

**Testimony Before the Special Committee on Aging,
United States Senate Regarding
Long Term Care After Olmstead:
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., L.L.M.
Assistant Research Professor

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

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Presented by Professor Rosenbaum

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, School of Public Health and Health Services, is one of the largest of public health school-based health law and policy programs in the U.S. today. This year nearly 40 J.D. and L.L.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 American 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 study² of "most integrated setting" administrative complaints filed since 1996 under the ADA 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.

¹ 527 U.S. 581 (1999)

² The first group of complaints was analyzed in late summer, 2001. 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 (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 to tell 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 non-elderly adults ages 22-64. At the same time, one in 7 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 family alone is 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 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 percent reported the presence of a physical disability along with one or more mental disability. Among nonelderly 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, Figure 10 shows that two-thirds report a single diagnosis. Among children, only about 40% experiencing 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 are also commonly reported in these requests.

Discussion

What does not and cannot come through in this presentation is the voices of the individuals themselves. Many of the complaints 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. This 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 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. These complaints indicate that a policy of long term care reform must encompass health care, housing, education and job training, income supplementation and support, transportation, 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.