifically, the ADA defines "disability" as (1) a physical or mental impairment that substantially limits one or more of an individual's major life activities, (2) a record of such an impairment, or (3) being regarded as having such an impairment. 42 U.S.C. §12102(2).

[10]States impose specific standards regarding who is sufficiently disabled to qualify for publicly funded long-term care. Only a subset of the population considered to be disabled within the meaning of the ADA may be affected by state long-term care programs targeted to people with extensive service needs.

Breadth of Population Affected by *Olmstead* Is Uncertain but Likely to Grow, With Medicaid the Dominant Payer

The breadth of the disabled population to whom *Olmstead* may eventually apply is uncertain. Much is unknown about the widely varying population of people with disabilities, the settings in which they are receiving services, and the extent to which their conditions would put them at risk of institutionalization. Demographic data show, however, that the response to *Olmstead* will take place in the context of significant increases in the number of people with disabilities. As the baby boom generation grows older, they are more likely to be affected by disabling conditions. Of the many public programs that support people with disabilities, the federal-state Medicaid program plays the most dominant role for supporting long-term care needs. Services through this program have been provided primarily in institutional long-term care settings, but a growing proportion of Medicaid long-term care expenses in the past decade has been for home and community-based services. At present, however, there are wide differences between states in the degree to which home and community-based services are provided. States also face varying challenges in supporting community living beyond what can be provided through long-term care programs, such as ensuring adequate supports for housing and transportation, and maintaining adequate programs to ensure quality care is provided in community settings.

Comprehensive Information on Those Institutionalized or at Risk Is Lacking

The *Olmstead* decision has been widely interpreted to apply to people with varying types of disabilities who are either in institutions or at risk of institutionalization. One reason for the uncertainty about how many may be affected is that, as the decision recognized, the appropriateness of a person's being placed in an institution or receiving home or community-based services would depend in part on the person's wishes and the recommendations of his or her treatment professionals. Another reason is that information on the number of people with disabilities who are at risk of institutionalization is difficult to establish.

Number of institutionalized individuals. On the basis of information from different sources, we estimate that the total number of people with disabilities who are being served in different types of institutional settings is at least 1.8 million. This figure includes about 1.6 million people in nursing facilities,[11] 106,000 in institutions for the mentally retarded or

[11]We earlier reported that approximately 1.6 million elderly and disabled residents were in nursing facilities in 1999. *Nursing Homes: Complaint Investigation Processes Often Inadequate to Protect Residents* (GAO/HEHS-99-80, Mar. 22, 1999), p. 1.

developmentally disabled,[12] and 57,000 in state and county facilities for the mentally ill.[13]

Number at risk of institutionalization. The number of people who are living in the community but at risk of institutionalization is difficult to establish. In an earlier study we estimated that, nationwide, 2.3 million adults of all ages lived in home or community-based settings and required considerable help from another person to perform two or more self-care activities.[14] More difficult to estimate is the number of disabled children at risk of institutionalization.[15]

Changing Demographics Will Drive Increased Demand for Long-Term Care

The demographics associated with the increasing number of aging baby boomers will likely drive the increased demand for services in a wide range of long-term care settings. Although a chronic physical or mental disability may occur at any age, the older an individual becomes, the more likely a person will develop disabling conditions. For example, less than 4 percent of children under 15 years old have a severe disability, compared with 58 percent of those 80 years and older. The baby boom generation—those born between 1946 and 1964—will contribute significantly to the growth in the number of elderly individuals with disabilities who need long-term care and to the amount of resources required to pay for it. The oldest baby boomers, now in their fifties, will turn 65 in 2011. In 2000, about 13 percent of our nation's population was composed of individuals

[12]David L. Braddock, unpublished data for 2000 from the State of the States Developmental Disabilities Project, Coleman Institute for Cognitive Disabilities and the Department of Psychiatry, University of Colorado. In surveys of state programs for people with developmental disabilities, Braddock identified nearly 35,000 people with developmental disabilities living in nursing facilities in addition to the 106,000 in state and private Intermediate Care Facilities for persons with Mental Retardation (ICF/MR) with seven or more beds.

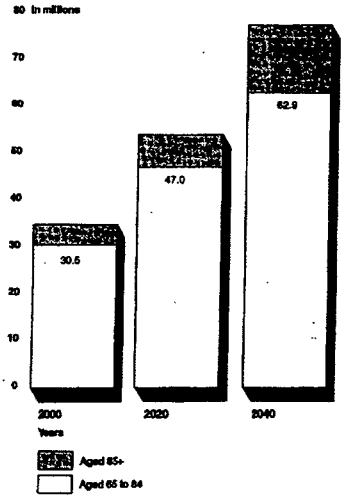
[13]*Additions and Resident Patients at End of Year, State and County Mental Hospitals by Age and Diagnosis by State, United States 1998* (Rockville, Md.: SAMHSA, Center for Mental Health Services, 2000). See also David L. Braddock, *Public Financial Support for Disability at the Close of the 20th Century*, Coleman Institute for Cognitive Disabilities and Department of Psychiatry (Denver, Colo.: University of Colorado, Aug. 1, 2001).

[14]Since there is no consensus on what constitutes a severe disability, we estimated, using National Health Interview Survey data, the number of adults who had either a lot of difficulty with or was unable to perform either three or more ADLs or two ADLs and four IADLs. See *Adults With Severe Disabilities: Federal and State Approaches for Personal Care and Other Services* (GAO/HEHS-99-101, May 14, 1999).

[15]See *Children With Disabilities: Medicaid Can Offer Important Benefits and Services* (GAO/T-HEHS-00-152, July 12, 2000).

aged 65 or older. By 2020, that percentage will increase by nearly one-third to about 17 percent—one in six Americans—and will represent nearly 20 million more seniors than there are today. By 2040, the number of seniors aged 85 and older will more than triple to 14 million (see fig. 1). However, because older people are healthier now than in the past, no consensus exists on the extent to which the growing elderly population will increase the number of disabled elderly people needing long-term care. Projections of the number of disabled elderly individuals who will need care range between 2 and 4 times the current number.

Figure 1: Estimated Number of Elderly Individuals in 2000, 2020, and 2040



Source: Bureau of the Census, "Projections of the Total Resident Population by 5-Year Age Groups and Sex With Special Age Categories: Middle Series," selected years, 2000 to 2040 (Washington, D.C.: Jan. 2000).

The changing demographics will also likely affect the demand for paid long-term care services. An estimated 60 percent of the disabled elderly living in communities now rely exclusively on their families and other unpaid sources for their care. Because of factors such as the greater geographic dispersion of families and the large and growing percentage of women who work outside the home, many baby boomers may have no option but to rely on paid long-term care providers. A smaller proportion of this generation in the future may have a spouse or adult children to provide unpaid care and therefore may have to rely on more formal or public services.

Medicaid Plays a Dominant Role in Financing Long-Term Care

Medicaid is by far the largest public program supporting long-term care.[16] States administer this joint federal-state health financing program for low-income people within broad federal requirements and with oversight from the Centers for Medicare and Medicaid Services (CMS),[17] the agency that administers the program at the federal level.[18] In 2000, Medicaid long-term care expenditures represented over one-third of the total $194 billion spent by Medicaid for all medical services. Although at least 70 different federal programs provide assistance to individuals with disabilities at substantial cost, Medicaid is the most significant source of federal funds

[16]People with disabilities generally become eligible for Medicaid through one of two routes. First, individuals become eligible if they meet a state's income and resource criteria for institutional care and are determined to require services equivalent to a nursing home level of care. This is how the elderly most often become eligible for Medicaid. The second route is through eligibility for the Social Security Administration's Supplemental Security Income (SSI) program. SSI is the federally-administered means-tested income assistance program that provides a financial safety net for disabled, blind, or aged individuals who have low incomes and limited resources. As of October 2000, 40 states provided Medicaid to all individuals who were receiving SSI payments. In the remaining states, a disabled individual's Medicaid eligibility was not automatic since these states have elected to continue using the SSI standards that were in effect on January 1, 1972, and are more restrictive than current SSI eligibility criteria.

[17]Formerly the Health Care Financing Administration (HCFA), until June 2001. We continue to refer to HCFA where agency actions were taken under its former name.

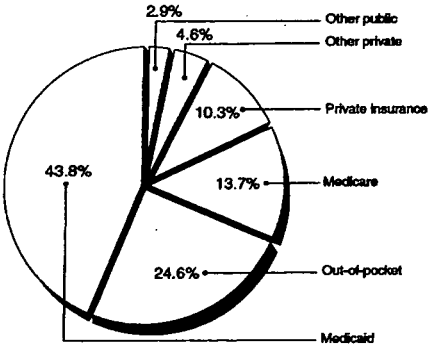
[18]Medicaid costs are shared by the federal government and states, and each state program's federal and state funding shares are determined through a statutory matching formula. The federal share of states' medical assistance payments ranges from 50 to 83 percent, depending on a state's per capita income in relationship to the national average. On average, the federal share of Medicaid expenditures is 57 percent.

for providing long-term care.[19] Earlier this year, we reported that Medicaid paid nearly 44 percent of the $134 billion spent nationwide for long-term care in 1999, including postacute and chronic care in nursing homes and home and community-based care. Individuals needing care, and their families, paid for almost 25 percent of these expenditures out-of-pocket. Medicare and other public programs covered almost 17 percent, and private insurance and other private sources (including long-term care insurance as well as services paid by traditional health insurance) accounted for the remaining 15 percent. (See fig. 2.) These amounts, however, do not include the many hidden costs of long-term care. For example, they do not include wages lost when an unpaid family caregiver takes time off from work to provide assistance.[20]

[19]Federal programs supporting people with disabilities can be categorized generally into two groups. The first group is programs with disability as a central eligibility criterion, composed of 30 programs largely providing cash benefits, with estimated expenditures totaling $110 billion in fiscal year 1999. The second group uses disability as one of many potential criteria for program participation and consists of 40 programs, including Medicaid, for which age, income, or both also serve as bases for eligibility. See *Adults With Severe Disabilities: Federal and State Approaches for Personal Care and Other Services* (GAO/HEHS-99-101, May 14, 1999).

[20]See *Long-Term Care: Baby Boom Generation Increases Challenge of Financing Needed Services* (GAO-01-563T, Mar. 27, 2001).

Figure 2: Percentage of Expenditures for Long-Term Care, by Source of Payment, 1999



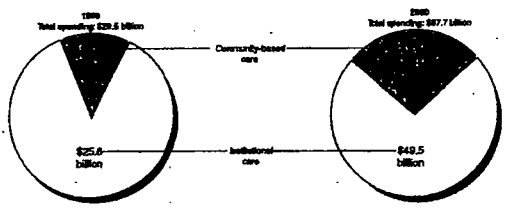
Note: Includes Medicaid expenditures for home and community-based services, which are considered as part of "other personal health care" in HCFA's national health care accounts.

Source: HHS, HCFA, Office of the Actuary, National Health Statistics Group, Personal Health Care Expenditures, 2001.

Medicaid Funding for Home and Community-Based Services Is Increasing

Historically, Medicaid long-term care expenditures have financed services delivered in nursing homes or other institutions, but the proportion of spending directed to home and community-based care has increased steadily over the past decade, as shown in figure 3. Federal and state Medicaid spending on home and community-based services was about $18 billion (27 percent) of the $68 billion spent on long-term care in fiscal year 2000.

Figure 3: Trends in Medicaid Long-Term Care Spending for Institutional and Home and Community-Based Care, 1990-2000



Source: The MEDSTAT Group, from HCFA 64 Data.

Much of the Medicaid coverage of home and community-based services is at each state's discretion. One type of coverage, however, is not optional: states are required to cover home health services for medically necessary care (see table 1). A second type of services, called personal care, is optional. The primary means by which states provide home and community-based services is through another optional approach: home and community-based services (HCBS) waivers, which are set forth at section 1915(c) of the Social Security Act.[21] States apply to the federal government for these waivers, which, if approved, allow states to limit the availability of services geographically, target specific populations or conditions, control the number of individuals served, and cap overall expenditures.[22] To receive such a waiver, states must demonstrate that the cost of the services to be provided under a waiver (plus other state

[21]These waivers are codified at 42 U.S.C. §1396n(c).

[22]Provisions of the Medicaid statute that may be waived include (1) "statewideness," which requires that the services be available throughout the state (a waiver allows services to be provided only in particular geographic locations); (2) comparability, which requires that all services be available to all eligible individuals (a waiver allows states to limit services to a specific number of individuals on the basis of certain criteria determined by the state, such as disease, condition, and age); and (3) the community income and resource rules for the medically needy (a waiver allows states to use institutional eligibility rules—which are more generous than community rules—for individuals residing in the community). For more information on these and other types of home and community services, see *Adults With Severe Disabilities: Federal and State Approaches for Personal Care and Other Services* (GAO/HEHS-99-101, May 14, 1999).

Medicaid services) is no more than what would have been spent on institutional care (plus any other Medicaid services provided to institutionalized individuals). States often operate several different waivers serving different population groups, and they have often limited the size and scope of the waivers to help target their Medicaid resources and control spending.

Table 1: Expenditures for Home and Community-Based Services Covered by Medicaid, by Type, Fiscal Year 2000

Dollars in billions

Type of service	Required or optional	Description	Medicaid expenditures
Home Health Care	Required	Home health care includes medically necessary nursing, home health aides, medical supplies, medical equipment and appliances suitable for use in the home.	$2.3
Personal Care Services	Optional	Personal care services include a range of assistance to enable people to accomplish tasks they would normally do for themselves if they did not have a disability. Types of assistance that may be provided may include light housework, laundry, meal preparation, transportation, grocery shopping, using the telephone, medication management, and money management.	$3.8
Home and Community-Based Services (HCBS) Waivers	Optional	HCBS provided under what is called the 1915(c) waiver program includes a broad range of services such as case management, homemaker, home health aide, personal care, adult day health, respite care, and, for individuals with chronic mental illness, outpatient clinic services.	$12.0

Source: HCFA.

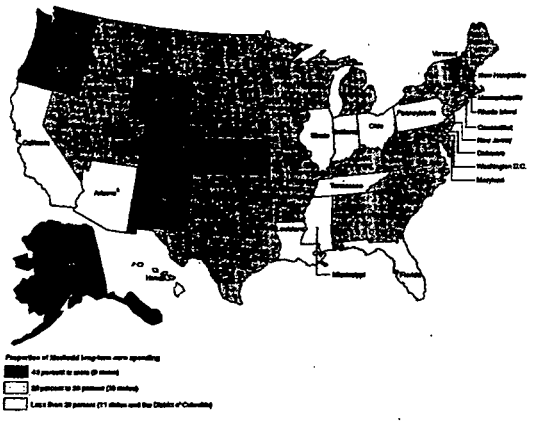
While expenditures for these services have generally grown over time, states' use of HCBS waivers to provide services in community settings has grown at the highest rate. Expenditures for services provided under HCBS waivers grew at an average annual rate of 28 percent between 1988 and 2000—twice as much as Medicaid's expenditures for home health services and three times as much as for personal care services.

Expenditures under the HCBS waivers vary widely with the type of disability covered. The average cost across all programs in 1999 was about $15,331 per recipient. For persons with developmental disabilities, the average cost was twice the average ($30,421); for programs serving the aged and aged disabled, the average cost was much lower ($5,849). This variation results from several factors, but primarily from differences in the type and amount of program services supplied versus services from other sources such as family members. The average costs for providing waiver and other home and community-based services is much lower than average costs for institutionalizing a person. However, the costs of these community-based services do not include significant other costs that must be covered when a person lives in his or her home or in a community-based setting, such as costs for housing, meals, and transportation, as well as the additional costs and burden for family and other informal caregivers.

Provision of Home and Community-Based Services Varies Widely by State

The proportion of Medicaid long-term care spending devoted to home and community-based services varies widely among states. Some states have taken advantage of Medicaid HCBS waivers to develop extensive home and community-based services, while other states have traditionally relied more heavily on institutional and nursing facility services. This variation is reflected in differences in the extent of states' total Medicaid long-term care spending devoted to home and community-based care (defined to include the waivers, home health, and personal care services). For example, in 1999, 9 states devoted 40 percent or more of Medicaid long-term care expenditures to community-based care, whereas 11 states and the District of Columbia devoted less than 20 percent. (See fig. 4.)

Figure 4: Proportion of Medicaid Long-Term Care Spending for Home and Community-Based Care, by State, 1999



Source: Based on data from the National Conference of State Legislatures.

States also vary in the amount of home and community-based services they offer specifically through HCBS waivers. According to data compiled by researchers, an estimated 688,000 disabled persons were being served under 212 HCBS waivers in 49 states (excluding Arizona) and the District of Columbia in 1999.[21] (See app. I.) These waivers covered several different types of disabled populations and settings. All but two states operated at least one waiver covering services for people with mental retardation or developmental disabilities, and all but the District of Columbia operated at

[21]Charlene Harrington and Martin Kitchener, *Medicaid 1915(c) Home and Community Based Waivers: Program Data, 1992-1999*, prepared for The Kaiser Commission on Medicaid and the Uninsured (San Francisco, Calif.: University of California, San Francisco, Aug. 2001).

least one waiver for the aged disabled. Overall, states had 73 waivers covering services for people with mental retardation or developmental disabilities serving nearly 260,000 participants, 65 waivers covering services for almost 382,000 aged or aged disabled participants, and 27 waivers serving about 25,000 physically disabled individuals.[34] Nationwide, the number of people served by waivers varies substantially across states. Oregon, for example, served more than 8 times as many people per capita in its large waiver for the aged and disabled, compared with several other states that had waivers for the same target population.

In most states, the demand for HCBS waiver services has exceeded what is available and has resulted in waiting lists.[35] Waiting list data, however, are incomplete and inconsistent. States are not required to keep waiting lists, and not all do so. Among states that keep waiting lists, criteria for inclusion on the lists vary. In one 1998-99 telephone survey of 50 states and the District of Columbia, Medicaid officials in 42 states reported waiting lists for one or more of their waivers, although they often lacked exact numbers. Officials in only eight states reported that they considered their waiver capacity and funding to be adequate and that they did not have waiting lists for persons eligible for services under those waivers.[36]

States Face Challenges in Supporting Community Living

The states face a number of challenges in providing services to support people with disabilities living in the community, and these challenges extend beyond what can be provided by the Medicaid program alone. The additional costs to the states of supporting people with disabilities in the community are a concern. For example, Medicaid does not pay for housing or meals for individuals who are receiving long-term care services in their own homes or in a community setting, such as an adult foster home. Consequently, a number of state agencies may need to coordinate the delivery and funding of such costly supports as housing and

[34]The remaining waivers served almost 22,000 individuals with AIDS, traumatic brain injuries, and children with severe medical disabilities.

[35]Waiting lists can result when states are providing services for the full number of participants or "slots" authorized by the waiver agreement with CMS. States may apply to CMS to amend their waivers to expand the number of authorized slots. However, waivers also allow states to cap overall expenditures, which my contribute to waiting lists.

[36]Charlene Harrington and others, "Met and Unmet Need for Medicaid Home and Community Based Services in the States," University of California, San Francisco, March 2001. This unpublished report has been accepted for publication in a forthcoming issue of the *Journal of Applied Gerontology*.

transportation. States may also find their efforts to move people out of institutions complicated by the scarcity of caregivers—both paid personal attendants and unpaid family members and friends—who are needed to provide the home and community services.

Finally, there are concerns about the difficulty of establishing adequate programs to ensure that quality care is being provided in the different types of noninstitutional service settings throughout the community. We have reported on quality-of-care and consumer protection issues in assisted living facilities, an increasingly popular long-term care option in the community. States have the primary responsibility for the oversight of care furnished in assisted living facilities, and they generally approach this responsibility through state licensing requirements and routine compliance inspections. However, the licensing standards, as well as the frequency and content of the periodic inspections, are not uniform across the states. In our sample of more that 750 assisted living facilities in four states, the states cited more than 25 percent of the facilities for five or more quality-of-care or consumer protection problems during 1996 and 1997. Frequently identified problems included facilities providing inadequate or insufficient care to residents; having insufficient, unqualified, and untrained staff; and failing to provide residents appropriate medications or storing medications improperly. State officials attributed most of the common problems identified in assisted living facilities to insufficient staffing and inadequate training, exacerbated by high staff turnover and low pay for caregiver staff.[27]

Full Implications of *Olmstead* for State Programs Not Yet Known

The Supreme Court's *Olmstead* decision left open questions about the extent to which states could be required to restructure their current long-term care programs for people with disabilities to ensure that care is provided in the most integrated setting appropriate for each person's circumstances. Interpretation of the *Olmstead* decision is an ongoing process. While the Supreme Court held in *Olmstead* that institutionalization of people with disabilities is discrimination under the ADA under certain circumstances, it also recognized that there are limits to what states can do, given available resources and the obligation to provide a range of services for people with disabilities. Most states are

[27] *Assisted Living: Quality-of-Care and Consumer Protection Issues* (GAO/T-HEHS-99-111, Apr. 26, 1999). See also *Assisted Living: Quality-of-Care and Consumer Protection Issues in Four States* (GAO/HEHS-99-27, Apr. 26, 1999).

responding to the decision by developing plans for how they will serve people with disabilities in less restrictive settings. These plans are works in progress, however, and it is too soon to tell how and when they may be implemented. State responses will also be shaped over time by the resolution of the many pending lawsuits and formal complaints that have been filed against them and others.

The Supreme Court Recognized Limitations to State Obligations

The Supreme Court held that states may be required to serve people with disabilities in community settings when such placements can be reasonably accommodated. However, it recognized that states' obligations to provide services are not boundless.[18] Specifically, the Court emphasized that while the ADA's implementing regulations require reasonable modifications by the state to avoid discrimination against the disabled, those regulations also allow a state to resist requested modifications if they would entail a "fundamental alteration" of the state's existing services and programs.

The Court provided some guidance for determining whether accommodations sought by plaintiffs constitute a reasonable modification or a fundamental alteration of an existing program, which would not be required under the ADA. The Court directed that such a determination should include consideration of the resources of the state, the cost of providing community-based care to the plaintiffs, the range of services the state provides to others with disabilities, and the state's obligation to provide those services equitably.[19] The Court suggested that if a state were to "demonstrate that it had a comprehensive, 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 modification standard would be met."[20]

Most States Are Preparing *Olmstead* Plans

The single most concrete state response to the *Olmstead* decision has been to develop plans that demonstrate how the states propose to serve people with disabilities in less restrictive settings, as suggested by the

[18] 527 U.S. 581, 603 (1999).

[19] 527 U.S. 581, 597 (1999).

[20] 527 U.S. 581, 605-606 (1999).

Supreme Court. HCFA provided early guidance and technical assistance to states in these efforts. But most of these state plans are still works in progress, and it is too soon to tell how and when they will be implemented.

To help states with their *Olmstead* planning activities, between January and July 2000, HCFA issued general guidance to the states in developing "comprehensive, effectively working plans" to ensure that individuals with disabilities receive services in the most integrated setting appropriate.[31] To encourage states to design and implement improvements in their community-based long-term care services, HCFA also announced a set of competitive grant initiatives, funded at nearly $70 million, to be awarded by October 1, 2001. (See app. II for details about these competitive grants.) In addition, HCFA made $50,000 starter grants available to each of the states and territories, with no financial match required, to assist their initial planning efforts. As of July 2001, 49 states (every state except Arizona) had applied for and received these starter grants, which must be used to obtain consumer input and improve services.[32]

As of September 2001, an estimated 40 states and the District of Columbia had task forces or commissions that were addressing *Olmstead* issues. According to the National Conference of State Legislatures (NCSL), which is tracking the states' efforts, the goal for most of these states was to complete initial plans by the end of this year or early 2002. Ten states were not developing *Olmstead* plans, for a variety of reasons. NCSL reported that some of the states that were not planning already have relatively extensive home and community care programs and may believe that such planning is not necessary. As the result of a 1999 lawsuit settlement, for example, Oregon had developed a 6-year plan to eliminate the waiting list

[31]The guidance for developing *Olmstead* plans included the following recommendations: involving individuals with disabilities and their representatives in the planning process, addressing the need to identify individuals who are eligible for community services, assessing the appropriateness and capacity (including waiting lists) of available community-based services, offering individuals with disabilities choices among services, and taking steps to ensure quality assurance in community services. HHS' Office for Civil Rights (OCR) also provides technical assistance to the states on planning issues. For example, states may choose to submit their draft *Olmstead* plans to OCR for review and assistance. According to officials, OCR does not approve or disapprove the plans, but the office assesses the extent to which the plans address the concerns raised in complaints.

[32]CMS also funds a contractor to maintain the *Olmstead* National Technical Assistance Center. The contractor operates a Web site to facilitate communication between states and consumers and provides research and summaries on HCBS programs and initiatives.

of more than 5,000 people for its waiver program serving people with developmental disabilities. Moreover, Oregon was the only state to dedicate more than half of its 1999 Medicaid long-term care spending to home and community-based services. Vermont also is not working on an *Olmstead* plan because it has implemented a range of activities over the years that are related to downsizing institutions and moving toward home and community-based care.[20]

On the basis of a preliminary review of about 14 draft *Olmstead* plans, NCSL reported that the contents are quite variable. A few plans are relatively extensive and well documented, including determinations of need, inventories of available services, funding needs, and roadmaps for what needs to be done. According to NCSL, other plans consist primarily of lists of recommendations to the governor or state legislature, without specifying how the recommendations are to be implemented, by which agencies, or in what time frame.

It is too early to tell how or when the states will implement the steps they propose in their *Olmstead* plans. On the basis of the information collected by NCSL, it appears that few states have passed legislation relating to *Olmstead*—for example, appropriating funding to expand community residential options or authorizing program changes. As of July 2001, NCSL was able to identify 15 *Olmstead*-related bills that were considered in eight states during 2001, of which 4 were enacted. One bill simply provided for development of the state plan, while others appropriated funding, required a new home and community-based attendant services program, or proposed long-term care reforms. Increased state legislative activity is expected in 2002, as more *Olmstead* plans are completed.

Resolution of Pending Lawsuits and Complaints Will Help Establish *Olmstead*'s Reach

State responses to *Olmstead* also will be influenced by the resolution of the numerous lawsuits and formal complaints that have been filed and are still pending. *Olmstead*-related lawsuits, now being considered in almost half the states, often seek specific Medicaid services to meet the needs of people with disabilities. Lawsuits on behalf of people with disabilities seeking Medicaid and other services in community-based settings often are initiated by advocacy organizations. According to the National

[20]According to NCSL, states not developing *Olmstead* plans were Michigan, Minnesota, Nebraska, New York, Oregon, Rhode Island, South Dakota, Tennessee, Vermont, and Virginia.

Association of Protection and Advocacy Systems (NAPAS), Protection and Advocacy Organizations report that about 30 relevant cases concerning access to publicly funded health services whose resolution may relate to *Olmstead* are still active.[34] Plaintiffs in the cases include residents of state psychiatric facilities, developmental disabilities centers, and nursing homes, as well as people living in the community who are at risk of institutionalization. Their complaints raise such issues as prompt access to community-based services, the limitations of Medicaid waiver programs, and the need for assessments to determine the most integrated setting appropriate to each individual.

It is difficult to predict the overall outcome of these active cases since each involves highly individual circumstances, including the nature of the plaintiffs' concerns and each state's unique Medicaid program structure and funding. According to a NAPAS representative, two recent cases in Hawaii and Louisiana illustrate some of the issues raised by *Olmstead*-related lawsuits and how they were resolved through voluntary settlements.

- The Hawaii case[35] shows how one federal court addressed the state's obligation to move people off its waiting lists at a reasonable pace, applying the *Olmstead* decision to people with disabilities who were not institutionalized. The plaintiffs claimed that Hawaii was operating its waiver program for people with mental retardation and developmental disabilities in a manner that violated the ADA and Medicaid law. The plaintiffs were living at home while on a waiting list for community-based waiver services—the majority of the plaintiffs had been on the waiting list for over 90 days and some for over 2 years. They could have obtained services if they had been willing to live in institutions, but they wished to stay in the community. The court found that *Olmstead* applied to the case even though the plaintiffs were not institutionalized. Hawaii argued that the plaintiffs were on the waiting list because of a lack of funds and that providing services for more people would cause the state to exceed funding limits set up in its waiver program.[36] The court rejected the state's

[34]Protection and Advocacy Organizations are part of a national protection and advocacy system established by federal statutes to provide legal representation and advocacy services for people with disabilities in every state. These organizations operate through federal grants.

[35]*Makin v. Hawaii*, 114 F. Supp. 2d 1017 (D.HI, 1999).

[36]Hawaii had 976 federally approved "slots" for its HCBS waiver program for people with mental retardation in 1998. In 1999, 801 people were on the waiting list.

argument and held that funding shortages did not meet the definition of a "fundamental alteration." The court also found that Hawaii did not provide evidence of a comprehensive plan to keep the waiting list moving at a reasonable pace, suggested by the *Olmstead* opinion. In July 2000, the parties settled the case by agreeing that Hawaii would fund 700 additional community placements over 3 years and move people from the waiting list at a reasonable pace.

- The Louisiana case[27] was filed in 2000 on behalf of people living in nursing homes, or at imminent risk of nursing home admission, who were waiting for services offered through three Medicaid HCBS waivers that provided personal attendant care, adult day health care, and other services to elderly and disabled adults. The plaintiffs claimed that the state was failing to provide services in the most integrated setting as required by the ADA. They also claimed that the state was not following Medicaid statutory requirements to provide services with reasonable promptness and to allow choice among available services.[28] As part of a settlement of this case, Louisiana agreed to make all reasonable efforts to expand its capacity to provide home and community-based services and to reduce waiting lists in accordance with specific goals. For example, the state will increase the number of waiver slots by a minimum of 650 slots by 2002, with additional increases planned through 2005. The state also agreed to apply to CMS to add a personal care service option to its Medicaid plan, thereby making personal care services available to all eligible Medicaid recipients who are in nursing homes, at imminent risk of nursing home admission, or recently discharged. In addition, the state agreed to determine the status of persons currently on waiting lists for waiver services and to take steps to inform Medicaid beneficiaries and health professionals about the full range of available service options.

Olmstead issues are also being addressed through a formal complaint resolution process operated by the Office for Civil Rights (OCR) within HHS. As part of its responsibility for enforcing the ADA, OCR receives and helps resolve formal complaints related to the ADA. When OCR receives

[27] *Barthelemy v. Louisiana Department of Health and Human Services*, Civil Action No. 00-1083 (E.D.LA).

[28] The Medicaid statute requires that states furnish assistance "with reasonable promptness to all eligible individuals." 42 U.S.C. §1396a(8). States with home and community-based care waiver programs must provide assurances to HHS that individuals who are determined to be likely to require institutional care be informed of the feasible alternatives and provision of services "at the choice of such individuals." 42 U.S.C. § 1392n(c)(2)(C). See also 42 U.S.C. §1396n(d)(2)(C).

Olmstead-related complaints from individuals and parties, it works through its regional offices to resolve them by involving the complainants and the affected state agencies. If a complaint cannot be resolved at the state and regional OCR level, OCR's central office may get involved. Finally, if these steps are not successful, the complaint is referred to the Department of Justice. As of August 2001, no *Olmstead*-related cases had been referred to the Department of Justice.

From 1999 through August 2001, OCR received 423 ADA-related complaints.[28] These complaints generally involved a concern that people did not receive services in the most integrated setting. OCR reported that, as of August 2001, 154 complaints had been settled and 269 remained pending. These complaints had been filed in 36 states and the District of Columbia, with more than half filed in seven states. A recent analysis of 334 *Olmstead*-related complaints indicated that 228 complaints (68 percent) were related to people residing in institutions.[29]

The ongoing resolution of *Olmstead*-related lawsuits and complaints will help establish precedent for the types of Medicaid program modifications states may have to make to their long-term care programs. Meanwhile, it is difficult to generalize about the potential impact of the many ongoing cases because each case will be decided on its own facts. The extent of what federal courts will require states to do to comply with the ADA as interpreted in *Olmstead* will become more clear over time as additional cases are resolved.

Concluding Observations

In the wake of the *Olmstead* decision, states may face growing pressures to expand services for the elderly and other people with disabilities in a variety of settings that allow for a range of choices. Despite the numerous activities under way at the state and federal levels to respond to this decision, the full implications of the *Olmstead* decision are far from settled. Ongoing complaints and legal challenges continue to prompt states to make incremental changes at the same time that they continue to frame states' legal obligations for providing services to the disabled. States face

[28]OCR officials indicated that they were in the process of updating their database with respect to *Olmstead*-related complaints and that the data should be considered preliminary.

[29]Presentation of Sara Rosenbaum, J.D., and Alexandra Stewart, J.D., School of Public Health and Health Services, The George Washington University, at the National Academy for State Health Policy Annual Conference, August 12, 2001, Charlotte, N.C.

challenges in determining who and how many people meet the criteria of needing and seeking services and also in balancing the resource and service needs of eligible individuals with the availability of state funds.

This balancing of needs and resources will be an even greater issue in the coming years as the baby boom generation ages and adds to the demand for long-term care services. While Medicaid has a prominent role in supporting the long-term care services provided today, other financing sources also play an important role in our current system. These include private resources—including out-of-pocket spending, private insurance, and family support—as well as many other public programs. Finding ways to develop and finance additional service capacity that meets needs, allows choice, and ensures quality care will be a challenge for this generation, their families, and federal, state, and local governments.

Mr. Chairman, this concludes my prepared statement. I will be happy to answer any questions you or the other Committee members may have.

Contacts and Staff Acknowledgments

For more information regarding this testimony, please contact me at (202) 512-7114 or Katherine Iritani at (206) 287-4820. Bruce D. Greenstein, Behn Miller, Suzanne C. Rubins, Ellen M. Smith, and Stan Stenersen also made key contributions to this statement.

Appendix I: Medicaid Home and Community-Based Services Waivers, by State, 1999

State	Number of waivers	Number of persons served, by waiver type: Mentally retarded/ developmentally disabled	Aged/disabled	Physically disabled	Other[a]	Total persons served	State expenditures (in millions)
AK	4	589	712	345	0	1,646	$38.3
AL	3	3,994	5,826	335	0	10,155	129.1
AR	3	1,104	8,158	298	0	9,560	46.8
CA	5	34,212	8,551	120	4,015	46,898	482.9
CO	10	6,517	11,481	0	1,929	19,927	209.6
CT	4	4,328	8,978	198	0	13,504	364.0
DC	1	29	0	0	0	29	51.5
DE	3	490	734	0	366	1,589	34.4
FL	8	13,316	16,805	0	6,337	36,458	287.1
GA	4	2,683	14,018	0	293	16,994	119.2
HI	4	948	923	0	66	1,937	34.2
IA	5	4,984	3,994	0	70	9,048	86.6
ID	3	549	1,000	0	0	1,549	17.5
IL	5	6,961	17,396	12,387	1,483	38,227	290.8
IN	4	1,868	2,338	0	131	4,335	84.5
KS	6	5,325	6,701	3,822	894	16,742	239.9
KY	3	1,060	13,339	52	0	14,451	97.3
LA	4	2,885	759	113	0	3,757	78.0
MA	2	11,076	5,132	0	0	16,208	427.7
MD	3	10,021	132	0	205	10,358	168.7
ME	4	1,624	1,395	697	0	3,716	119.5
MI	3	8,748	6,328	0	0	15,076	253.2
MN	5	7,413	7,838	3,625	367	19,243	429.5
MO	5	7,779	20,821	11	80	28,691	232.0
MS	3	348	2,540	127	0	3,015	14.9
MT	2	980	1,514	0	0	2,494	41.7
NC	4	5,016	11,159	0	273	16,448	316.3
ND	3	1,845	347	0	14	2,206	41.1
NE	4	2,394	2,357	0	21	4,772	88.3
NH	3	2,535	1,367	0	90	3,992	117.4
NJ	9	7,027	4,587	290	611	12,515	292.3
NM	4	1,752	1,404	0	212	3,368	119.2
NV	4	867	1,235	131	0	2,233	15.1
NY	7	36,179	19,732	0	964	56,875	1,784.9
OH	4	5,897	26,135	0	0	32,032	316.8
OK	3	2,687	9,042	0	0	11,729	172.9
OR	2	3,583	26,410	0	0	29,993	298.9
PA	8	10,553	2,463	1,948	70	15,034	516.2
RI	4	2,833	2,304	58	0	5,195	109.7
SC	5	4,242	14,361	32	1,390	20,025	151.7
SD	4	1,784	791	52	0	2,607	48.8
TN	3	4,063	511	0	0	4,574	118.4

State	Number of waivers	Number of persons served, by waiver type: Mentally retarded/ developmentally disabled	Aged/disabled	Physically disabled	Other*	Total persons served	State expenditures (in millions)
TX	6	6,227	27,978	100	895	35,200	506.0
UT	5	0	3,422	21	97	3,540	66.0
VA	6	3,650	11,835	235	523	16,243	211.2
VT	5	1,553	1,014	0	208	2,775	67.7
WA	4	5,071	25,718	0	35	30,824	332.2
WI	4	8,884	13,900	0	205	22,989	387.9
WV	2	0	5,284	0	0	5,284	110.3
WY	3	1,110	982	0	0	2,092	45.4
Total	212	259,581	381,751	24,997	21,843	688,152	$10,550.0

*"Other" includes waivers that serve the conditions other populations, such as children with special health care needs, persons with AIDS, individuals with mental health needs, and individuals with traumatic brain injuries and head injuries.

Source: Charlene Harrington and Martin Kitchener, Medicaid 1915(c) Home and Community Based Waivers: Program Data, 1992–1999, prepared for The Kaiser Commission on Medicaid and the Uninsured (San Francisco, Calif.: University of California, San Francisco, Aug. 2001).

Appendix II: HCFA's "Systems Change for Community Living" Grant Initiative

In January 2001, HCFA announced a set of grant initiatives called "Systems Change for Community Living." These grants are intended to encourage states to design and implement improvements in community long-term support services. Total funding for these grants is $70 million for fiscal year 2001. States will have 36 months to expend the funds. States and other organizations, in partnership with their disabled and elderly communities, were invited to submit proposals for one or more of these four distinct grant programs (see table 2). Agency officials reported receiving 161 separate applications for these grants for more than $240 million. The agency expects all grant awards to be made by October 1, 2001.

Table 2: Overview of "Systems Change for Community Living" Grants

Name of grant	Description of grant	Total grant funding available	Maximum award	Estimated number of awards
Nursing Facility Transitions	To help states transition eligible individuals from nursing facilities to the community.	$10 million to $14 million	$1.2 million	16 to 26
Community-Integrated Personal Assistance Services and Supports	To improve personal assistance services that are consumer-directed or offer maximum individual control.	$5 million to $8 million	$1.2 million	9 to 12
Real Choice Systems Change	To help design and implement effective and lasting improvements in community support systems to enable children and adults of any age who have a disability or long-term illness to live and participate in their communities.	$41 million to $43 million	$3.5 million	30 to 40
National Technical Assistance Exchange for Community Living	To provide technical assistance, training, and information to states, consumers, families, and other agencies and organizations.	$4 million to $5 million	$4.0 million to $5.0 million	1

Source: Coordinated Invitation to Apply for "Systems Change Grants for Community Living," (Washington, D.C.: HHS, HCFA, May 17, 2001).

Related GAO Products

Long-Term Care: Baby Boom Generation Increases Challenge of Financing Needed Services (GAO-01-563T, Mar. 27, 2001).

Mental Health: Community-Based Care Increases for People With Serious Mental Illness (GAO-01-224, Dec. 19, 2000).

Long-Term Care Insurance: Better Information Critical to Prospective Purchasers (GAO/T-HEHS-00-196, Sept. 13, 2000).

Children With Disabilities: Medicaid Can Offer Important Benefits and Services (GAO/T-HEHS-00-152, July 12, 2000).

Adults With Severe Disabilities: Federal and State Approaches for Personal Care and Other Services (GAO/HEHS-99-101, May 14, 1999).

Assisted Living: Quality-of-Care and Consumer Protection Issues in Four States (GAO/HEHS-99-27, Apr. 26, 1999).

Nursing Homes: Complaint Investigation Processes Often Inadequate to Protect Residents (GAO/HEHS-99-80, Mar. 22, 1999).

Long-Term Care: Baby Boom Generation Presents Financing Challenges (GAO/T-HEHS-98-107, Mar. 9, 1998).

Medicaid: Waiver Program for Developmentally Disabled Is Promising but Poses Some Risks (GAO/HEHS-96-120, July 22, 1996).

Long-Term Care: Current Issues and Future Directions (GAO/HEHS-95-109, Apr. 13, 1995).

Medicaid Long-Term Care: Successful State Efforts to Expand Home Services While Limiting Costs (Aug. 11, 1994).

Health Care Reform: Supplemental and Long-Term Care Insurance (GAO/T-HRD-94-58, Nov. 9, 1993).

(290083)

STATEMENT OF SARA ROSENBAUM, DIRECTOR, GEORGE WASHINGTON UNIVERSITY SCHOOL OF PUBLIC HEALTH AND HEALTH POLICY, WASHINGTON, DC

Ms. ROSENBAUM. Thank you very much, Mr. Chairman and Senator Craig.

The George Washington University School of Public Health greatly appreciates this opportunity to testify before you today. We have been asked to present testimony on a special study that we have conducted over the past year which examines in detail, on an anonymous basis, the Olmstead complaints, that is, complaints filed with the Office for Civil Rights at HHS alleging a failure to provide care in the most integrated setting under Title II.

With the support of the Center for Health Care Strategies, part of the Robert Wood Johnson Foundation, we have been analyzing these complaints for about 12 months. We have analyzed the 334 complaints that have been filed since 1996, and I am going to summarize the findings from the analysis; you have the full analysis, of course, with you.

The CHAIRMAN. Excuse me. You said since 1996, so that is prior to Olmstead?

Ms. ROSENBAUM. Yes. The Olmstead case, of course, originated well before the year that the Supreme Court actually handed down its decision, so there have been most integrated setting complaints filed under the ADA for a number of years; and before that, of course, under 504 of the Rehabilitation Act, many of these claims also would have been germane.

In brief, our review of the complaints, which should not as a body be understood to be representative of all people who might be medically unjustifiably institutionalized—we do not know if they are representative of that whole group of Americans; nonetheless we think these complaints shed a lot of light on the situations facing people who believe they are in this situation—our review of the complaints reveals certain distinct patterns which we think will be extremely helpful to the committee as it begins to fashion recommendations.

The first observation is that this is a nationwide problem, not confined to any one State or any one region of the country. It is all over. The number of complaints by region varies, but it is safe to say that there is not a State that is not facing this issue, and it affects all residents of the United States.

The age range of the complainants is predominantly focused on adults ages 22 to 64. This is where many of the complainants are. There is a fair number of children. There is a smaller number of persons over age 65 who filed complaints; we believe that that is an artifice of the complaint process and is not reflective of the lack of a problem related to medically unjustifiable institutionalization among elderly people.

Residential status of the complainants, as Ms. Allen noted, is a broad decision, and indeed, 30 percent of all the complaints and 40 percent of the children's complaints involved residents of the community, not residents of institutions. So when you think about this problem, you need to think about it across residential status.

Within the group of people who are in the community, almost two-thirds are living with their families and clearly feeling under

threat over the ability to maintain a family residential status. Thirty-five percent are struggling to live on their own or in another setting in the community, but we were quite struck by the fact that so many do live with their families—an indication that something is wrong with the mechanism for providing community supports if you feel this unable to maintain a community residential status even with your own family.

Within the group of institutionalized beneficiaries or complainants, most are in nursing facilities overall; a fair number, one-quarter, are in psychiatric facilities. Among children, however, the picture is quite different. Among children, a fair number—we simply could not tell where they were, but there appeared to be a fair number of complaints from long-term hospitals, from residential treatment facilities, from the kinds of facilities that children with profound mental and emotional needs may be in for special education purposes.

In the case of the diagnosis—and we think this may be some of the most helpful information to you—a physical disability diagnosis is the overwhelmingly common diagnosis. There is a very substantial presence of mental diagnoses, mental retardation, mental illness, but if I had to draw a picture for you today of the typical person filing a complaint alleging unjustifiable institutionalization, it would be an adult with very significant physical disabilities. In the case of children, however, again, the presence of dual and trebly diagnosed children is very high. Mental illness, mental retardation, developmental disabilities, in combination with a physical disability, are much more common.

The service needs that people seek should be no surprise. The two biggest service needs are a place to live and health services in the home, and this I think is consistent with the nature of who is complaining. People want to have a place to live that is not an institution, they obviously cannot secure it, and they need in-home services to be able to achieve that result.

This is a very rapid statistical overview of the findings. Many of the letters are just simply heartbreaking in the description of the predicaments that people find themselves in. As you think through a remedy for this issue, it is clear that it extends well beyond the Medicaid program in its current form; it extends into housing, social services, education, and other supports needed to thrive in a community.

Thank you very much.

The CHAIRMAN. Thank you very much, Professor Rosenbaum.

Next, Ms. Lowe.

[The prepared statement of Ms. Rosenbaum follows:]

SCHOOL OF PUBLIC HEALTH AND HEALTH SERVICES
HIRSH HEALTH LAW AND POLICY PROGRAM

Testimony Before the Special Committee on Aging, United States Senate Regarding Long-Term Care After *Olmstead v. L.C.*: Developing the Building Blocks for Change

Sara Rosenbaum, J.D.
Harold and Jane Hirsh Professor, Health Law and Policy

Alexandra Stewart, J.D.
Research Scientist

Joel Teitelbaum, J.D., LL.M.
Assistant Research Professor

The George Washington University Medical Center
School of Public Health and Health Services
Washington, D.C.

September 24, 2001

Presented by Professor Rosenbaum

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Mr. Chairman and Members of this Committee;

We greatly appreciate the opportunity to appear at the third hearing in the Committee's series of hearings on long-term care. This particular hearing focuses on the need for reform of the U.S. long-term care system, the local, state, and national context in which this reform effort will take place (including the anticipated impact on reform as a result of the United States Supreme Court's 1999 decision in *Olmstead v L.C.*[1]), the appropriate mechanisms for encouraging and facilitating reform, and recommendations for change.

The Hirsh Health Law and Policy Program, located at the George Washington University Medical Center's School of Public Health and Health Services, is one of the largest public health school-based health law and policy programs in the U.S. today. This year nearly 40 J.D. and LL.M. candidates will study health law and policy under our direction as part of formal training in public health. In addition, the Hirsh Program, in conjunction with the University's Center for Health Services Research and Policy (which I also direct) conducts extensive research on the relationship between the changing legal environment and the rapidly evolving U.S. health care system. One of the areas in which we specialize is the study of disability law and policy reform and its intersection with the health system.

To that end, beginning in the summer of 2000 and with support from the Center for Health Care Strategies in Princeton, New Jersey, we undertook a rolling, point-in-time, descriptive study[2] of "most integrated setting" administrative complaints filed since 1996 under the Americans With Disabilities Act and Section 504 of the Rehabilitation Act of 1973. The United States Department of Health and Human Services' Office for Civil Rights generously provided us access to these complaints on an anonymous basis. Each complaint was reviewed for its material facts in accordance with a survey instrument developed specifically for the purpose of this review and in consultation with experts both within and outside of government. Today we present you with the aggregated findings from this anonymous analysis.

The 334 complaints analyzed in our study cannot be said to be representative of all persons in the U.S. who have sufficiently serious disabilities to be at risk for institutional care in the absence of reasonable modifications in services. At the same time, we believe that in light of the sheer volume of complaints, as well as their consistency over time (each phase of the analysis has produced similar aggregated results), the complaints offer invaluable insight into the extent of the long-term care problem in the U.S. among individuals who believe that they are experiencing -- or are at risk for -- medically unjustifiable institutionalization, and could live and thrive in their communities with reasonable restructuring of public programs. The prevention of unjustifiable institutional segregation of persons with disabilities is of course the heart of the policy and operational imperative created by the *Olmstead* decision.

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[1] 527 U.S. 581 (1999).

[2] The first group of complaints was analyzed in late summer, 2000. The second group was analyzed in the spring of 2001. The third cluster was analyzed in the summer of 2001. All results have been compiled into a single data base.

Findings in Brief

The slides attached to this testimony are numbered for ease of review.

Location of complaints: Figure 1 shows that this is a nationwide problem. The complaints are from all regions of the country. Although certain HHS regions (e.g., IV, V, VI and VIII) are disproportionately represented, we believe that this may be more an indication of the strength of family and community advocacy efforts in these particular areas of the nation than of the underlying problem itself.

Age range of complainant: It is not always possible ascertain the age of the complainant, but among the complaints where age can be discerned, the evidence presented in Figure 2 suggests that unnecessary institutionalization (or its risk) affects persons of all ages. Most prevalent are adults ages 22-64. At the same time, one-in-seven complainants whose age is known is a child or adolescent. Given what is known about the desire and ability of older persons with disabilities to live in communities with proper support, the small number of elderly complainants is in all likelihood a function of the complaint process and the dynamics of representation, rather than an indicator of the scope of the problem of medically unjustifiable institutionalization among this population.

Residential status: Figure 3 indicates that while the majority of complainants were institutionalized when they filed their complaints, a significant proportion -- 30% -- were residing in the community but at risk for what they at least considered medically unjustified institutionalization. Figure 4 shows that an even higher proportion of child and adolescent complainants reside in a community setting but are at risk for what they perceive as medically unjustifiable institutionalization.

Living arrangements of community complainants: Figure 5 underscores the variable nature of the problems faced by community residents, in terms of current living arrangements. Well over half -- 57% -- were living with families but considered themselves to be in danger of medically unjustified institutionalization in the absence of assistance. Another 36% were living on their own (either alone or in another form of arrangement) at the time they filed their complaints. This slide underscores that living with a family member or members is alone no buffer against medically unjustifiable institutionalization, given the complex and extended supports that may be required to successfully maintain an individual in his or her home.

Institutional placement of institutionalized complainants: Figure 6 shows that nursing homes were the single most common institutional setting among complainants, accounting for 60% of all complaints filed by institutionalized persons. Another 30% arose in psychiatric facilities, similar to the facts of the *Olmstead* case itself. In the case of children and adolescents, Figure 7 shows that hospitals, skilled nursing facilities, and psychiatric facilities comprised the largest number of settings for the complaints among institutionalized persons. In the case of non-elderly adults, nursing home residents accounted for nearly half of the institutionalized complainants, as Figure 8 shows.

Nature of the disability: Figure 9 underscores the wide range of conditions that can lead to medically unjustified institutionalization or the threat thereof. The most dominant condition by far was physical disability: nearly half of all complainants reported a single diagnosis attached to a physical disability, while another nearly-10% reported the presence of a physical disability along with

one or more mental disabilities. Among non-elderly adults, Figure 10 indicates that the dominance of physical disabilities was even more pronounced, present either alone or in combination with a mental disability of some type in 70% of all cases. Figure 11 indicates that in the case of children and adolescents, physical disabilities either alone or in combination with mental disabilities were present in more than one-third of all complaints.

Compared to adults, the picture for children suggests a greater prevalence of multiple, layered conditions. Among adults, according to Figure 10, two-thirds report a single diagnosis, while only approximately 40% of children experience a single diagnosis. Conversely, among children, over one-third experience either dual or triple diagnoses; among non-elderly adults, Figure 10 indicates that only one-quarter experience dual or triple diagnoses.

Service needs: Regardless of age, complainants report similar service needs, and among both children and non-elderly adults, in-home health care and affordable and appropriate housing dominate the requests. A significant proportion report qualitative and/or quantitative difficulties with current services. Education, training, equipment, and transportation services are also commonly reported in these requests.

Discussion

What do not and cannot come through in this presentation are the voices of the individuals themselves. Many of the complainants are simply overwhelming in their eloquence and their articulation of their personal situations. We can only aggregate patterns and present analysis to this Committee, but we are no substitute for the voices of the children and adults who should be an integral part of your deliberations.

That said, even these limited aggregated statistics underscore several points:

First, any long-term care reform has to be structured to reach persons of all ages. The problem of unjustified institutionalization of the disabled is not a problem associated with age. The presence of disabilities serious enough to limit daily activity and create the risk of institutionalization may increase with age, but for purposes of broad policy formulation, the issue should be approached as universal.

Second, this is not an issue confined to a subset of persons with disabilities. It is not an issue associated only with mental illness, mental retardation, and developmental disabilities; indeed, physical disability standing alone is the most prevalent reported condition among non-elderly adult complainants. In this regard, the Americans With Disabilities Act test of disability is clearly the appropriate definition to use in the effort to formulate a policy and programmatic framework for disability because its criteria (i.e., the presence of one or more physical or mental impairments that limits a major life activity) are sufficiently broad to encompass the range of individuals in need of assistance, not merely those with specific conditions or who are unable to perform substantial gainful activity. Put another way, the *Olmstead* decision, and the ADA itself, underscore how antiquated the Social Security Act test of disability is today.

What may still be a marginally defensible test of disability to govern a cash benefit program designed to replace lost earnings or earning capacity (i.e., SSDI insurance or the SSI program), does not even begin to suffice where other forms of assistance and supports are concerned. Not only do

health care, housing assistance, in-home services and other forms of in-kind supports transcend the question of earnings, so too does cash assistance where the purpose of the cash is not to replace lost earnings but to make affordable supports and services that no wage earner can reasonably be expected to afford. Congress has already begun to respond to this reality through programs such as the Ticket to Work Act, with its emphasis on aid to workers with disabilities. This type of effort should be expanded.

Finally, it is clear that a solid long-term care policy for the U.S. will transcend the jurisdiction of any single House or Senate authorizing Committee. The reviewed complaints indicate that a policy of long-term care reform must encompass health care, housing assistance, education and job training, income supplementation and support, transportation services, and other types of interventions. Broad remedial thinking is in order here.

We assume of course that the reforms needed to put a long-term care policy in place will be costly. We assume also that in the long run many of these costs will be offset, either through institutional savings or through the revenues created through increased productivity and opportunity. We are aware of the fact that the current means of cost estimation and budget scoring often highlight the cost of investing without accurately capturing the savings and good that these types of investments can yield. We therefore hope that in approaching the issue of cost estimation, this Committee will seek to establish an innovative approach to this task in order to avoid destruction of this type of long-term policy reform before it can even begin.

Long-Term Care After *Olmstead v. L.C.*: Developing the Building Blocks for Change

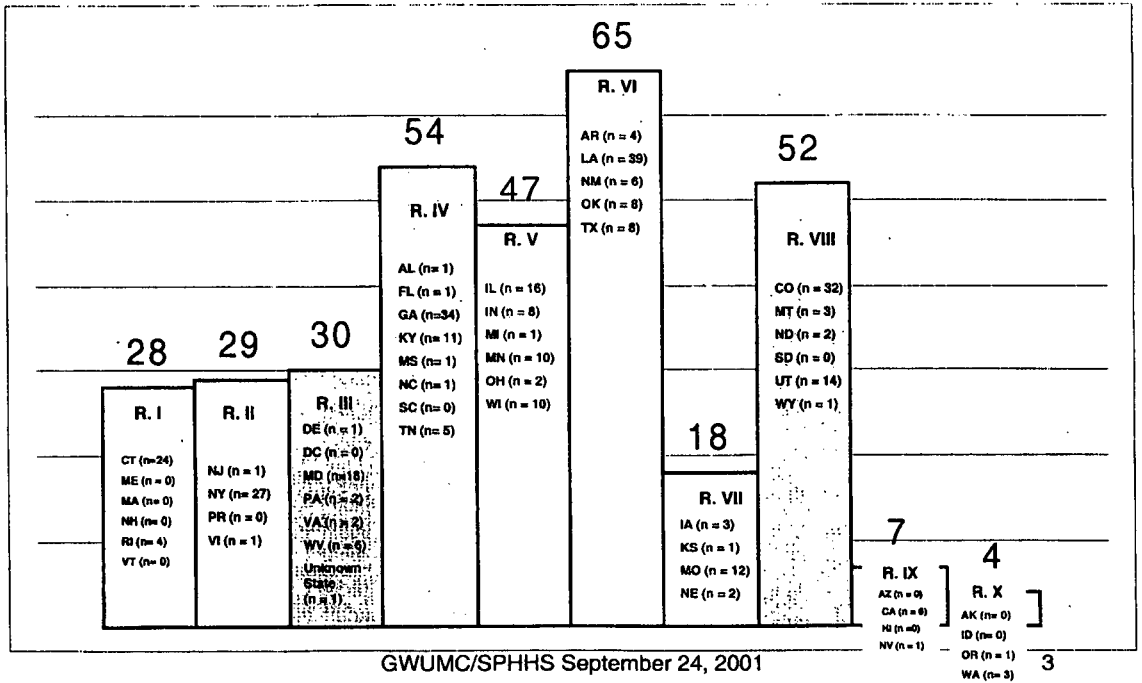
Sara Rosenbaum, J.D.
Alexandra Stewart, J.D.
Joel Teitelbaum, J.D., LL.M.
The George Washington University Medical Center
School of Public Health and Health Services
September 24, 2001

Study: Purpose and Methods

- **Review of 334 "most integrated setting" complaints received by HHS/OCR between 1996-2001 (90% between 2000 and 2001)**
- **Analytic Methods: Complaint aggregation and descriptive analysis using review instrument designed to capture key elements**
- **Review elements:**
  - **Region**
  - **State**
  - **Complaint by type of complainant**
  - **Age range of complainant**
  - **Residential status of complainant**
    - **Type of institutional placement**
    - **Type of community living arrangement**
  - **Nature of complainant's disability**
  - **Complainant's service requests**
- Limits: representativeness of complainants compared to all persons with serious disabilities who are at risk for unnecessary institutionalization, but valuable for planning and analytic purposes

1. Complaints by Region

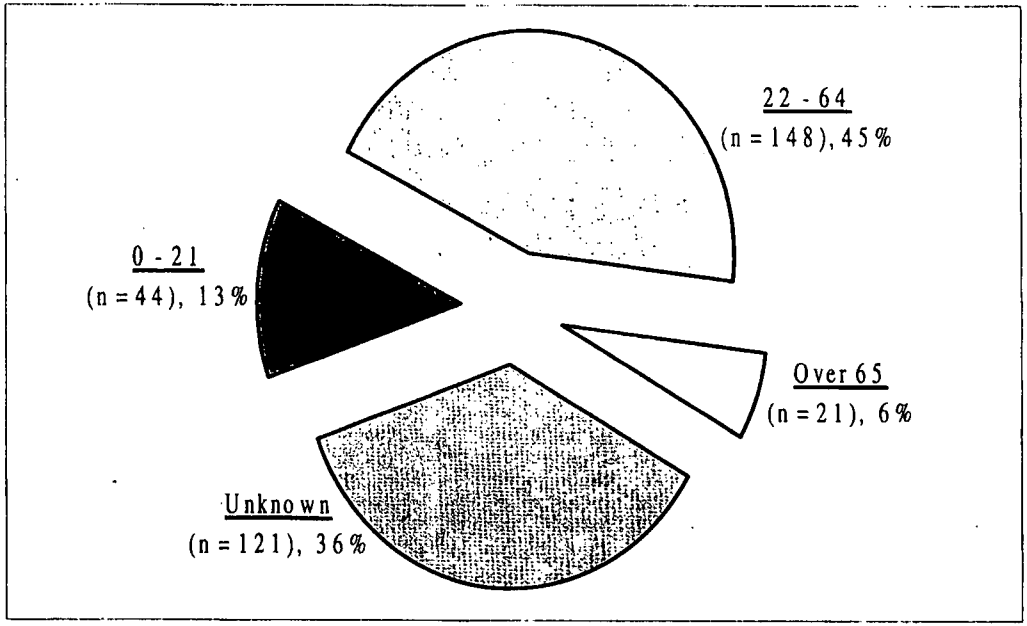
Complaints (n = 334)



GWUMC/SPHHS September 24, 2001

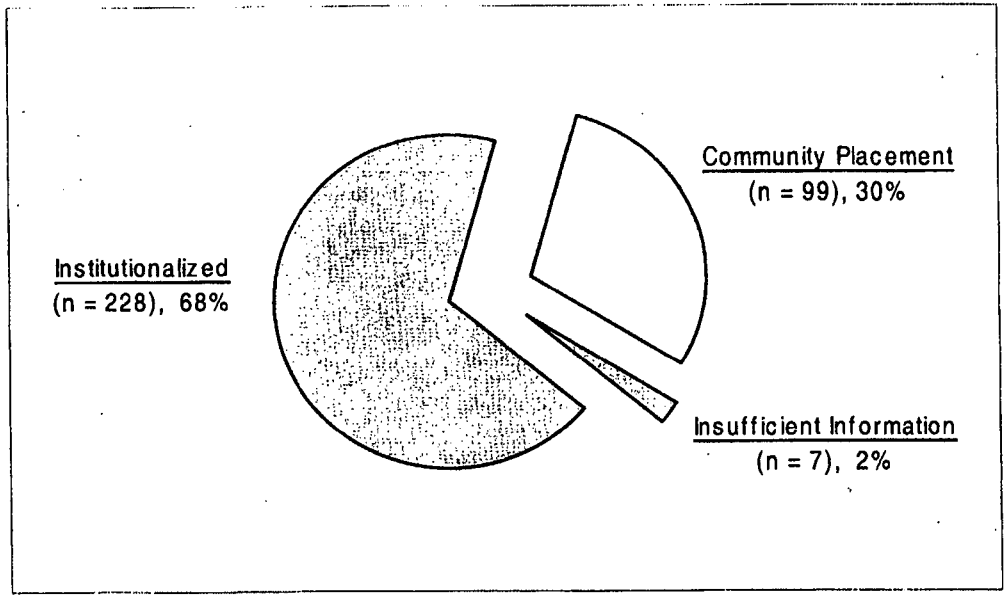
2. Age Range of Complainant

Total Complaints (n = 334)



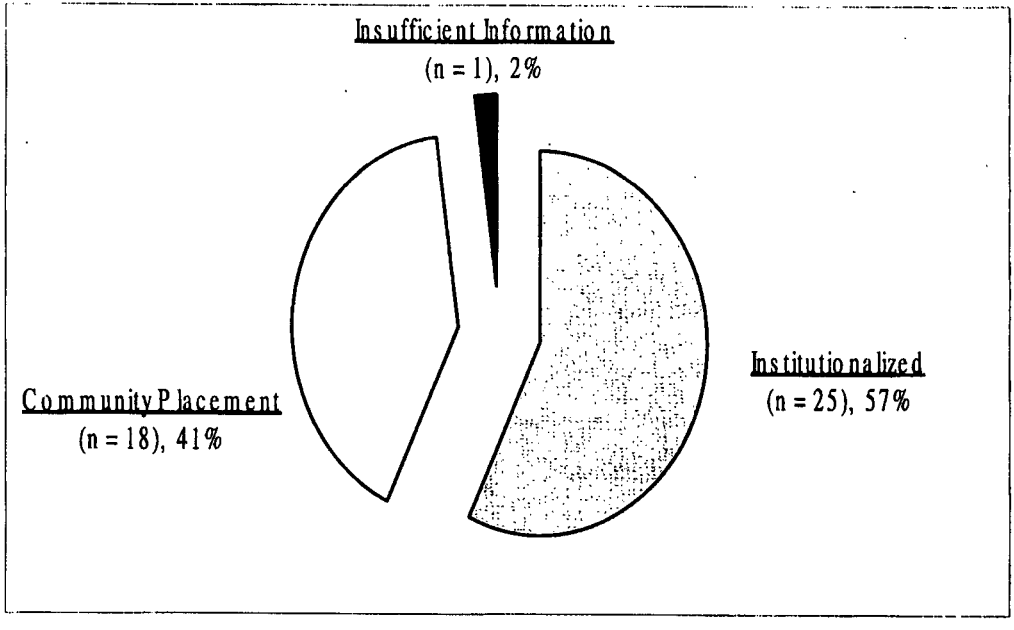
3. Complainant Residential Status

Total Complaints (n = 334)



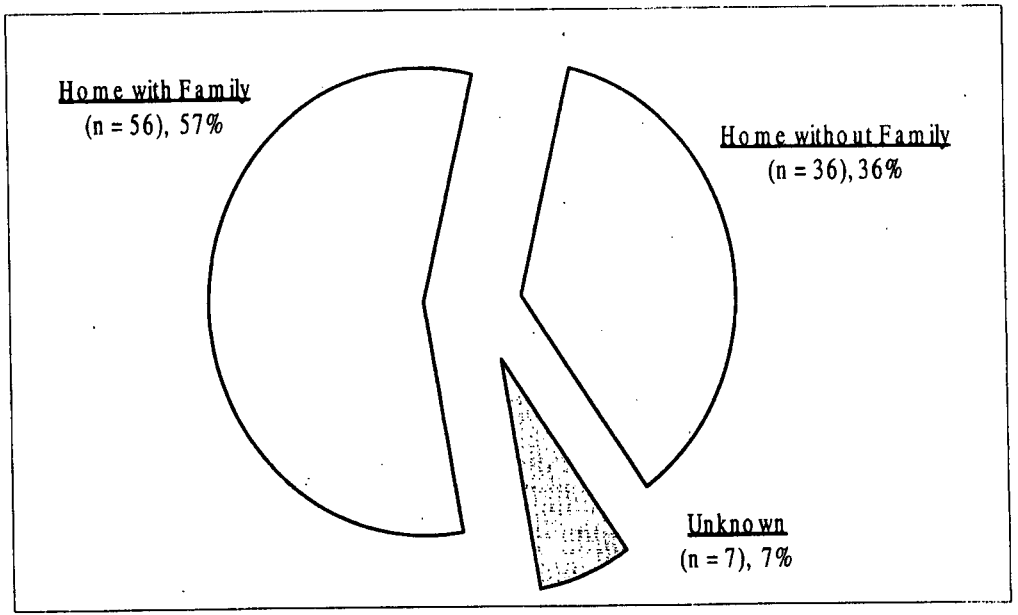
4. Residential Status of Complainants Ages 0 - 21

Complainants Ages 0 - 21 (n = 44)



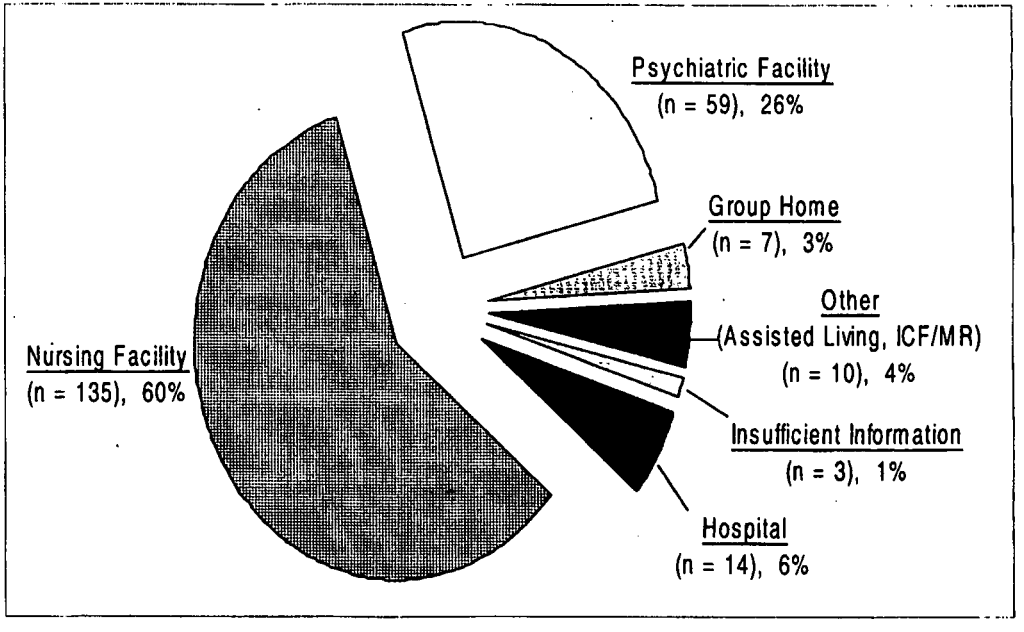
5. Living Arrangements of Community Complainants

Community Complainants (n = 99)

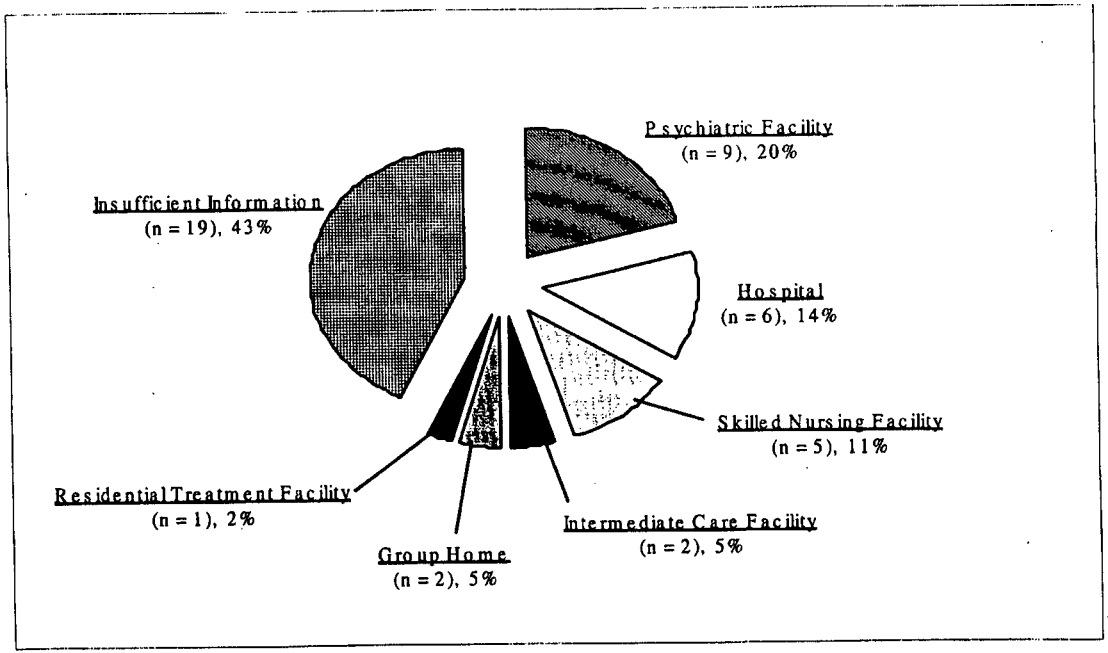


6. Institutional Placement

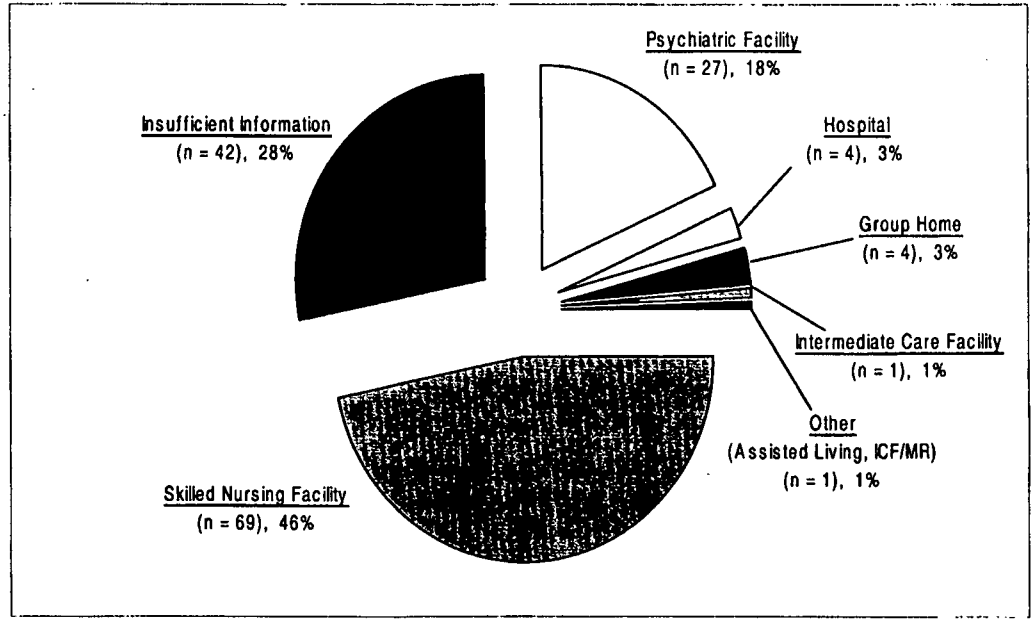
Institutionalized Complainants (n = 228)



7. Institutional Status of Complainants Ages 0 - 21
Institutionalized Complainants Ages 0 - 21 (n = 44)

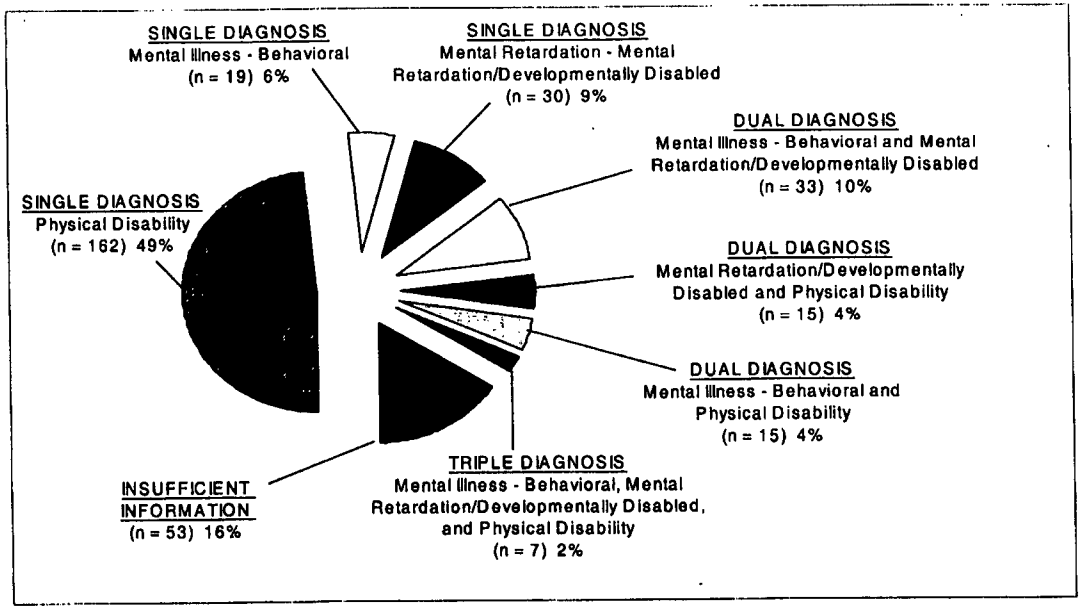


8. Institutional Status of Complainants Ages 22 - 64
Institutionalized Complainants Ages 22 - 64 (n = 148)



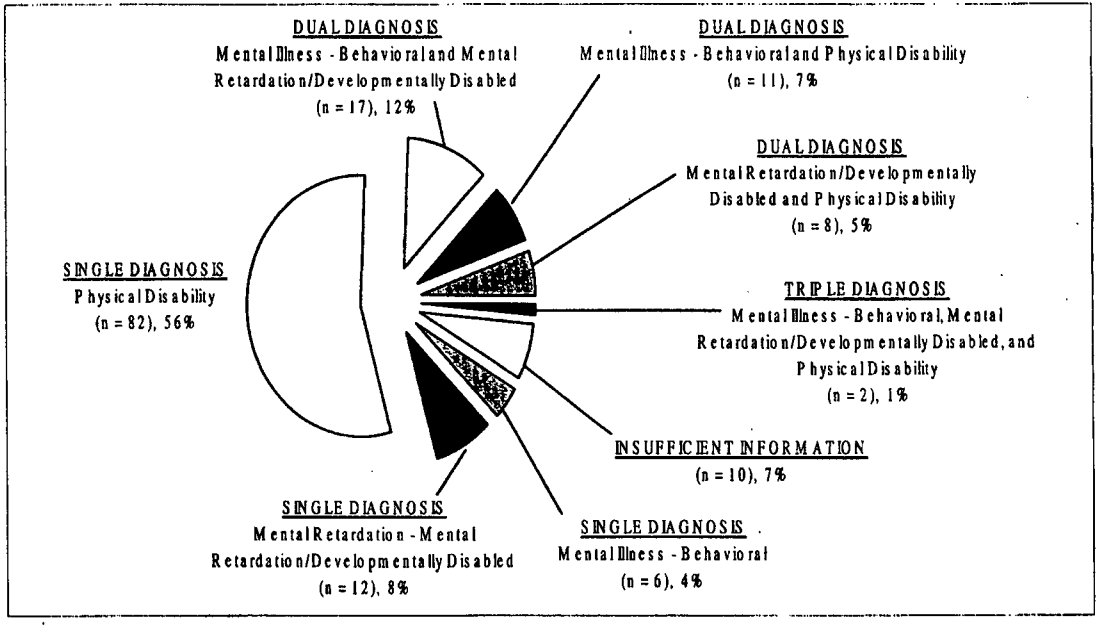
9. Nature of Complainant's Disability

Number of Complaints (n = 334)



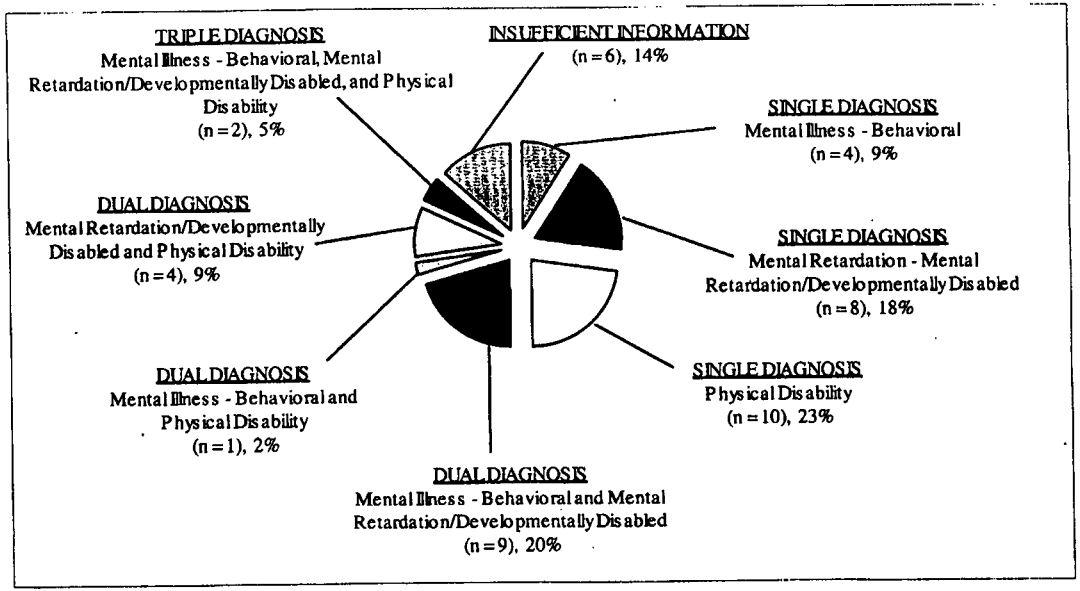
10. Complainants by Disability Ages 22 - 64

Complainants Ages 22 - 64 (n = 148)



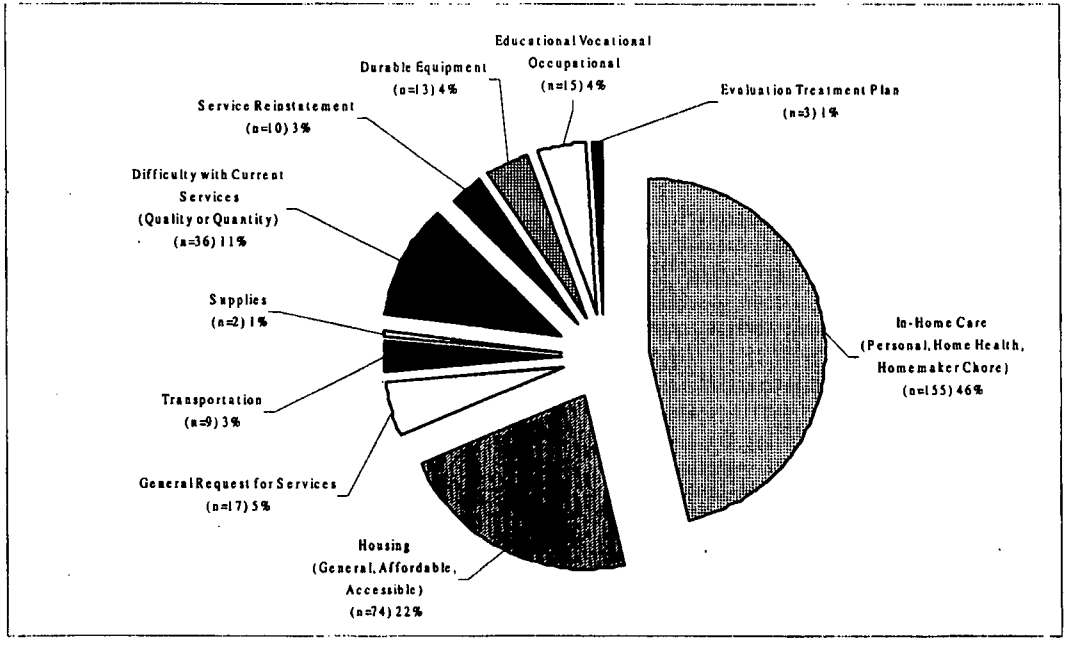
11.Complainants by Disability Ages 0 - 21

Complainants Ages 0 - 21 (n = 44)

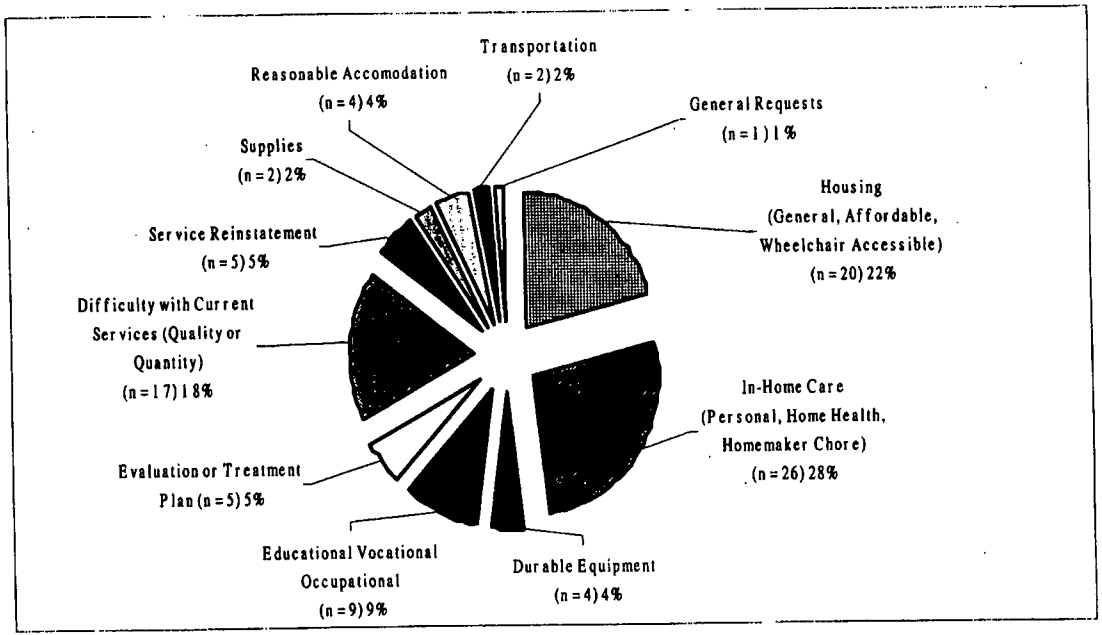


12. Service Requests by Complainants Ages 22 - 64

Complainants Ages 22 - 64 (n = 148) Total Service Requests (n =334)



13. Service Requests by Complainants Ages 0 - 21
Complainants Ages 0 - 21 (n = 44)



STATEMENT OF JANE ISAACS LOWE, SENIOR PROGRAM OFFICER, ROBERT WOOD JOHNSON FOUNDATION, WASHINGTON, DC

Dr. LOWE. Mr. Chairman and Senator Craig, good afternoon. Thank you for inviting me to testify this afternoon on the work the Robert Wood Johnson Foundation has done to improve long-term care in America.

I am pleased to share some of the lessons we have learned from our grant-making in this area. But let me begin first by putting a human face on this complex issue by telling you about Mrs. K, who lived on a farm by herself in rural Illinois.

At age 85, Mrs. K suffered from hearing and vision loss and was increasingly confined to a wheelchair due to severe arthritis. An Illinois home care specialist visited several times a week, as did several of her children, but she was slowly losing the ability to live independently without help. Although she resisted giving up her home, she was amenable to living in a senior apartment complex; however, the nearest facility was far from her home town and also beyond her financial means. She feared that it was just a matter of time before she would have to go to a nursing home.

Mrs. K was lucky. An affordable assisted living facility was built 10 miles from her home as a result of the Foundation's Coming Home Program, a national program designed to increase the number of affordable assisted living programs in rural America.

Mrs. K was one of the first seniors to qualify for residence in Cache Valley, located in a town of 550 people. Today she has her own apartment, filled with her furniture, receives meals and help with dressing, bathing and medications, and as a result has friends, her independence, and help when she needs it.

There are many people like Mrs. K who are living in rural, suburban, and urban areas. They are alone and isolated, living with chronic illnesses and limited resources and, like Mrs. K, they need affordable housing and service options.

Mrs. K's story is just one example of our work to develop long-term care programs for vulnerable and frail older persons and people with disabilities. The Robert Wood Johnson Foundation's work in this area is funded as part of our goal to improve care and support for people with chronic illness. This has been one of our principal programming goals since 1991.

Since that time, the Foundation has awarded more than 3,000 grants totaling close to $1 billion to improve long-term care and care for people with chronic illness. Through our grant-making, we test new ideas and develop new models, and these innovations necessarily fall short of broad-scale change, but with careful interpretation provide valuable lessons.

The three most salient lessons we have learned from our grant-making are as follows. First, consumers and/or their families must be involved in decisions about their care. Second, more alternatives to institutional long-term care must be created. And third, financing must be more flexible in order to support these options.

Let me talk for just a moment about consumer-directed care. One very promising model that the Foundation has supported in the past decade is consumer-directed care or self-determination. This model is based on the premise that control over the nature, extent,

and duration of services and supports that are available to people with disabilities and older persons should rest with the person receiving those services and their families.

Beginning with our work with Monodnock Development Services in Keene, NH, we supported several iterations of the self-determination model—Self-Determination for People with Developmental Disabilities, a 19-state replication of the Monodnock model; Independent Choices, a consumer-directed program for older adults; and Cash and Counseling, a Medicaid consumer-directed demonstration for older adults and persons with disabilities.

Our work on these programs suggests several lessons. First, when consumers, to the extent they desire, control decisionmaking about their care, they experience improved quality of life, greater self-confidence and personal autonomy, and improved access to services.

Second, implementation of this model and its values requires a serious commitment to change to ensure that decisionmaking rests with consumers and that services meet their needs.

Third, supportive services are necessary to promote independence and are integral to this effort.

The second lesson we have learned is about the alternatives to institutional care. Today the only widely available service for most Americans with long-term care needs is nursing home care. As a foundation, we have worked to expand the number of home and community-based long-term care options for all Americans, most especially low-income seniors and disabled adults.

Linking housing with services has been one successful model that we have invested in. Two Robert Wood Johnson Foundation programs for low-income seniors—No Place Like Home and Coming Home—have worked extensively in this area.

Another grant to the Corporation for Supportive Housing resulted in the development of housing-based integrated service models for low-income adults with chronic physical and mental illnesses.

For many people, receiving supportive services in their housing environment can make the difference between institutionalization in a nursing home and aging in one's own apartment or home—what we in the field call "aging in place"—and can also reduce hopelessness for chronically ill and disabled adults.

We have also supported innovations in community-based services. Three examples of this work include Building Health Systems for People With Chronic Illness; the Program of All-inclusive Care for the Elderly, or PACE; and Partners in Caregiving. Building Health Systems focused on the difficult challenges of overcoming fragmentation of services, financing barriers, and the prevalence of episodic care through 24 different programs.

The PACE program in contrast replicated a single successful model that integrates Medicare and Medicaid financing streams and acute and long-term care services within a single delivery system.

In addition, our support for the Partners in Caregiving Program ensures that adult day centers help family caregivers by providing crucial services during work hours when many family members are not able to look after their loved ones.

Lesson three relates to the financing. Any discussion of long-term care reform would be incomplete without addressing financing questions.

Financial support for a variety of services is obviously critical to the viability of the service delivery system and other models we have funded. However, demonstration programs on their own cannot solve the underlying questions about the sources and nature of financing for long-term care services.

At the same time, our demonstration experiences do suggest lessons about the use of long-term care dollars. For example, we have learned that funding sources should cover a variety of services and a range of medical and social services in order to make consumer choice a reality.

We have also learned that the ability to leverage multiple funding sources, such as creating interrelationships between housing and supportive services, best enables older adults and adults with disabilities to remain in the community.

As we move forward, the Foundation's program efforts will focus on assisting family caregivers and strengthening the paid work force, encouraging communities to design, build, and strengthen their capacity for providing long-term care services, and promoting changes in public policy to increase consumer choice and to improve the coordination and financing of supportive services.

The Robert Wood Johnson Foundation recognizes that reforming the system must be complemented by a national effort to improve the health of older members of our society. To encourage this work, the Foundation is supporting numerous efforts, including a program to increase physical activity among mid-level and older adults, and also to improve clinical services for people with chronic illness and improve public awareness of issues related to chronic illness and disability.

We also hope to assist Federal and State policymakers as they consider a variety of issues through improved information and resources, through technical assistance, and through the development of policy options. Our work suggests that long-term care reform will need to incorporate the Federal, State and community perspectives and foster public-private partnerships in order to find solutions to the most pressing issues confronting vulnerable older adults and their caregivers.

The several decades of experience in this field demonstrate the formidable challenges of improving America's long-term care system. Our experiences also highlight many opportunities and provide significant lessons for the nation as we embrace this challenge. We will need to develop delivery systems, service capacity, and financing streams that provide vulnerable and frail elders and people with disabilities with choices about how to live their lives and receive the care they need.

We will need to pay particular attention to supportive services and housing issues, which determine whether those individuals can maintain the autonomy and independence they desire.

The Foundation will continue to work with providers, public agencies, consumers, researchers and others to refine the models we have, test new ideas, and build capacity within our communities and our nation to meet these challenges. We would be happy to

connect you with projects that we support across the country that are grappling with these issues.

I thank you for your attention and look forward to your questions.

The CHAIRMAN. Thank you very much, Dr. Lowe.

Next, Dr. Laura Brackin from Louisiana.

[The prepared statement of Dr. Lowe follows:]

Statement of Jane Isaacs Lowe, PhD

Senior Program Officer

The Robert Wood Johnson Foundation

Before the

Special Committee on Aging

United States Senate

September 24, 2001

Statement of Jane Isaacs Lowe, PhD
Senior Program Officer
The Robert Wood Johnson Foundation

Mr. Chairman and members of the committee, good afternoon. My name is Jane Isaacs Lowe. I am a senior program officer at The Robert Wood Johnson Foundation in Princeton, NJ, whose mission is to improve the health and health care of all Americans. Thank you for inviting me to testify this afternoon on the work the Foundation has done to improve long term care in America. I am pleased to share our experiences with long term care delivery systems and financing issues that may be of use to the committee.

Introduction

Let me begin by telling you about Mrs. K. Mrs. K lived by herself on a farm in rural Illinois where she raised six children, taught school, and cared for invalid relatives. At 85, she suffered from hearing and vision loss, and was increasingly confined to a wheelchair due to severe arthritis. An Illinois home care specialist visited several times a week as did several of her children, but she was slowly losing the ability to live independently without help. Although she resisted giving up her home, she was amenable to living in a senior apartment complex. However, the nearest facility was far from her hometown and also beyond her financial means. She feared that it was just a matter of time before she would have to go to a nursing home.

Mrs. K was lucky—an affordable assisted living facility was built ten miles from her home as a result of the Foundation's Coming Home Program, a national program designed to increase the number of affordable assisted living programs in rural America. Mrs. K was one of the first seniors to qualify for residence in Cache Valley located in an Illinois town of 550 people. Today, she has her own apartment filled with her furniture and adorned with prized possessions reflecting her long life. Mrs. K receives meals, and help with dressing, bathing and medications. As a result, Mrs. K feels more connected to others, and to quote her, "I have friends, my independence and help when I need it."

There are many people like Mrs. K who are living in rural, suburban and urban areas. They are alone and isolated, living with chronic illnesses and limited resources. Like Mrs. K, they need affordable housing and service options.

Mrs. K's story is just one example of our work to develop long term care programs for vulnerable and frail older persons and people with disabilities. The Robert Wood Johnson Foundation's work in this area is funded as part of our goal to improve care and support for people with chronic illnesses, which has been one of our principal programming goals since 1991. Since that time, the Foundation has awarded more than 3,000 grants totaling close to one billion dollars to improve long term care and care for people with chronic illnesses. Our strategies to advance long term care transcend any single approach--together with our grantees, we have developed many solutions to ensure that consumers have a voice in their own care, to build a flexible and responsive delivery system and to design and test a range of financing mechanisms.

It is apparent to observers from every perspective that the current health care and social service system do not meet long term care needs. The health care delivery system, which favors acute and institutional care over preventive and community-based care, and clinical services over supportive and enabling services, is often unresponsive to older persons and people with disabilities. Today, in the wake of the *Olmstead* decision, there are continued concerns about long term care coverage and costs, building community capacity for care, and the anticipated growth in the number of older Americans. As a result, there is heightened interest in changing long term care systems at the national, state, and local level. Our experience with demonstration programs and our other grantmaking activities have particular relevance as policymakers seek to guide these changes.

What We've Learned

Through our grantmaking, we test new ideas and develop new models. These innovations necessarily fall short of broad-scale change, but with careful interpretation, provide valuable lessons. The three most salient lessons we've learned from our grantmaking are:

- Consumers and/or their families must be involved in decisions about their care.
- More alternatives to institutional long term care must be created.
- Financing must be more flexible in order to support these options.

Consumer Directed Care

One very promising model of care that the Foundation has supported in the past decade is consumer directed care. This model is based on the premise that control over the nature, extent and duration of services and supports that are available to people with disabilities and older persons should rest with the person receiving those services and their families.

The Robert Wood Johnson Foundation's involvement with consumer directed care began with Monodnock Developmental Services in Keene, New Hampshire. The goal of the project was to improve the lives of 45 individuals with developmental disabilities by improving the quality and cost effectiveness of their care. These consumers, with dollars instead of services, took charge of their own lives and selected and were able to pay family and professional caregivers alike for their care. And these arrangements were no more costly than the system they replaced.

Based on the success of the Monodnock program, the Foundation created a national program to test self determination in 19 states. We later applied the lessons learned from this demonstration project to support Independent Choices, a consumer directed program for older adults, and Cash and Counseling, a Medicaid consumer directed demonstration for older adults and persons with disabilities.

Our work on these programs suggests three further lessons. First, when consumers – to the extent they desire – control decision-making about their care, they experience improved quality of life, greater self confidence and personal autonomy, and improved access to services. Second, implementation of this model and its values requires a serious commitment to change. Successful implementation requires new clinical and financial incentives for providers, as well as cultural change within public agencies to ensure that decision-making rests with consumers and that services meet their needs. Third, supportive services are necessary to promote independence and are the keystone of this effort. Such services must be broadly defined, and they may range from providing at-home personal care to making it possible for a consumer to purchase a motorized wheelchair that will allow them to move more freely through their community and do their own grocery shopping.

Increasing the Availability of Alternatives to Institutional Care

Today, the only widely available service for most Americans with long term care needs is nursing home care. As a Foundation, we have worked to expand the number of options for all Americans, most especially low income seniors. We have supported the expansion of affordable home and community based long term care options and have invested successfully in linking housing with services. Two Robert Wood Johnson Foundation programs for low income seniors, No Place Like Home and Coming Home, have worked extensively in this area.

No Place Like Home provided technical assistance and grant support to help state and local housing finance agencies finance and deliver supportive services for older people living in subsidized housing developments. For many people, receiving supportive services in their housing environment can make the difference between institutionalization in a nursing home and aging in one's own apartment or home—what we in the field call "aging in place."

The second program, Coming Home, demonstrates another way to link housing with supportive services, in this case within affordable assisted living facilities. This program combines real estate development with Medicaid coverage for supportive services within assisted living facilities.

Beyond the two housing programs that I have described, we have supported innovations by providers delivering community care services. Three examples of this work include Building Health Systems for People with Chronic Illnesses, the Program of All-Inclusive Care for the Elderly (PACE) and the Partners in Caregiving Program.

Building Health Systems focused on the difficult challenge of better coordinating the delivery of medical services and supportive services for people with long term care needs. This program supported the development of 24 models throughout the country to overcome fragmentation of services, financing barriers, and the prevalence of episodic care.

In the early 1990s, Robert Wood Johnson funded the development and replication of the PACE Program. Based on the On Lok model, PACE integrates Medicare and Medicaid financing streams and acute and long-term care services within a single

delivery system. The PACE program continues to evolve, as PACE sites experiment with greater use of home-based services.

Adult day centers, which RWJF has supported through its Partners in Caregiving program since 1986, provide formal day services for aging adults with long term care needs. Adult day centers are of tremendous help to family caregivers, because they provide crucial services during work hours, when many family members are not able to look after their loved ones. In that way, they allow people with long term care needs to continue living at home by taking the daytime burden off their families.

Financing

Any discussion of long-term care reform would be incomplete without addressing financing questions. Financial support for a variety of services is obviously critical to the viability of the service delivery systems and other models we have funded. A number of our programs use existing money in new ways, such as combining housing funding with Medicaid funding, or integrating acute and long-term care benefits from a combination of public insurance programs. However, demonstration programs cannot, on their own, solve the underlying questions about the sources and nature of financing for long term care services.

At the same time, our demonstration experiences do suggest lessons about the use of long-term care dollars. For example, we have learned that funding sources should cover a variety of services, and a range of medical and social services, in order to make consumer choice a reality. We have also learned that the ability to leverage multiple funding sources, such as creating inter-relationships between housing and supportive services, best enables older Americans to age in place.

Future Directions

As we move forward, the Foundation's work will be driven by our nation's need to prepare for the significant increase in the number of older adults, which will have a profound effect on our health care and social services systems as well as our broader culture. The Foundation's program efforts will focus on:

a) Assisting family caregivers and strengthening the paid workforce;

b) Encouraging communities to design, build and strengthen their capacity for providing long term care services;
c) Promoting changes in public policy to increase consumer choice and to improve the coordination and financing of supportive services.

Some of these efforts are still on the drawing board--such as our interest in enhancing the workforce--and others have been underway for some time. For example, the Foundation recently received letters of intent from 450 communities seeking to participate in Community Partnerships for Older Adults, an effort to improve local infrastructure for delivering long-term care services and social supports to vulnerable and frail elders and their caregivers. We believe that these new community efforts will provide inspiration to other communities struggling with similar concerns.

The Robert Wood Johnson Foundation recognizes that reforming the system must be complemented by a national effort to improve the health of older members of our society. To encourage this work, the Foundation is supporting numerous efforts. A new program, Increasing Physical Activity Among Mid-Life and Older Adults will work to encourage more older adults to remain or become physically active. The Foundation is also committed to improving clinical services for people with chronic illness, and improving public awareness of issues related to chronic illness and disability. This rich portfolio will certainly evolve over time.

We also hope to assist Federal and State policymakers as they consider a variety of issues through improved information and research, through technical assistance, and through the development of policy options. For example, we have funded a three-year project at Georgetown University to nurture a range of ideas for improving long-term care financing at the national level. This project will generate new creative proposals related to the financing and delivery of long term care as well as provide policymakers with thought-provoking ideas as they contemplate policy changes. We also provide technical assistance and mentoring support for state-level officials working on home and community-based long-term care programs.

Our work suggests that long term care reform will need to incorporate the Federal, State and community perspectives in order to find solutions to the most pressing issues confronting vulnerable older Americans and their caregivers.

Conclusion

The Robert Wood Johnson Foundation's decades of experience in this field demonstrate the formidable challenges of improving America's long-term care system. Our experiences also highlight many opportunities and provide significant lessons for the nation as we embrace this challenge. We will need to develop delivery systems, service capacity and financing streams that provide vulnerable and frail elders and people with disabilities with choices about how to live their lives and receive the care they need. We will need to pay particular attention to supportive services and housing issues, which determine whether these individuals can maintain the autonomy and independence they desire. The Foundation will continue to work with providers, public agencies, consumers, researchers and others to refine the models we have, test new ideas, and build capacity within our communities and our nation to meet these challenges. We'd be happy to connect you with projects in your state in your state that are grappling with these issues. I thank you for your attention, and look forward to your questions.

STATEMENT OF LAURA BRACKIN, DIRECTOR, LOUISIANA GOVERNOR'S OFFICE OF DISABILITY AFFAIRS, BATON ROUGE, LA

Ms. BRACKIN. Mr. Chairman, Senator Craig, my name is Laura Brackin, and I am Executive Director of the Governor's Office of Disability Affairs in the State of Louisiana.

I thank you for the opportunity to appear before you today and provide testimony regarding long-term care reform. My role here today is to share with you a State's perspective on long-term care reform, including the impact of Olmstead and Barthelemy, and the process of partnership-building and solution-sharing between the aging and disability communities in Louisiana.

The 1999 U.S. Supreme Court decision, *Olmstead* v. *L.C.*, had a dual effect on the State of Louisiana. First, it became the legal basis for Louisiana's version of Olmstead, which is *Barthelemy* v. *Department of Health and Hospitals.* Second, it was the central force that led to a partnership between the aging and disability communities in the State of Louisiana.

In April of 2000, the Advocacy Center, which is the State's protection and advocacy system, filed a class action lawsuit which we refer to as "Barthelemy." This lawsuit was filed on behalf of persons in nursing homes or at imminent risk of being placed in nursing homes. The main provisions of the lawsuit, which are included in Attachment A of my written testimony, are designed to increase the options for community services, ensure that individuals are informed of their options and that professionals are trained regarding the availability of community services.

The implementation of the provisions in the lawsuit will form some of the initial action steps of long-term care reform in Louisiana.

During the time that the Barthelemy lawsuit was being negotiated, Olmstead was creating action at both the State department level and the grassroots level. On July 26, 2000, at the request of the Office of Civil Rights, the Louisiana Department of Health and Hospitals held a meeting between DHH officials, consumers, family members, advocates, and other stakeholders. Unsure as to whether DHH would proceed with the development of an Olmstead plan, aging and disability advocates held a meeting of their own in August to discuss common ground. It was there that Olmstead became the catalyst in forming a partnership between the aging and disability communities.

Aging and disability advocates realized that they had similar needs, that they were fighting for the same pots of money, and that they would be a greater force if they were united. They formed a group called the Louisiana People's Olmstead Planning Group, which was called LAPOP, although I must say they hate the name and have since changed it to LADAP, Louisiana's Disability and Aging Partnership.

The intention was to develop a "people's plan" since they were unsure as to whether or not the State was going to proceed with an Olmstead plan. It was co-chaired by a representative of the developmental disabilities community and a representative of the aging community. Strong efforts were placed on ensuring that the

members of the adult disability community and the mental health community were also involved as part of their steering committee.

This was a very strong and positive collaborative effort, because not only for the first time were the developmental disability community and the aging community working on the same goals, but all four disability groups were at the same table, being equal decisionmakers in the direction of an Olmstead plan for Louisiana.

In January of 2001, the LAPOP group determined that legislation supporting the development of their "people's plan" would help to ensure effective implementation of the plan. Therefore, they worked collaboratively with legislators, the Department of Health and Hospitals, the Governor's Office of Disability Affairs, and numerous disability and aging organizations to develop and seek passage of Senate Bill 855. This bill was signed into law by Governor Mike Foster and is now Act 1147.

Act 1147 creates the Disability Services and Support Systems Planning Group, which is led by a consumer task force. It is comprised of numerous aging and disability consumers, family members, advocates, State agencies, and other interested individuals, and is now the entity responsible for the development of a plan for long-term care reform in the State of Louisiana.

On a national level, Olmstead, the President's Executive Order, the systems change grants, and other Federal directives were some of the innovative initial steps in establishing Federal and State environments which were conducive to long-term care change.

On a State level, implementation of the provisions of the Barthelemy lawsuit will function as a change agent for future reform of long-term care in Louisiana.

There are several other factors, though, which will force our long-term care system to change. The rapid growth in the aging population, including a cohort, namely the baby boomers, who may not accept institutionalization as a prerequisite for receiving long-term support and services, will create a greater demand for long-term care services, including greater demands upon State and Federal budgets and on family members.

Reduction in birth rates, greater mobility of working Americans, and the increased participation of women in the work force will decrease the capacity for family members to provide care for family members who are aging or disabled.

Another factor is the new, reinvigorated, and politically potent coalitions between aging advocates and disability advocates who have been brought together and fueled by Olmstead.

Cross-fertilization between the fields of disability and aging are evolving such that advocates for the aging will begin demanding the same civil rights, community integration, and consumer-directed supports for older adults with disabilities as advocates and self-advocates have been demanding for younger adults with disabilities.

Our society is rapidly evolving such that consumers, family members, and advocate are no longer buying into the notion of predetermined categories for disability or aging. Instead, they are banding together and working toward a universal system for all people with disabilities regardless of age.

One of the most important mechanisms for long-term care change will be the development of partnerships such as in the Displaced Services and Support System Planning Group in the State of Louisiana. Partnerships also need to be formed between State agencies that provide services, partnerships between State and Federal Government, public and private partnerships, but most importantly, partnerships between States and consumers, family members, and advocates. And these partnerships need to include collaboration on grants, policies and procedures, program development and strategic planning.

We have an ingrained system, and therefore, incentives are needed to change that system. I would like to share with you a couple of short-term or quick fixes that I believe may help us in moving toward long-term care reform.

One is that regulations need to be changed so that family members can be reimbursed for care. There needs to be flexibility in the use of long-term care dollars so that family members can do what they are able to do for other family members who are aging or disabled, but they can get the support in the way that they need it most. Costs will be controlled because they are not going to be reimbursed for unnecessary 24-hour care.

States must be allowed to bundle Medicare and Medicaid services for a definable population across all age groups and use the money as a research and demonstration waiver to allow more flexibility. It is anticipated that this will be cost-neutral for Louisiana and also cost-neutral for the Federal Government.

We must enhance the Federal match rate for home and community-based services similar to what was done with the Family Opportunity Act, by either removing nursing home care as a required entitlement benefit under Medicaid and making long-term care services the required benefit so that States have some flexibility in how and where to deliver long-term care services, or make home and community-based long-term care services a required benefit under Medicaid to be on the same level as nursing homes. Another option that would put them on the same footing would be the passage of MiCASSA.

We must provide Federal dollars to assist poor States with excess institutional capacity to buy back certificates of need for surplus nursing home beds. This will produce cost savings in States with too many nursing home beds and should provide nursing homes with the resources for them to retool. Bed buybacks and bed-banking could be used to encourage the retooling of nursing homes so they would move toward more home and community-based care.

We must change Federal laws and regulations to allow for Cash and Counseling programs.

We must de-link eligibility requirements for home and community-based services from eligibility requirements for institutional care. I would like to point out that it is easier to get into an institution than it is to receive home and community-based care. Eligibility determination requires that you describe an individual's deficits as opposed to his strengths and weaknesses. This forces an approach of viewing the negatives as opposed to viewing a broad array of options. Eligibility is deficit-based; therefore, the family is

forced to describe the person as being as needy as possible to get the minimum amount of care.

We must have an enhanced Federal match and short-term Federal program to buy back nursing home beds in States where there is excess nursing home capacity. This would be a one-time-only option; then, nursing homes would enter into a competitive market. This would require nursing homes to retool and would create incentives for them to provide other kinds of services and supports.

We currently have a long-term care system that was built on a model for acute care—namely, the hospital—rather than for chronic care. We must rationalize our system of long-term care so that health care is incorporated into the context of everyday life. Normal, everyday life in the community should not have to stop just because a person needs chronic care and long-term support.

There are a few long-term issues that would need to be addressed in dealing with long-term care reform. Incentives are needed to create equity in States between the public and private sector for direct-support professionals. This could be achieved by funding the recommendations as outlined in the reauthorization of the Developmental Disabilities Act.

Another issue that needs to be addressed is that there is currently a work force crisis. Studies show that care from family members is a huge unreimbursed service. This is a double dilemma for the developmental disabilities population being cared for by aging family members.

The services that they provide keep individuals out of more costly and restrictive environments. However, as the caregivers are aging, it takes a toll on them, impacting women more than men. One way to deal with this is to support family members so that they may provide care for the family member who is aging or has a disability. This will not replace the current work force but will help build a more comprehensive work force that is capable of meeting growing consumer demands.

Overall, we need a comprehensive long-term care system that addresses issues such as flexibility, supporting rather than replacing family caregiving, reimbursement rates, workforce capacity, housing, consumer direction, financial incentives for providers to re-tool in order to meet consumer demand, development of a broad array of options, informed choices, transportation and recreation.

This new system should be guided by a focus on serving all persons with disabilities, regardless of whether the disability was acquired by birth, accident or injury, or by the aging process.

But most importantly, I would like to leave you with one final concept. There is a term that is used in the disability community and that is: "Nothing about me without me." What that means is that services and systems should not be developed unless the consumers are meaningfully involved in the development of the services that affect their lives.

Thank you.

[The prepared statement of Ms. Brackin follows:]

State of Louisiana

Office of the Governor
Office of Disability Affairs

Special Committee on Aging
United States Senate
September 24, 2001
1:00 p.m.

Long Term Care After *Olmstead*: Aging and Disability Groups Seek Common Ground

Testimony by:

Laura Brackin, M.A., Executive Director
Governor's Office of Disability Affairs
State of Louisiana

Mr. Chairman and Members of this Committee,

Thank you for the opportunity to appear before you today and provide testimony regarding long-term care reform. This hearing, the third in a series of hearings dedicated to long-term care, is focused on: the need for reform of our current system for providing and financing long term care; the local, state, and national context within which that reform will occur; appropriate mechanisms for encouraging and facilitating the process of reform; and recommendations for both immediate and long range system changes. My role here today is to share with you a state's perspective on long term care reform, including the impact of Olmstead and Barthelemy, and the process of partnership-building and solution-sharing between the aging and disability communities in Louisiana.

The Impact of Olmstead on Louisiana

The 1999 U.S. Supreme Court decision, Olmstead v. L.C., had a dual effect on the state of Louisiana. First, it became the legal basis for Louisiana's version of Olmstead, the Barthelemy v. Department of Health and Hospitals lawsuit. Second, it was central force that led to a partnership between the aging and disability communities in the state of Louisiana.

In April 2000 the Advocacy Center, the state's Protection and Advocacy System, filed a class action lawsuit, L.B. et al. V. Department of Health and Hospitals, referred to as "Barthelemy". This lawsuit was filed on behalf of persons in nursing homes or at imminent risk of being placed in nursing homes. This main provisions of the lawsuit (see attachment A) are designed to increase the options for community services, ensure that individuals are informed of their options, and professionals are trained regarding the availability of community services. The implementation of the provisions in this lawsuit will form some of the initial steps of long-term care reform in Louisiana.

During the time that the Barthelemy settlement was being negotiated, Olmstead was creating action both at the state department level and at the grassroots level. On July 26, 2000, at the request of the Office of Civil Rights, the Louisiana Department of Health and Hospitals (DHH) held a meeting between DHH officials, consumers, family members and advocates. Unsure as to whether DHH would proceed with the development of an Olmstead plan, aging and disability advocates held a meeting in August of 2000 to discuss common ground. It was there that Olmstead became the catalyst in forging a partnership between the aging and disability communities. Aging and disability advocates realized that they had similar needs, were "fighting for the same pots of money," and that they would be a greater force if they were united.

The aging and disability advocates formed a group called the Louisiana People's Olmstead Planning Group (LaPOP), with the intention of developing a "People's Plan." LaPOP was co-chaired by a representative of the developmental disabilities community and a representative of the aging community. Strong efforts were placed on ensuring that members of the adult disability community and the mental health community were also involved as part of the LaPOP steering committee. This was a very strong and positive collaborative effort. Not only were the developmental disability community and the elderly community working together toward a common goal, but all four disability groups were at the same table and were equal decision makers in the direction of an Olmstead plan for the state of Louisiana.

In January of 2001, the LaPOP group determined that legislation supporting the development of their "People's Plan" would help to ensure effective implementation of the plan. Therefore, LaPOP worked collaboratively with legislators, DHH, the Governor's Office of Disability Affairs, and numerous disability and aging organizations to develop and seek passage of Senate Bill 855. This bill was signed into law by Governor M.J. "Mike" Foster and became Act 1147. Act 1147 creates the Disability Services and Supports System Planning Group (DSSS), which is led by a Consumer Task Force. The DSSS planning group, comprised of numerous aging and disability consumers, family members and advocates, is now the entity responsible for the development of a plan to reform long term care in the state of Louisiana.

Environments for Long-Term Care Change

On a national level, Olmstead, the President's Executive Order, the Systems Change grants, and other federal directives were some of the innovative initial steps in establishing federal and state environments conducive for long term care change. On a state level, implementation of the provisions of the Barthelemy lawsuit will function as a change agent for future reform of long-term care in Louisiana.

There are several other factors, which will force our long-term system to change. The rapid growth in the aging population, including a cohort – namely Baby Boomers – who may not accept institutionalization as a prerequisite for receiving long term supports and services, will create a greater demand for LTC services, including greater demands upon state and federal budgets and upon families. Reduction in birth rates, greater mobility of working Americans, and the increased participation of women in the workforce will decrease the capacity for family members to provide care for family members who are aging or disabled. New, reinvigorated, and politically potent coalitions between aging advocates and disability advocates who have been brought together and fueled by Olmstead. Cross-fertilization between the fields of disability and aging are evolving, such that advocates for the aging will begin demanding the same civil rights, community integration, and consumer-directed supports for older adults with disabilities as advocates and self-advocates have been demanding for younger adults with disabilities. Our society is rapidly evolving such that consumers, family members and advocates are no longer buying into the notion of predetermined categories for disability or aging. Instead, they are banding together and working towards a universal system for ALL people with disabilities, regardless of age.

Mechanisms for Long-Term Care change

One of the most important mechanisms for long-term care change will be the development of partnerships. This includes partnerships between state agencies that provide services, partnerships between state and federal government, public and private partnerships, and most importantly partnerships between states and consumers, family members and advocates. Partnerships with consumers, family members, and advocates should include, but not be limited to: collaboration on grants, policy and procedures development, program development, strategic planning, etc.

Substance of Reform – Short Term

- Change regulations so that family members can be reimbursed for care.

- Flexibility in use of LTC dollars so that family members can do what they are able to do for the family member who is aging or disabled, but they can get the support in the way that they need it most. Costs will be controlled because they are not reimbursed for unnecessary 24 hour care.
- Allow states to bundle Medicare and Medicaid services for a definable population across all age groups, and use the money as a Research and Demonstration waiver to allow more flexibility
  a.) Totally cost neutral for Louisiana
  b.) Neutral to Federal government
- Enhance the federal match rate for Home and Community Based Services, similar to what was done for the Family Opportunity footing by either:
  a.) Removing nursing home care as a required benefit (entitlement) under Medicaid and making LTC services the required benefit so that states have some flexibility in how and where to deliver LTC, or
  b.) Make Home and Community-based LTC services a required benefit under Medicaid to be on the same level as nursing homes.
  (Another option is to put them on the same footing by passing MiCASSA. MiCASSA would make home and community based care a required benefit.)
- Provide federal dollars to assist poor states with excess institutional capacity to "buy back" certificates of need for surplus nursing home beds. This will produce cost savings in states with too many nursing home beds and should provide nursing homes with resources to re-tool Bed buy-backs and bed-banking could be used to encourage the retooling of nursing homes to provide home and community-based care.
- Change federal laws and regulations to allow for Cash and Counseling programs.
- Delink eligibility requirements for HCBS from eligibility requirements for institutional care. (Note: It is easier getting into an institution than it is to receive HCBS. Eligibility determination requires that you describe the individual's deficits as opposed to their strengths/assets. This forces an approach of viewing the negatives as opposed to creating a broad array of options. Eligibility is deficit based, therefore the family is forced to describe the person as being as needy as possible to get the minimal amount of care. "Why should we prove that she has the highest level of need to get the lowest level of care....skilled nursing versus active treatment and social opportunity in the community."
- Enhanced federal match and short-term federal program to buy back nursing home beds in states where there is excess nursing home capacity. This program would be a one time only option. Then nursing homes would enter a competitive market. This would require nursing homes to re-tool and would create incentives for nursing homes to provide other kinds of services and supports.

Substance of Reform – Long-Term

We currently have a long term care system that was built on a model for acute care – namely the hospital – rather than for chronic care. We must rationalize our system of long term care so that "healthcare is incorporated into the context of everyday life" (Kane, Kane, & Ladd, 1998). Normal, everyday life in the

community should not have to stop just because a person needs chronic care and long-term support.

Incentives are needed to create equity in states between the public and private sector for Direct Support Professionals (i.e. salaries, benefits, and career ladder). This can be achieved by funding the recommendation as outlined in the Reauthorization of the Developmental Disabilities Act.

There is a workforce crisis. Studies show that care from family members is a huge unreimbursed service. This is a double dilemma for the Developmental Disabilities population being cared for by aging family members. Of home and community based individuals, 90% of long term care for elders is provided by family members. The services they provide keep individuals out of more costly and restrictive environments, i.e. institutions. However, those caregivers are aging and caregiving takes a toll on the health of the caregivers, impacting women more than men. One way to deal with this is to support family members so that they may provide care for the family member who is aging or has a disability. This will not replace the current workforce but will help build a more comprehensive workforce that is capable of meeting consumer demands.

Overall, we need a comprehensive long term care system that addresses issues such as: flexibility, supporting rather than replacing family caregiving, reimbursement rates, workforce capacity, housing, consumer direction, financial incentives for providers to re-tool in order to meet consumer demand, development of a broad array of options, informed choice, transportation, recreation and social activities. This new system should be guided by a focus on serving all persons with disabilities regardless of whether the disability was acquired by birth, accident/injury, or by the aging process. But most importantly, we should adhere to the concept of "Nothing about me, without me," meaning that services and systems should not be developed unless consumers are meaningfully involved in all aspects of the development of the services that affect their lives.

Appendix A

Barthelemy Case Settlement

Louisiana's Advocacy Center announces agreement to settle a statewide class action lawsuit that will have a dramatic impact on long-term care services in Louisiana. Lois Simpson, Executive Director of the Advocacy Center, says the Barthelemy settlement represents the first crack in the wall that has kept Louisianians with disabilities imprisoned in institutions. "People want change and this settlement will help people with disabilities and seniors achieve the changes they have long been waiting for."

The suit, Barthelemy v. Louisiana Department of Health and Hospitals, was filed over a year ago in federal court on behalf of five individuals then living in nursing homes, one individual at risk of nursing hoe admission and one non profit group that serves people with sever disabilities. Because the suit is a class action, the 36-page agreement potentially covers hundreds – and possibly thousands – of the state's 27,000 nursing-home residents, as well as those in hospitals or living at home but at imminent risk of going into nursing homes.

Home and community based services for adults with disabilities and seniors in Louisiana are generally provided through Medicaid "waiver" programs. Such waiver programs have years-long waiting list for very few spaces. These programs offer personal care, home modification, adult day care, and emergency response systems, and are key to avoiding institutionalization, advocates say.

Key provisions of the settlement are as follows:

- The settlement applies to persons who are in nursing homes or are at "imminent risk" of having to go into a nursing home. "Imminent risk" is defined as having a primary caregiver with a disability or over the age 70, or likely to require admission to a nursing facility, or to face deterioration in condition, within the next 120 days.

- The State will make "all reasonable efforts" to expand capacity to provide home and community based services to class members by seeking necessary approvals from the federal government, and working to increase provider capacity.

- Over the next four years, the State will reduce the existing waiting lists to the point at which class members have to wait no longer than 90 days for waiver services, after hey have been found eligible for those services

- The reductions will require minimum increases in the number of waiver slots in 3 different waiver programs, totaling 650 in 2002, 650 in 2003, 250 in 2004, 150 in 2005 and 150 in 2004.

- Information about community services will be made available through a statewide toll free hotline, and through the development of accessible written material disseminated by a variety of organizations, governmental agencies, and providers.

- The State will develop training material about the availability and advantages of community services for employees of medical facilities, case managers, physicians, social workers, and others involved in referring people for post-hospital care or other long-term care. It will train employees of state-operated medical facilities who are involved in that process, and will make training available for other providers.

- The State will advise all nursing home residents of community options for delivery of long term care services, will assure them that receipt of such services will not prejudice their receipt of nursing facility services pending the availability of community services, and will place them on appropriate waiting lists if they so desire.

- The State will amend the State Medicaid plan to include the optional "personal care services" as a Medicaid services, for persons in nursing homes or at imminent risk of nursing home placement, for a maximum of 56 hours per week.

- The State will develop and implement assessment procedures to identify the long-term care service needs and preferences of class members. Consumers, advocates, and providers of community services will participate in the development of these procedures.

- The assessment process will be reviewed by Plaintiffs' counsel following the assessment of a number of individuals in nursing facilities and in the community, with an opportunity for conferring as to proposed changes.

- Class members will be fully informed about he assessment process prior to being assessed. If it is found that community services are appropriate, class members will participate in the development of their comprehensive plans of care and transition plans. Fair hearings will be provided for areas of disagreement about the assessment process or the nature or amount of community service needed.

- The rates of pay of personal care attendants under the waiver programs at issue will be increased to $12 per hour by January 1, 2002. Case management fees will be increased in the largest waiver program. Caps on services will be removed to allow services to be provided up to the aggregate cost effectiveness limit.

- The State will report on programs in implementing the agreement, including numbers of class members assessed and the results, length of time the assessment process took, length of time to commencement of services, number of persons admitted to nursing facilities, and the numbers of persons transferred from nursing facilities to community placements.

A team including Philadelphia disability rights attorney Steve Gold, local Advocacy Center attorneys Nell Hahn and Terri Bewig, and Texas attorney, David Kahne represent the class.

For a copy of the settlement, contact the Advocacy Center Lafayette office: 1-800-822-0210.

The CHAIRMAN. Thank you, Ms. Brackin, and I thank all the members of the panel for their very important testimony.

Let me start with a question of a general nature on the Olmstead decision. It was brought under the Americans with Disabilities Act. The question that I think Ms. Allen and Ms. Rosenbaum particularly talked about was the coverage of the decision and that there is some uncertainty about what is covered and what is not, and there is a question in my opinion as to whether Congress needs to clarify that uncertainty.

Is the coverage of the requirement of the Supreme Court decision intended, do you think, to cover disabilities outside of the disabilities that that the Americans with Disabilities Act covers? I am thinking that you have mental disabilities, you have physical disabilities, and I guess you have disabilities that are just brought on by old age, which is not specifically diagnosed as being a hip problem or an Alzheimer's problem or some other type of mental disability.

Does the Olmstead decision cover people who are just old, for instance, who do not have a, "disability" in the more traditional sense, or is in fact just becoming very old a disability in and of itself under the terms of this decision? Can I get some discussion on that?

Ms. ROSENBAUM. Yes, Mr. Chairman. The way the ADA is structured is actually quite notable given your question. It is structured not to turn on specific conditions or specific groups of people. It defines "disability" in terms of your relative ability to function in relation to how people in your age and class would function. So, for example, as people age—the ADA definition of "disability" is that you have a physical or mental impairment which essentially affects your normal daily functioning, has a major impact on normal functions. Well, of course, as you age, what becomes normal daily functioning changes somewhat, so the presence of a disability in a person who is old is not measured against what that person should do when the person is 37. In that sense, it does not have an infinite capacity to classify everybody who is old as a person with a disability, and in fact, a couple of years ago, the Supreme Court made clear that there are real limits on who is disabled under the ADA.

The CHAIRMAN. So is it fair to say that the Olmstead decision, in your opinion, would cover any individual who needs care from the State program?

Ms. ROSENBAUM. It really covers any individual who, because of any kind of physical or mental impairment—and there is a long listing, but that is by class of impairments; there are a few exclusions under the Act—but who is unable to perform the normal tasks of living. It gets us away from the kind of work test that is in the Social Security Act or a "specific crippling conditions" test. So it is a very factual evaluation, and one of the big issues in the "Olmstead cases," as they are known, as access to the kinds of evaluations that assure that you are part of the group, figuring out what you need and how much resources and services you will then be eligible to receive.

So in terms of further congressional clarification, I actually think that the law is broadly enough conceived to allow a fair amount of policy implementation go forward under it.

The CHAIRMAN. Ms. Allen?

Ms. ALLEN. Yes, if I could add to that, the ADA—specifically, Title II—which was at question in this Supreme Court Decision, applied to people who are considered "qualified individuals." Within the context of public programs, what that means is that the individual needs to qualify for or meet the eligibility standards for that public program—for example, if a person is Medicaid eligible by reason of either disability as defined within the program or because of income standards, that person would be covered as a qualified individual under the ADA. If a person is at a much higher income standard and does not meet the qualifications to be eligible for the Medicaid program, that person would not specifically be covered by this provision of the ADA. I believe that is the case.

The CHAIRMAN. Ms. Allen, in your opinion, do you think this is something that Congress needs to elaborate on or clarify, or do you think the decision stands on itself and there is enough information to the various State providers to be able to operate with some degree of assurance that they are doing the right thing?

Ms. ALLEN. At this point, there are just scores of lawsuits that have been brought and are being settled. At this point, we have not analyzed and summarized the outcome of those. Ms. Rosenbaum perhaps has done more of that than we have. I am uncertain as to whether Congress needs to act yet, or does it need to instead better understand the resolution at lower courts and then how that is playing out.

The CHAIRMAN. And of course, we have to understand that this is not just for the elderly; children who are disabled would be eligible for the program and would come under the Olmstead requirements as well.

Ms. ALLEN. Absolutely.

Ms. ROSENBAUM. If I could just add, Mr. Chairman, in terms of what an individual who is covered by the Act could get a court to order, while the coverage under the Act is very broad, in fact, the remedies that the ADA allows are relatively narrow.

For example, there has now been a series of decisions, including one by the Supreme Court, saying that a court could not order a State Medicaid program to change its plan, to add services that are not in its plan. You could require a State to spend up to the limits of its State plan; if it says it has 3,000 waiver slots, as they are known, and is only funding 1,000 waiver slots, the State would have to spend up to 3,000. But you could not make a State—at least, not under current law—you could not make a State add State plan services that are not already covered under the plan.

You probably could not make a State add a housing program where there was none, but if a State had a housing program that had no capacity in it whatsoever for people with disabilities, that would be a different issue.

So it has to do with how you are administering your program.

The CHAIRMAN. It is a chicken-and-egg situation. There will not be a lot of other assisted living-type facilities if they know they are not going to be reimbursed through a State Medicaid program——

Ms. ROSENBAUM. That is right.

The CHAIRMAN [continuing.] but if they know that they are going to be reimbursed, you are going to see the creation of an entire in-

dustry trying to provide services that are outside the traditional institutionalized care.

Ms. Brackin, I take it our State of Louisiana was one of the first to reach an agreement or a settlement of the suit based on the Olmstead decision.

Ms. BRACKIN. Yes, sir. Our State was one of the first, and it provides more choice for individuals and ensures that individuals will be informed about the services. One of the problems right now is that people are not exposed to what their options are and feel that nursing home care is the only option that is available to them. So that is one of the things that will actually change by the Barthelemy lawsuit.

The CHAIRMAN. Do you mean the information being provided that there are alternatives?

Ms. BRACKIN. Yes.

The CHAIRMAN. Professor Rosenbaum spoke to the fact that because we have always had an institutional bias in all States—that that is what you do with disabled people—there are not in fact a lot of alternatives out there—and I am sure that our State is no different from the majority of them, where there are not a lot of alternatives.

How do you think that is going to change, and is it going to change?

Ms. BRACKIN. One thing that is also included in the Barthelemy lawsuit is that more options need to be available for individuals, so what will happen because of this lawsuit is that options will be created, and people will be informed about what those options are.

The CHAIRMAN. When you say "options will be created," are you envisioning State-constructed options, or are you talking about the ability to have people stay in a family type of setting, or both?

Ms. BRACKIN. Options will be created by both Federal and State policies and procedures. Right now, the infrastructure does not exist completely for anybody who is currently in a nursing home to move into the community and receive the supports and services that they need. One of the issues that I spoke about is the work force crisis. If you have an institutional setting, and one individual is supervising 20, and 20 move out into the community, you need to build the work force in order to meet that greater demand for personal care services. So what will happen is that as more and more people move into the community, we will start building that infrastructure to meet their needs; more programs will be developed.

Another issue that is going to be a problem that we are going to need to work on is transportation and recreation. There are so many issues that will need to be addressed. Some of them will be long-term, and some of them will be short-term, but we will develop a lot of those programs as people move into the community.

The CHAIRMAN. I note under "Substance of Reform, Short-Term Suggestions"—are those things that we are doing with the settlement agreement in Louisiana, or are these just recommendations for future consideration?

Ms. BRACKIN. Those are recommendations for future consideration.

The CHAIRMAN. Because you include some things that I know are going to be somewhat controversial, and that is not surprising because we are dealing with something that has been operating in only one fashion for a long period of time, but you are talking about changing regulations so that family members can be reimbursed for care.

Ms. BRACKIN. Yes. That is one way to address the work force crisis. Right now, family members are providing a lot of the care which is alleviating the burden on State and Federal Governments. We need to compensate family members to some degree for the care they provide so they can continue to provide that care.

The alternative, if that is not happening, is that some individuals will be forced to go into 24-hour nursing home care when 24-hour care is not what they need and would wind up being more costly.

The CHAIRMAN. You also mentioned that you have had some discussion on what is a required benefit and an entitlement, if you will. Removing nursing home care is a required benefit and entitlement under Medicaid, and making home and community-based long-term services a required benefit under Medicaid to be on the same level as nursing homes.

Can you give me some discussion on what your thinking is on that?

Ms. BRACKIN. Well, I could probably put together a more formal report at a later date and research some of the policies and procedures so that I do not misquote anything; but the point is that right now, they are not on the same footing, so it is creating an institutional bias when money is available for nursing home care, and it is not available for home and community-based services, so people are forced to go into that environment in order to receive services at all because that is where the money is.

The CHAIRMAN. I take it that under our State and probably under most of the States, if you are a Medicaid-eligible person, you are entitled to an institutional setting, i.e., nursing home, but you are not necessarily entitled to a home health care assistance program?

Ms. BRACKIN. Right.

The CHAIRMAN. Thank you.

Senator Craig.

Senator CRAIG. I will ask this question first because of the time involved; I think, Mr. Chairman, we have a vote planned for around 2 o'clock.

Dr. Lowe, I understand that in the early 1990's, with a grant from your organization, four States—California, Connecticut, Indiana, and New York—initiated programs to create public-private partnerships to provide for long-term care coverage without having to spend down the Medicaid eligibility.

Do you have any information on the status of those partnerships?

Dr. LOWE. I do not, sir, but I will be happy to get that information for you.

Senator CRAIG. If you would, I would appreciate it. I think that that is a potential model that we would want to look at to see how that is working.

[Information of Dr. Lowe follows:]

The Robert Wood Johnson Foundation's Partnership for Long Term Care was designed to explore alternatives for long term care financing by encouraging the blending of public and private insurance. Four States, California, Connecticut, Indiana and New York, received grants to implement programs that combine long term care insurance with Medicaid. All four of the program use private insurance to cover the initial costs of long term care. Consumers who purchase Partnership approved policies become eligible for Medicaid services after their private insurance is exhausted without spending down all their assets as is required to meet Medicaid eligibility criteria. All Partnership approved policies must meet quality guidelines established by the individual States.

To date, the four Partnership states report that a total of 70,027 policies have been issued with 57,963 policies in force. These data are from the States' internal reporting systems. A comprehensive analysis of this program can be found in the book, *Who will Pay for Long Term Care? Insights from the Partnership Programs,* Editor, Nelda McCall, Chicago: Health Administration Press, 2001.

Senator CRAIG. Ms. Allen, your testimony highlights that changing demographics will drive an increased demand for long-term care services. Are you expecting these demographics to result in demand for different services than are currently available? Does your analysis look at it in that way?

Ms. ALLEN. We were not specific in terms of the types of services, but we can expect they would be fairly comparable to what we have today. The services are actually quite far-ranging. Some of them are very hands-on, very physical, for people who have severe physical disabilities who might need help just moving about. But for many people, particularly aging seniors who have perhaps more cognitive disabilities, it might require more assistance just in managing their lives in terms of prompting them to do certain things for self-management.

The real issue, though, is simply the volume of additional services that will be needed. There are now about 35 million individuals who are age 65 or older, and by the year 2040, we are projecting that number to more than double, to more than 77 million people. That sheer volume of people alone will dictate that more care be available.

Senator CRAIG. It is a matter of cost per individual on an average out in that community of services searching for the service that fits them. By that very character, I assume you are extrapolating that the costs will go up dramatically.

Ms. ALLEN. Exactly, just because of the sheer numbers of affected individuals.

Senator CRAIG. Ms. Rosenbaum, beyond the work that you have done and the studies that are being done at the university, are you prepared to make specific policy recommendations to Congress or to us as we look toward reforming the country's long-term care system based on the analysis that you have done through these complaints?

Ms. ROSENBAUM. We are, Senator Craig, and I do concur with many of the recommendations made by Ms. Brackin. Within the Medicaid program itself, which of course, as Ms. Allen pointed out, is the biggest source of at least the health and health-related financing that is needed for all of this, there are a number of recommendations that would significantly improve the availability of Medicaid funding to States for these activities, and I think that probably Congress is going to have to confront head-on. In particular, there are a couple of different medical assistance limits that have always been in the program. One is the sacred cow that it

does not pay for room and board except in a skilled nursing facility. We need somehow to pay for physical adaptive housing at this point that goes beyond a simple apartment and can deal with all of these people with physical disabilities.

The other issue is exactly the issue that Ms. Brackin identified, which is that Medicaid does not do well by people who are trying to live at home with their own families. Whether it is because the family members are not paid, whether it is because the eligibility criteria do not work very well for people who are in their own homes, you cannot even trigger your coverage—that is a second problem.

The third problem is how poorly Medicaid works under the current structure for people with mental illness, because in order to qualify for these home care services, you have to essentially demonstrate your need for institutional care services, and of course, Medicaid coverage for institutional care services for people with mental illness is really not very available.

So I think that Congress is looking at some fundamental revisiting.

The final point I would make is that Medicaid runs off the Social Security definition of "disability," which is a work definition. That is so outdated today. If we are serious about being able to retool the program to support people living in their communities and working, we need to do more of what you did as part of the Ticket to Work Act, which is to rethink Medicaid's availability to people who are working and playing and living at home, but who need some extra services and supports. And today, Medicaid cannot really do that.

Senator CRAIG. Do you know of any analyses—I know that we have some limited working programs that actually go into the home—you talked about the physical characteristics of the home and adapting that or changing that to fit the needs of the individual. I was recently visited by a group that blends Federal and private money toward going in and making a home more accessible and usable by the senior who might otherwise need to be institutionalized or at least in a setting that would accommodate that. Out of that which you have looked at, does that seem to come forward as a fairly important part of the requirements or the requests of need?

Ms. ROSENBAUM. It is essential. If you look at the programs that the Johnson Foundation has funded over the years which build, of course, really, all on the original On Lok demonstration, which is the hallmark of Congress' thinking—if you go back 25 or 30 years, you could find the model back then—we have never really succeeded in building the elements of On Lok into ongoing policy options or requirements. We keep funding demonstrations or waivers or add-ons or alternative for subclasses of people.

I think that Ms. Brackin is exactly right that the very nature of the entitlement to assistance in Medicaid needs to be rethought. The days of having it simply be a recovery-based nursing home are behind us.

The other group that I would suggest to this committee is the Center for Independent Living, which has done pioneering work

over the years in thinking about what people with disabilities need to be able to adapt to a community.

Senator CRAIG. Thank you.

Mr. Chairman, I thank you.

The CHAIRMAN. I just have a few other questions.

Ms. Allen, you mentioned in your statement that some have interpreted the Olmstead decision as perhaps going farther than it actually did. Can you elaborate on that? What are they thinking—and that may not be correct.

Ms. ALLEN. I did not intend to suggest that it is incorrect. I was simply trying to portray that many, including the Health Care Financing Administration early on and now, of course, the Centers for Medicare and Medicaid Services, early interpreted that the reach of the decision was beyond the specific circumstances of the Olmstead case because it was an interpretation of the Americans with Disabilities Act, which has a broader definition.

This is what is helping, I think, to raise the concern for many, recognizing that we have this larger population, not only of those directly affected by mental illness or mental disability, but also aging seniors, and that is perhaps driving the concern about how to respond to this.

The CHAIRMAN. Thank you.

Dr. Lowe, you had talked about additional information for consumers. It seems like we always have an overabundance of information. I notice there is a whole list of different programs and things that are available. Is there, for instance, one website that would be helpful to people who are looking for the various services that may be available for someone who finds himself or herself in an Olmstead type of decision—because I take it that most of these decisions are not going to be made by the person who would benefit from the service directly as much as they will be by the children and grandchildren who are perhaps involved in taking care of that person.

If I had a person in my family, for example, and I wanted to know what was available, where would I go? Is there any single good place to start, rather than having a committee hearing like this?

Dr. LOWE. There are actually literally hundreds of websites out there that help people navigate the system by identifying sources of care. Some of the States and communities themselves have developed navigational internet systems. Charlotte, NC has one called "Just One Call" which connects people to actual services rather than just the giving them information.

But in terms of just one, I do not think there is just one. I think the situations that people find themselves in are complicated by their own individual circumstances, so there is no single site where every person who is looking for information go.

The CHAIRMAN. Is it something that we can encourage, maybe through the Centers for Medicare and Medicaid Services, that each State would develop some kind of a one-stop shopping center for information on this?

Dr. LOWE. I think there are examples of State one-stop shopping that would be worth looking at. New Jersey has developed the New Jersey EASE Program. I think the success of trying to match peo-

ple with services on the State level, when what they are really looking for are local services, makes these things very complex. So there is probably a need for State and local partnerships.

There are plans at the Federal level to develop a 211 information and referral telephone number. I am not sure where that stands but I think that that is something we ought to become more informed about.

The CHAIRMAN. Ms. Brackin, what about in Louisiana, if I were looking to find out what would be available for my father, for instance, is there a place I could go to find out? I think most people, when they think about an elderly person who is disabled because of problems associated with aging, instantly think of a nursing home; and for many, that is clearly the right solution, but for a large segment of them, it is probably not the correct and best available solution to the problem.

How can we help convey that additional information?

Ms. BRACKIN. There are two provisions of the Barthelemy lawsuit that were designed specifically to address that issue. One is that a toll-free number will be established that individuals can call to find out about the long-term care options that are available to them. The second is that there is a provision that the Department of Health and Hospitals will develop a training component for professionals that would be most likely to interact with individuals who would need long-term care services so that they are aware of the options that are available to individuals.

In addition, because of the Real Choice Systems Change Grants that came out from CMS recently, the Disability Services and Support Systems Planning Group is looking at a single point of entry instead of one-stop—now, with the Work Force Investment one-stop issues, we are trying to get away from the "one-stop" term—but a single point of entry for all populations is what they are looking at. They are in the process of developing an individual report that will go to David Hood, the Secretary of the Department of Health and Hospitals, and that single point of entry concept will be included in that report—not that the State needs to move on it very quickly but only that they want to mention that this is something that is very important that the Disability Services and Support Systems Planning Group wants to focus on and move toward in the State of Louisiana.

The CHAIRMAN. Under the concept of the 1–800 number if it is to be fully implemented, when you call that number, what is the concept, and to whom are you likely to speak?

Ms. BRACKIN. I cannot answer that because the settlement was just finalized not too long ago, but I can find that out.

The CHAIRMAN. I was just wondering if you were writing the recommendation as far as who would be at the other end of that 1–800 phone call, who would it be—what would your recommendation be?

Ms. BRACKIN. I have not been involved in it, but I will find out what that is going to look like.

The CHAIRMAN. I will tell you what I think, and I am not a party to the lawsuit, but I would want to be able to call a 1–800 number and say, "Look, my father is 90 years old, and he is having problems. What are my options?" and I would want that person to be

able to tell me, "Here are your options, and here is what the State helps with financially, and here is what the Federal Government helps with financially." At a minimum, I think that that is what the person should be able to convey to the caller.

Does anybody else have any ideas about that?

Ms. ALLEN. Yes, Mr. Chairman. As part of the Family Caregiver Support Act that was passed last year, a very essential component of that is to help connect family caregivers with community-based services where they live. The Act was funded at about $125 million for this year, which some would say there is some question about how far that will go, but certainly, one of the principles there was to establish a point of contact that one could call in one's own community.

Often, these are connected with the area agencies on aging, which are very pervasive, so to the extent that people know to look in their local telephone books and contact that agency, that is a good place to start.

The CHAIRMAN. We have so many programs, and sometimes you can get lost in the numbers; you do not know where to go. So it is sometimes very, very confusing.

Well, I think this has been very helpful. I would hope that all of the States could pay attention to the things that have been discussed at the hearing today and the information that is out there, because to a certain degree, I think there is a difference or a lack of understanding as to what Olmstead really stands for, what it requires the States to do, and States are in various modes of trying to reach agreements and settlements as a result of this decision. I am very pleased that Louisiana is one of the first to have actually reached a settlement which outlines a procedure for responding to the Olmstead decision. I think that everyone can be congratulated for that.

I think all of this points to a rather obvious problem. The Medicaid program was never intended to be a long-term care program for seniors in this country. It was a program that was intended to provide medical assistance for poor people. And now, I am sure that up to 20 percent of people—and more in my State—probably 90 percent-plus of the people in nursing homes in Louisiana, right——

Ms. BRACKIN. That is right.

The CHAIRMAN [continuing.] are covered by Medicaid—at least 90 percent if not more than that, and some of them, it is 100 percent of the people in nursing home settings being paid for through Medicaid, which requires you to become poor before you become eligible, when the truth in fact is that we ought to be looking at long-term care for everybody in this country. And we are in the process of trying to come up with some concepts and ideas for the next session to look at some recommendations on long-term care—how do we provide it; how do we help people have insurance for it, for instance; how do we get younger people to be more concerned about what their long-term care is going to look like when they become eligible for it and in fact become in need of that kind of care—because when you are 25 years old, you are not thinking about what it is going to be like when you are 75 or 85 or older than that in today's society.

So we are going to be looking at some recommendations to the relative committees in Congress to address the question of long-term care. But in the meantime, we are sort of stuck with trying to make a round peg fit into a square hole by using the Medicaid program to pay for long-term care coverage, although it was never intended to do that. So we come up against all of these difficulties, and that is one of the difficulties we have discussed today.

I thank all of you very much for being with us. I think you have enlightened a lot of people out there about what they can and cannot do and what they need to be doing, and we thank you for that.

With that, the Aging Committee will be adjourned.

[Whereupon, at 2:15 p.m., the committee was adjourned.]

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