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WORKING PAPER

An Analysis of *Olmstead* Complaints: Implications for Policy and Long-Term Planning

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Introduction

To better understand how the landmark Supreme Court decision in *Olmstead v. L.C.*¹ has influenced disability law, policy reform, and the health system, The George Washington University's Center for Health Services Research and Policy undertook a rolling, point-in-time, descriptive study² of "most integrated setting" administrative complaints filed with the United States Department of Health and Human Services' (HHS) Office for Civil Rights. These complaints were filed between 1996 and mid-2001 under Title II of the Americans with Disabilities Act (ADA)³ and Section 504 of the Rehabilitation Act of 1973.

This study was funded by the Center for Health Care Strategies in Lawrenceville, New Jersey. The Office for Civil Rights generously provided access to the 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. This Working Paper presents the aggregated findings from this anonymous analysis.

Background

The *Olmstead* decision represents the United States Supreme Court's first consideration of whether the institutionalization of disabled persons who could appropriately receive treatment in the community is permissible under Title II of the ADA. The Court's opinion, authored by Justice Ginsburg, reflects the enormous shift in how society views persons with disabilities, as well as what Americans have come to expect in terms of the integration of persons with disabilities into the broader community.⁴

The Supreme Court recognized that the ADA required the placement of persons with mental disabilities in community settings rather than institutions upon the satisfaction of three conditions:

Such action is in order when the State's treatment professionals have determined that the community placement is appropriate, the transfer from institutional care to a less restrictive setting is not opposed by the affected individual, and the placement can be reasonably accommodated, taking into account the resources available to the State and the needs of others with mental disabilities.⁵

Since the decision, persons with disabilities have filed hundreds of complaints with the Office for Civil Rights, alleging that they are either inappropriately institutionalized in violation of Title II of the ADA, as interpreted by *Olmstead*, or that they are at serious risk of institutionalization because of the lack of appropriate health services in the most integrated setting.

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 *Olmstead v. L.C.*, 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.

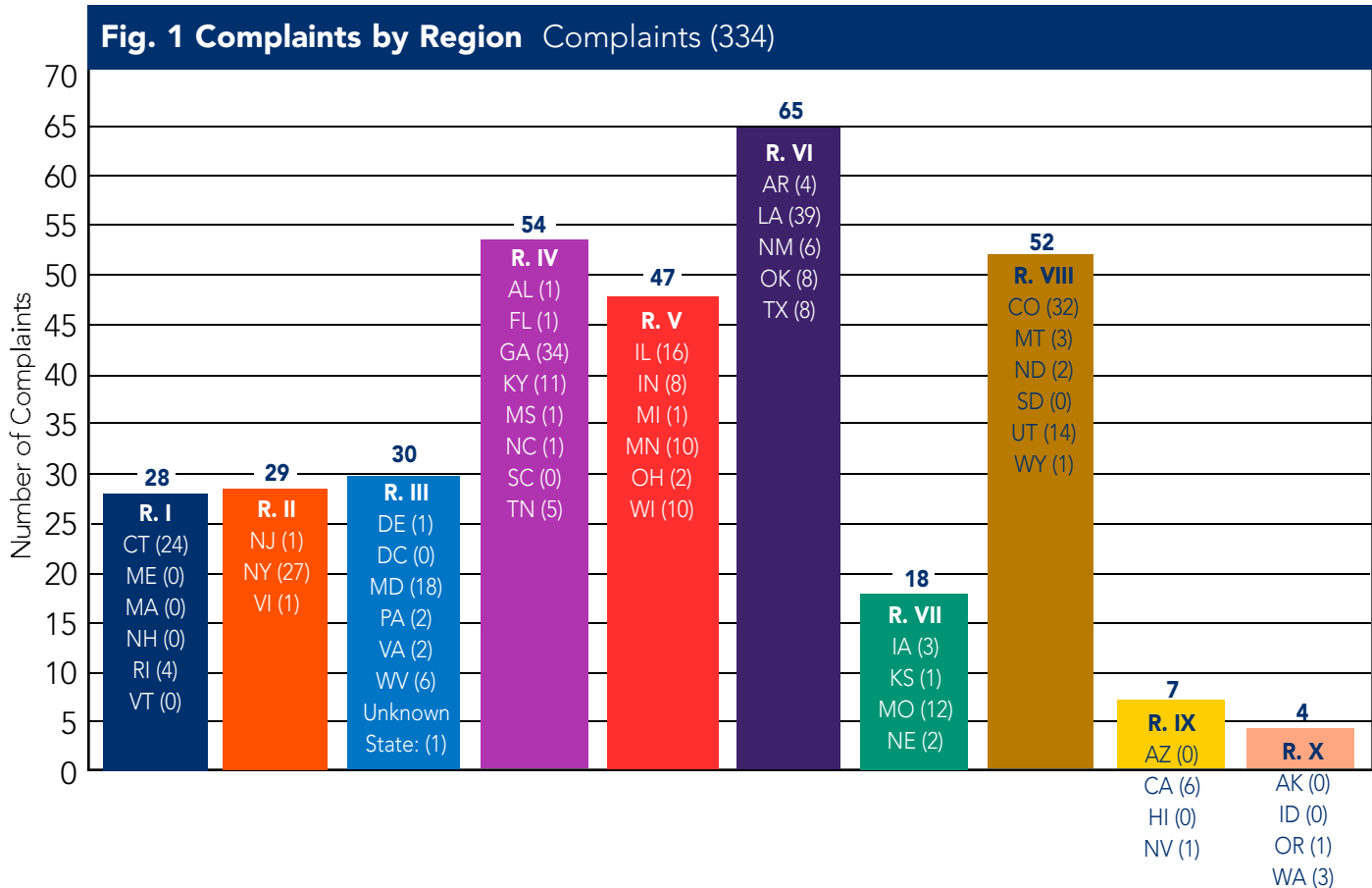
³ 42 U.S.C. §§ 12101 et seq.

⁴ Sara Rosenbaum, *Olmstead v. L.C.: Implications for Family Caregivers*, Address Before the Family Caregiver Alliance Conference (Oct. 27-28, 2001).

⁵ *Olmstead*, 527 U.S. at 587.

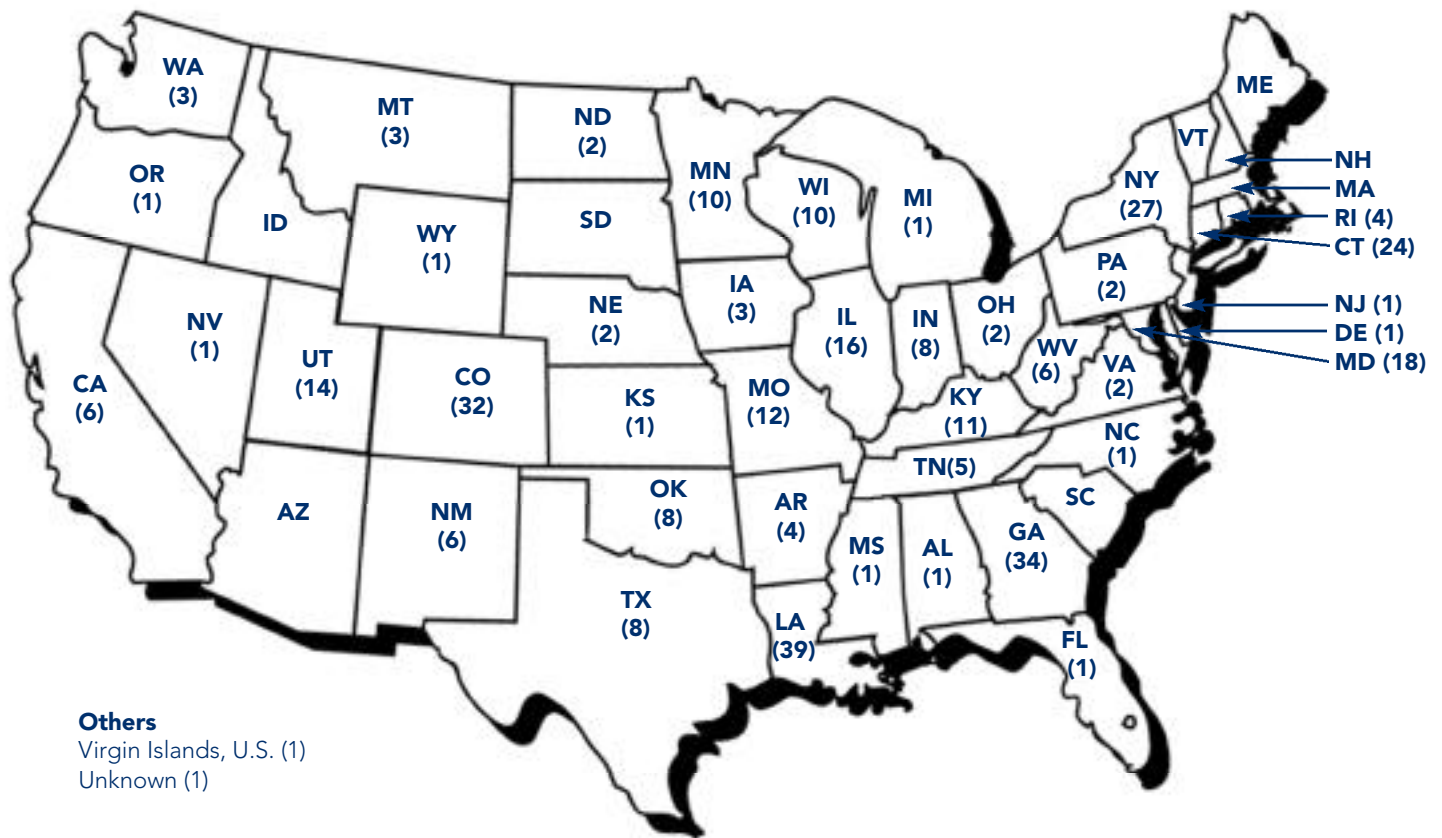
Findings

Location of complaints: Figures 1 and 2 show 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 ascertain the age of the complainant, but among the complaints where age can be discerned, unnecessary institutionalization (or its risk) affects persons of all ages (although adults ages 22-64 are the most prevalent complainants in our analysis). 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.

Fig. 2 Complaints by State Total Complaints (334)



Residential status: While the majority of complainants were institutionalized when they filed their complaints, a significant proportion — 30 percent — were residing in the community but at risk for what they at least considered medically unjustified institutionalization. Among child and adolescent complainants, an even higher proportion — 41 percent — reside in a community setting, but are at risk for what they perceive as medically unjustifiable institutionalization.

Living arrangements of community complainants: Well over half of the community resident complainants — 57 percent — were living with families but considered themselves to be in danger of medically unjustified institutionalization in the absence of assistance. Another 36 percent were living on their own (either alone or in another form of arrangement) at the time they filed their complaints. These numbers underscore that living with a family member or members alone, fails to provide a 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: Nursing homes were the single most common institutional setting among complainants, accounting for 60 percent of all complaints filed by institutionalized persons. Another 30 percent of complaints arose in psychiatric facilities, similar to the facts of the *Olmstead* case itself. Group homes, assisted living facilities, and hospitals comprised the remainder of institutional settings. In the case of children and adolescents, hospitals, skilled nursing facilities, and psychiatric facilities comprised the largest number of settings for the complaints among institutionalized persons, but a large portion of complaints — 43 percent — had insufficient information to make a determination. In the case of non-elderly adults, nursing home residents accounted for nearly half of the institutionalized complainants.

Nature of the disability: Figure 3 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 disabilities. Among non-elderly adults, Figure 4 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 percent of all cases. Figure 5 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 3 shows that two-thirds report a single diagnosis, while only approximately 40 percent of children experience a single diagnosis. Conversely, among children, more than one-third experience either dual or triple diagnoses; among non-elderly adults, Figure 4 indicates that only one-quarter experience dual or triple diagnoses.

Fig. 3 Nature of Complainant’s Disability Number of Complaints (334)

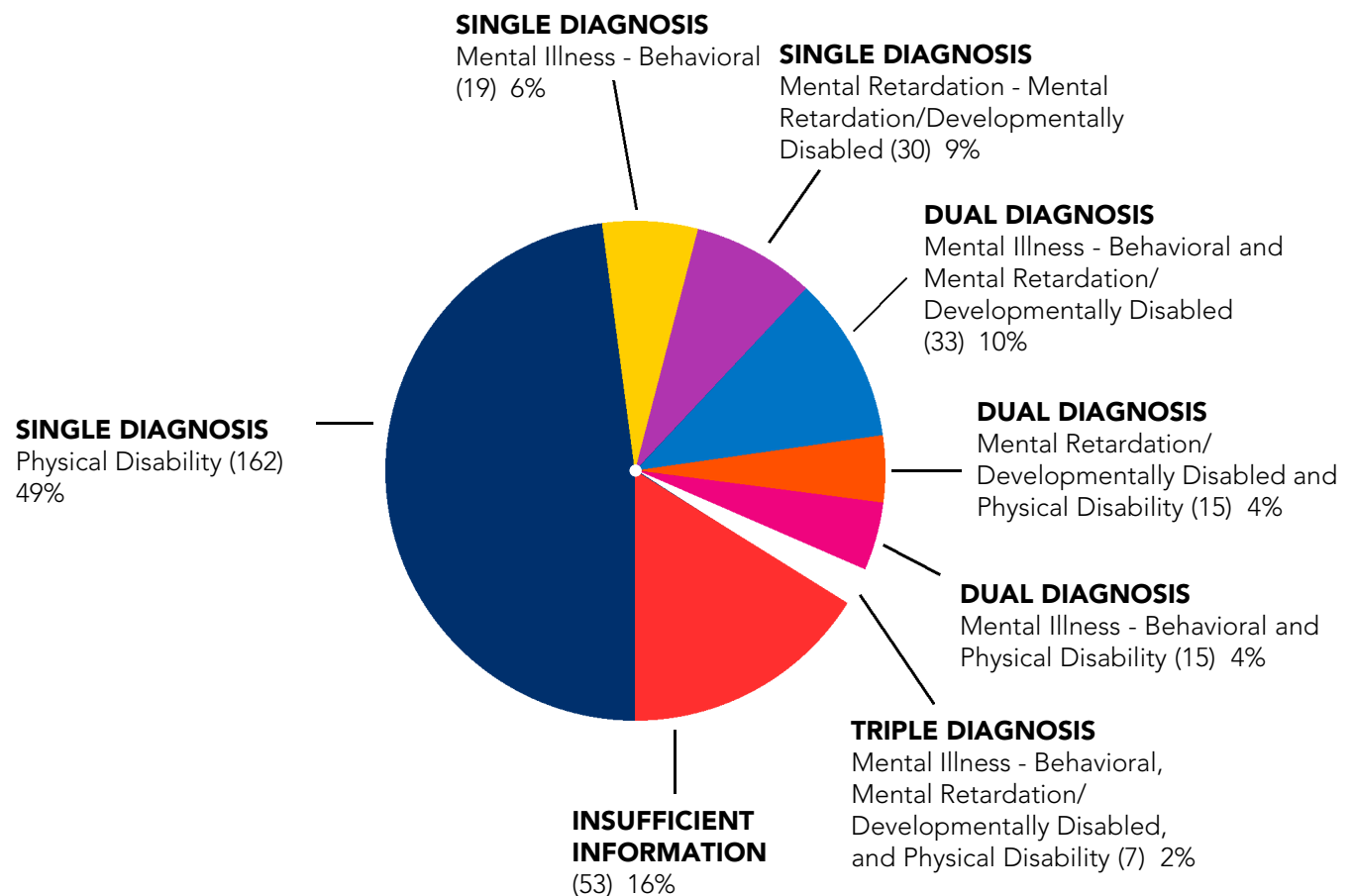


Fig. 4 Complainants by Disability Ages 22-64 (148)

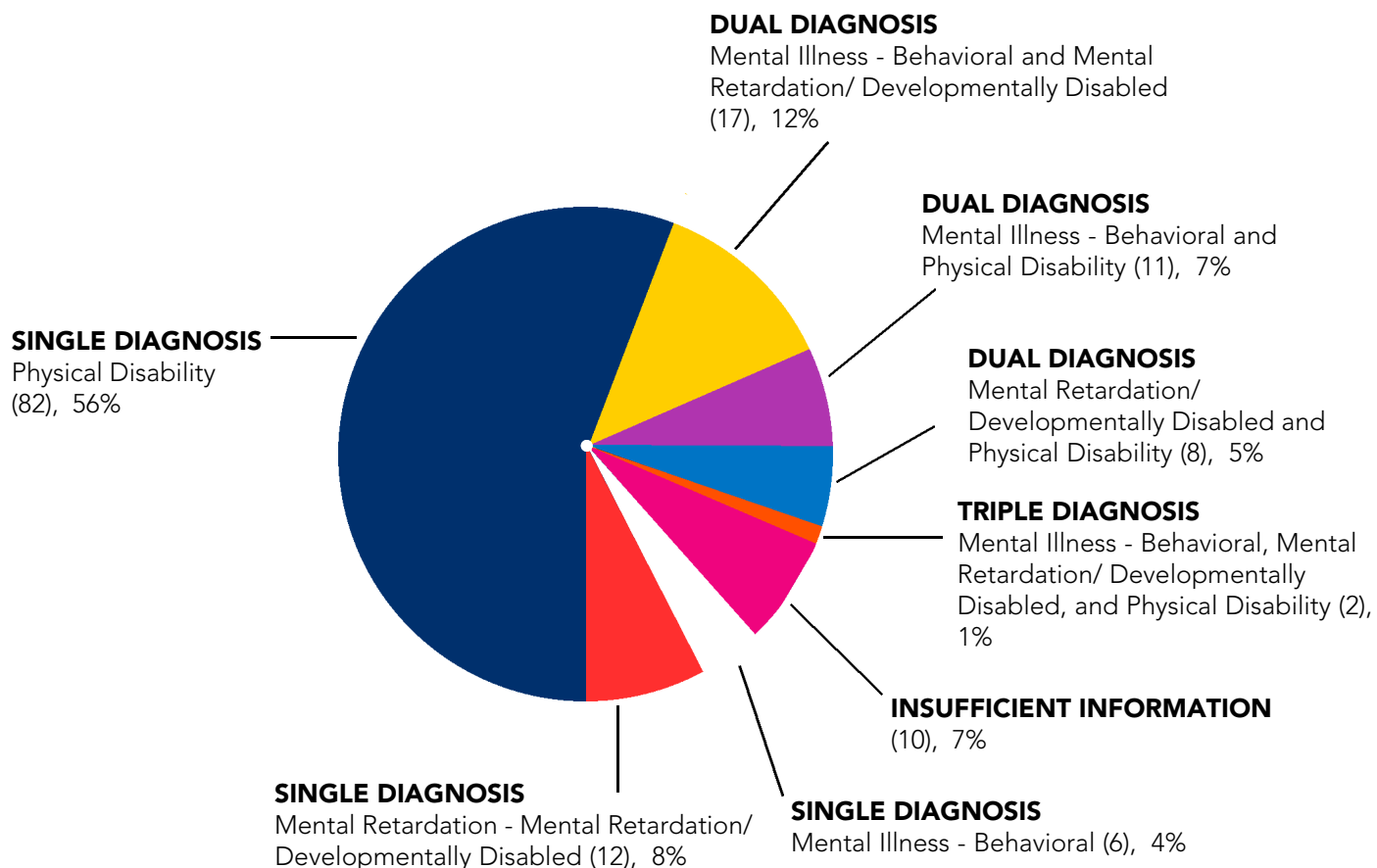
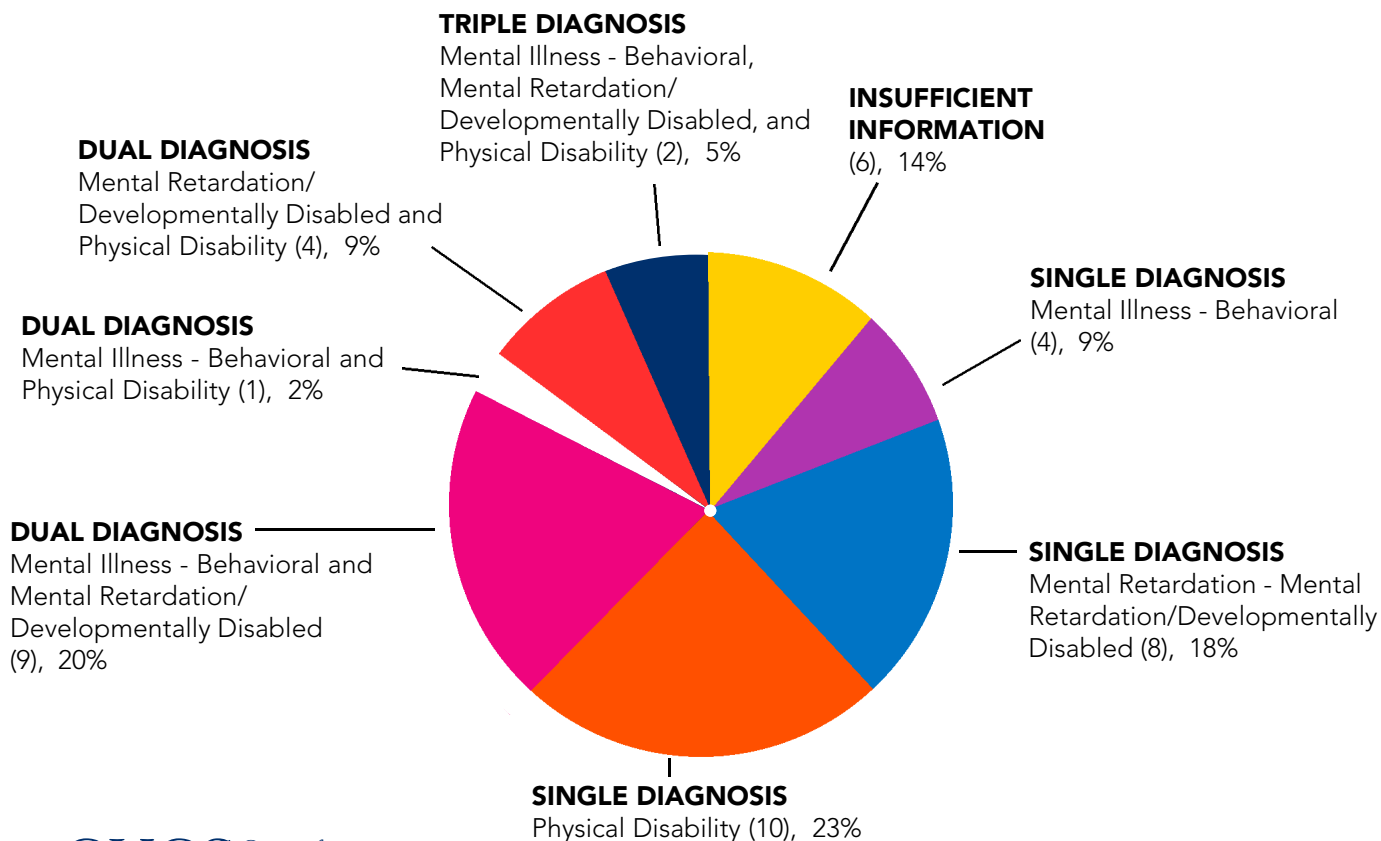


Fig. 5 Complainants by Disability Ages 0-21 (44)



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.

Conclusion

What do not and cannot come through in this Working Paper 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 analyses in this Working Paper, but we are no substitute for the voices of the children and adults who should be an integral part of any deliberations regarding their well-being. Nonetheless, the aggregated statistics underscore several points:

First, any long-term care reform has to be structured to reach persons of all ages. The problem of medically unjustified institutionalization 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. Similarly, unjustified institutionalization 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 already has 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, broad remedial thinking is required. It is clear that the administrative 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. We assume of course that the reforms needed to put a long-term care policy in place will be costly. We further assume 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, policymakers 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.