



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.

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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'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 study² 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.

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.

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

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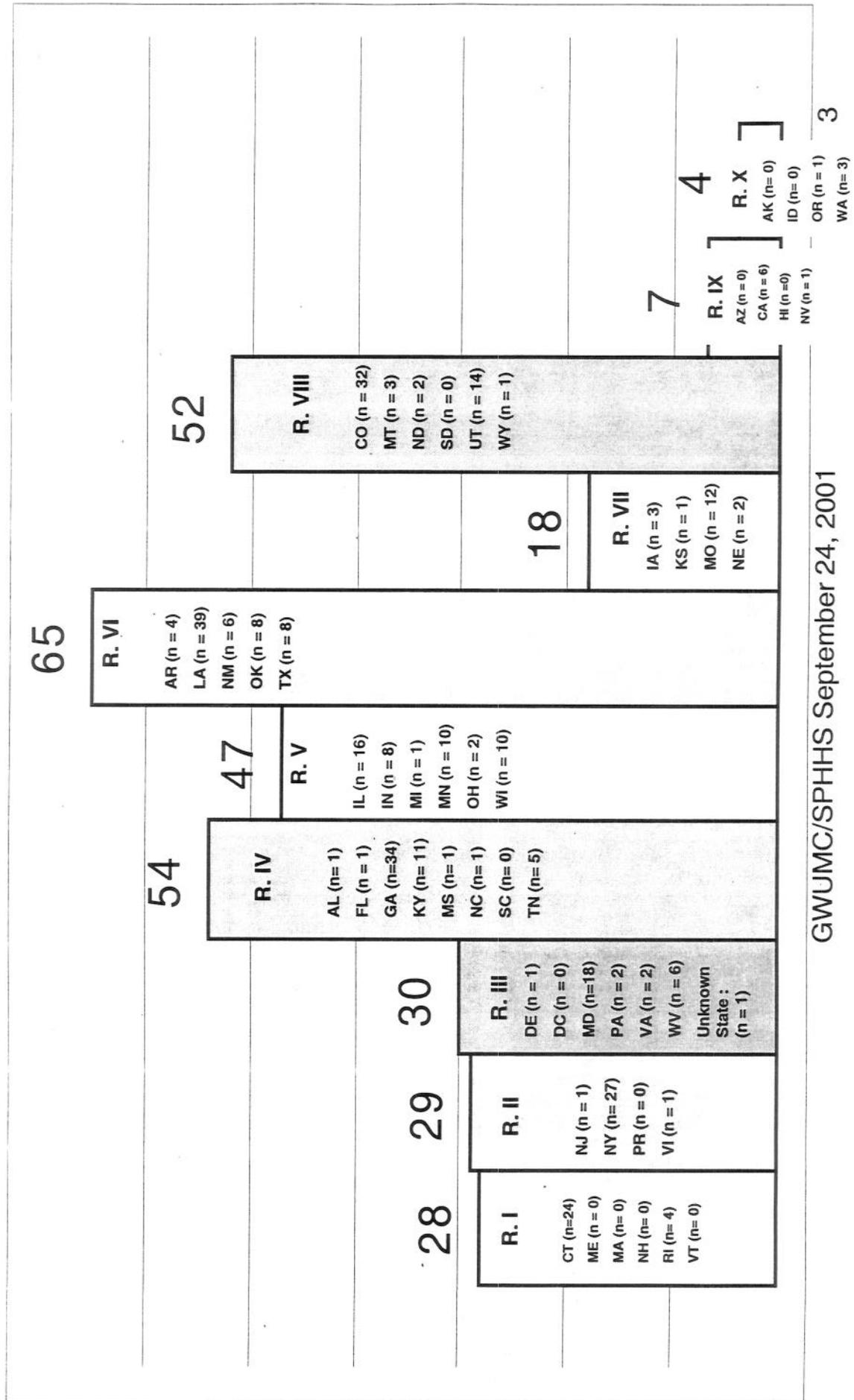
September 24, 2001

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

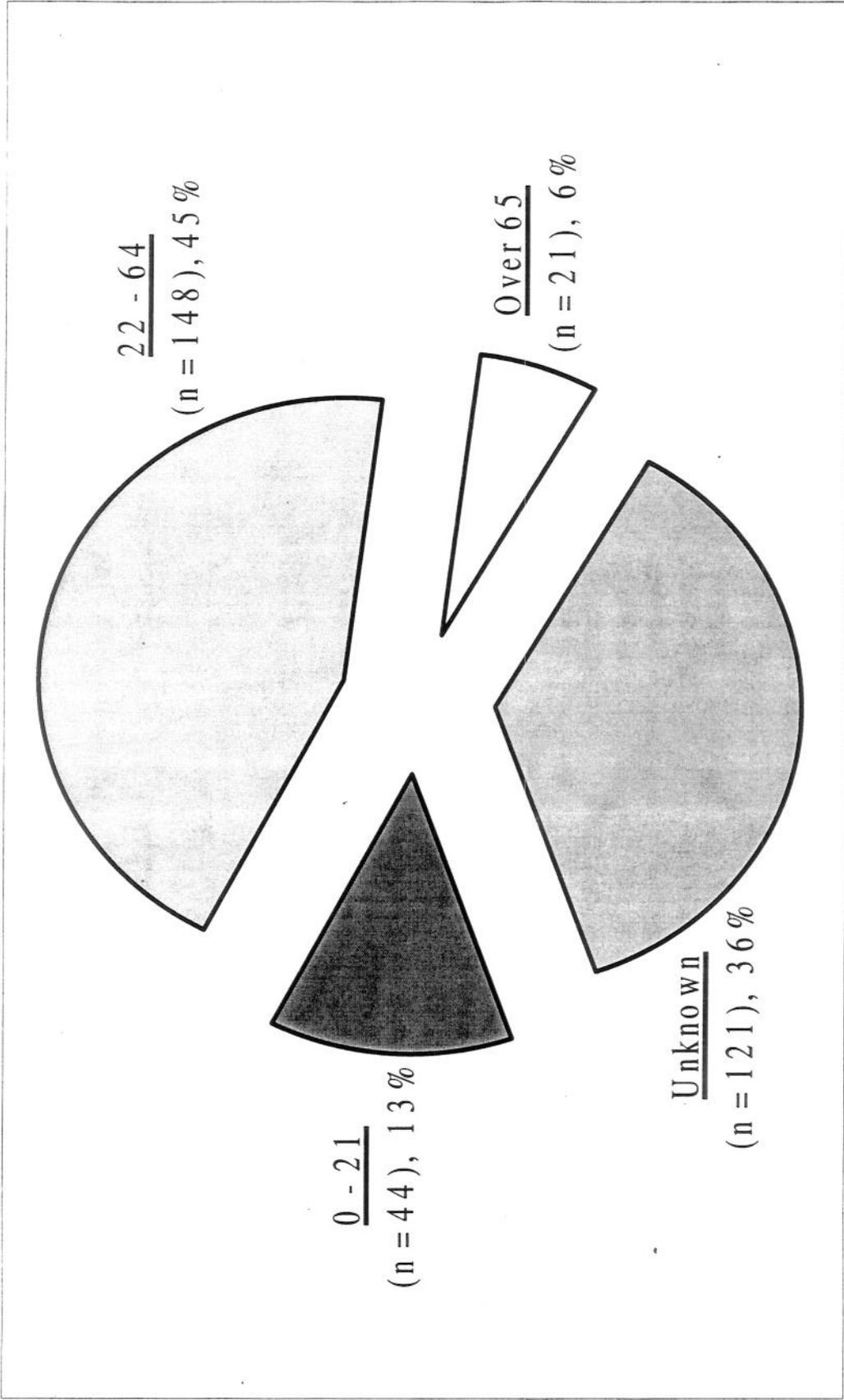
1. Complaints by Region

Complaints (n = 334)



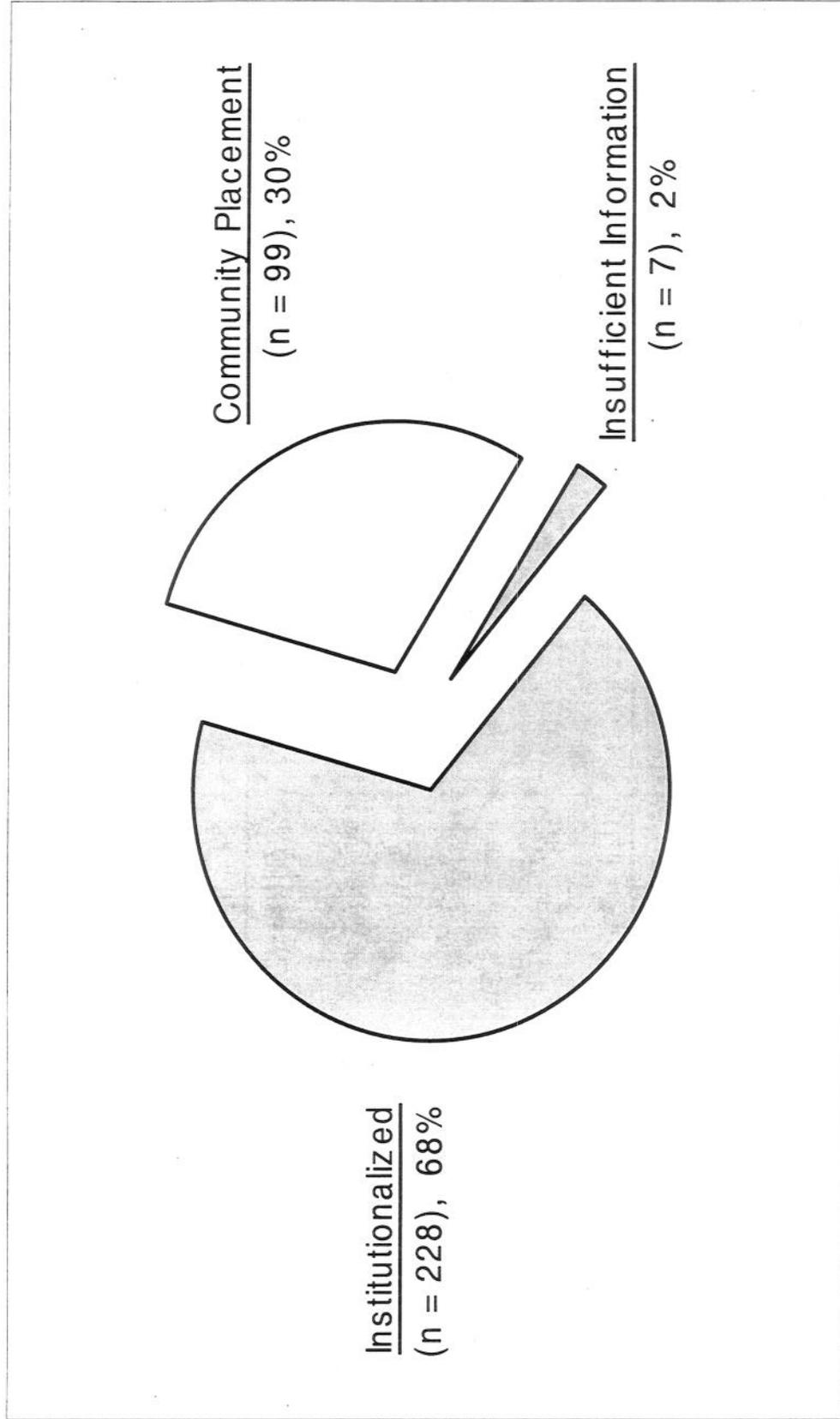
2. Age Range of Complainant

Total Complaints (n = 334)

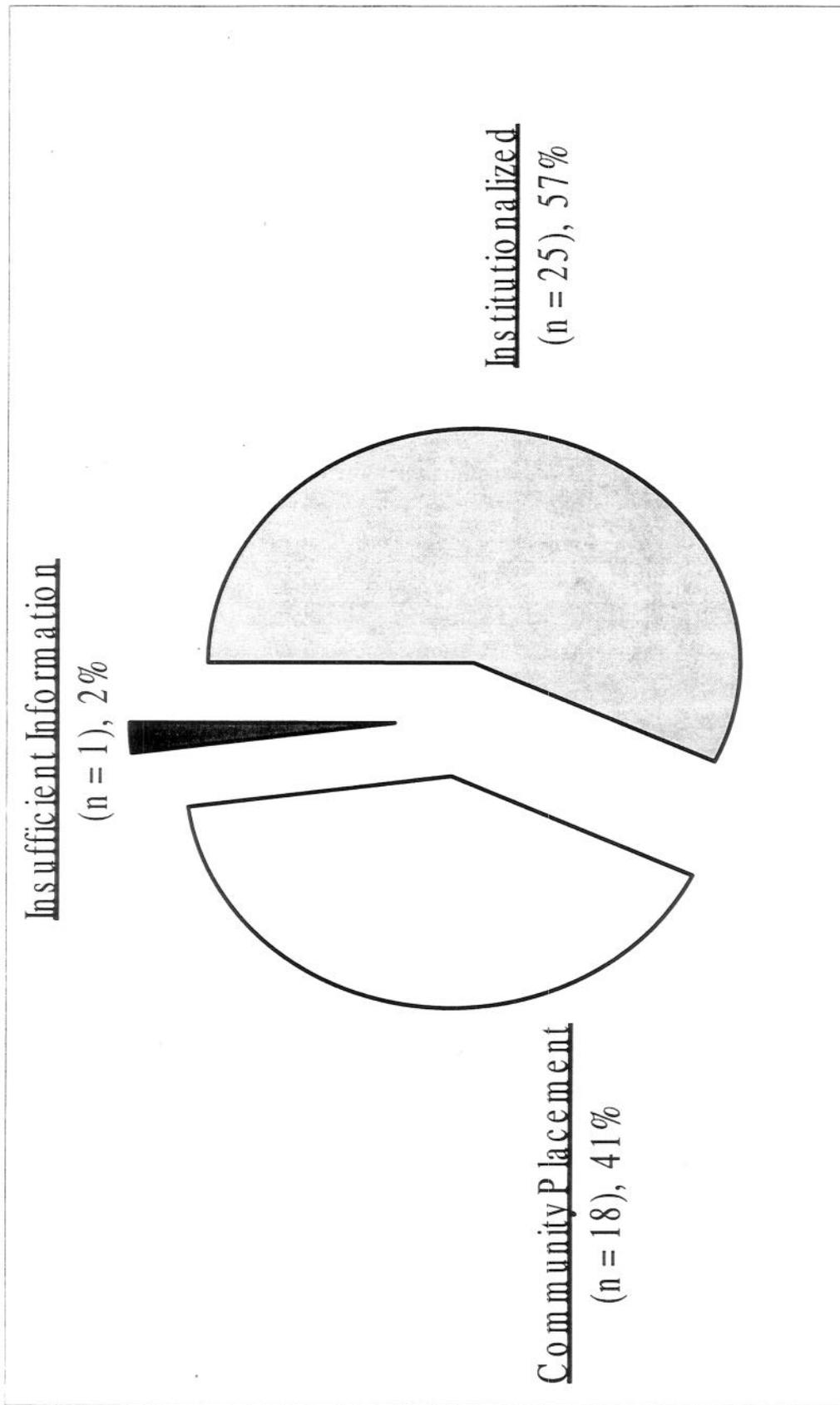


3. Complainant Residential Status

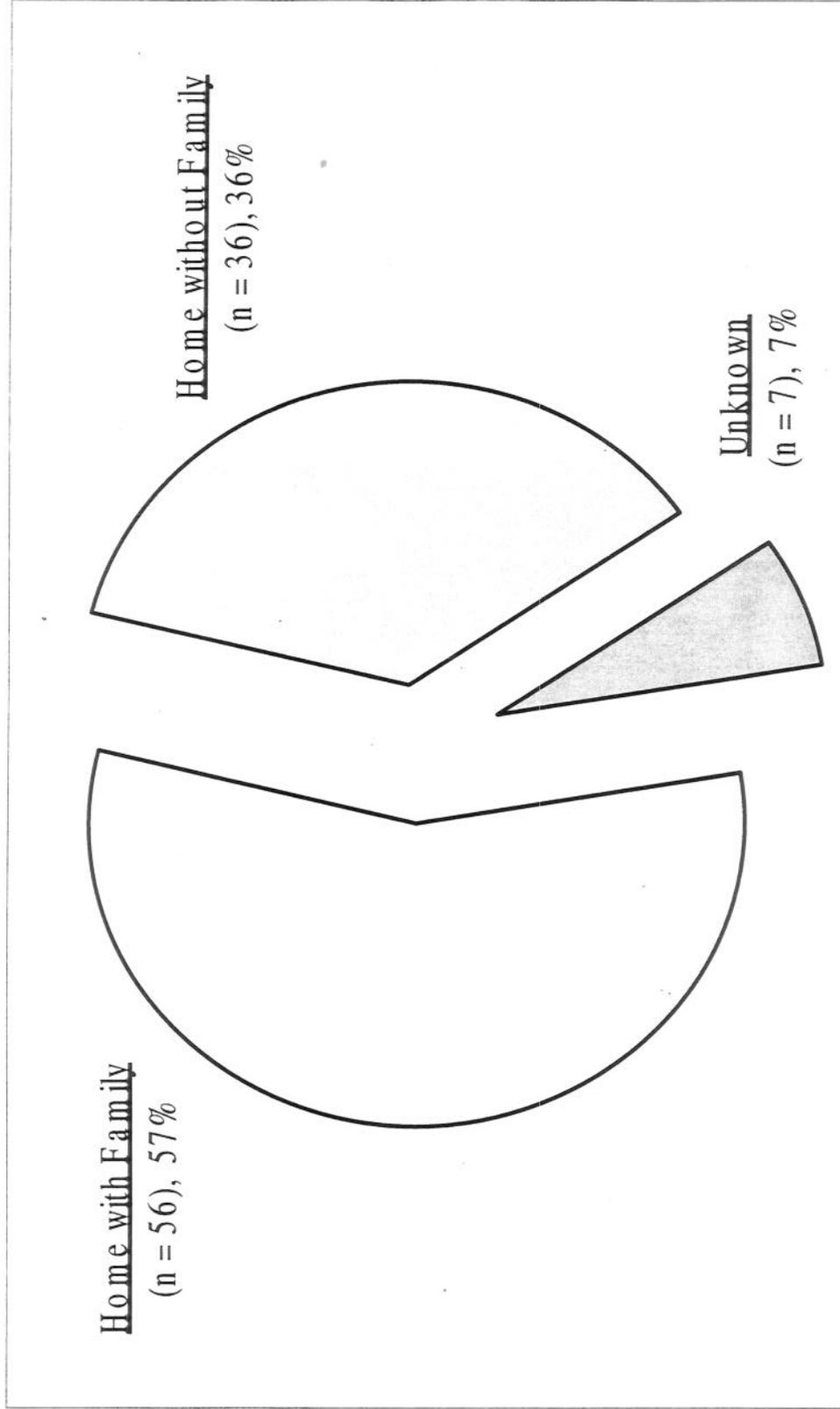
Total Complaints (n = 334)



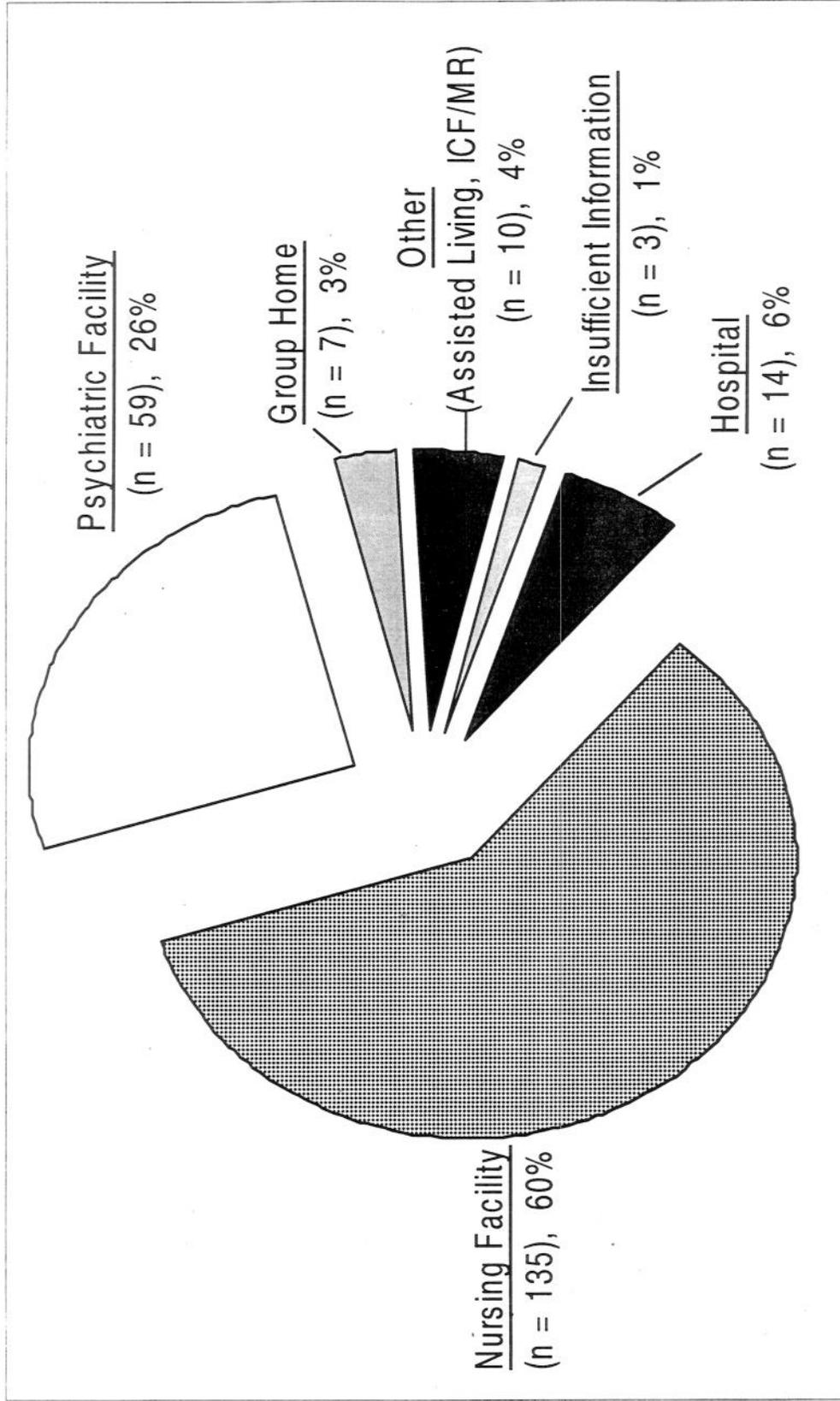
4. Residential Status of Complainants Ages 0 - 21 Complainants Ages 0 - 21 (n = 44)



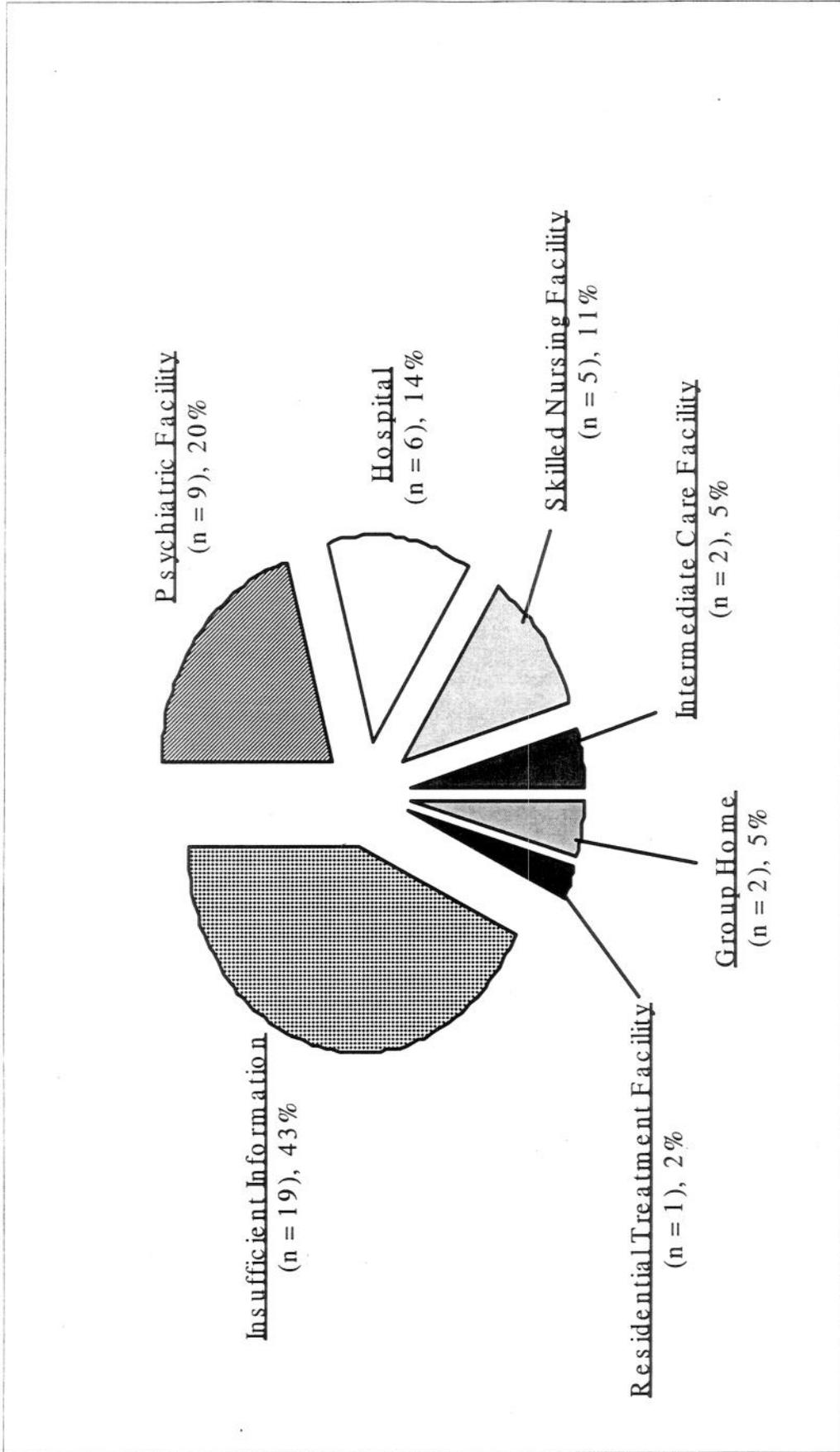
5. Living Arrangements of Community Complainants Community Complainants (n = 99)



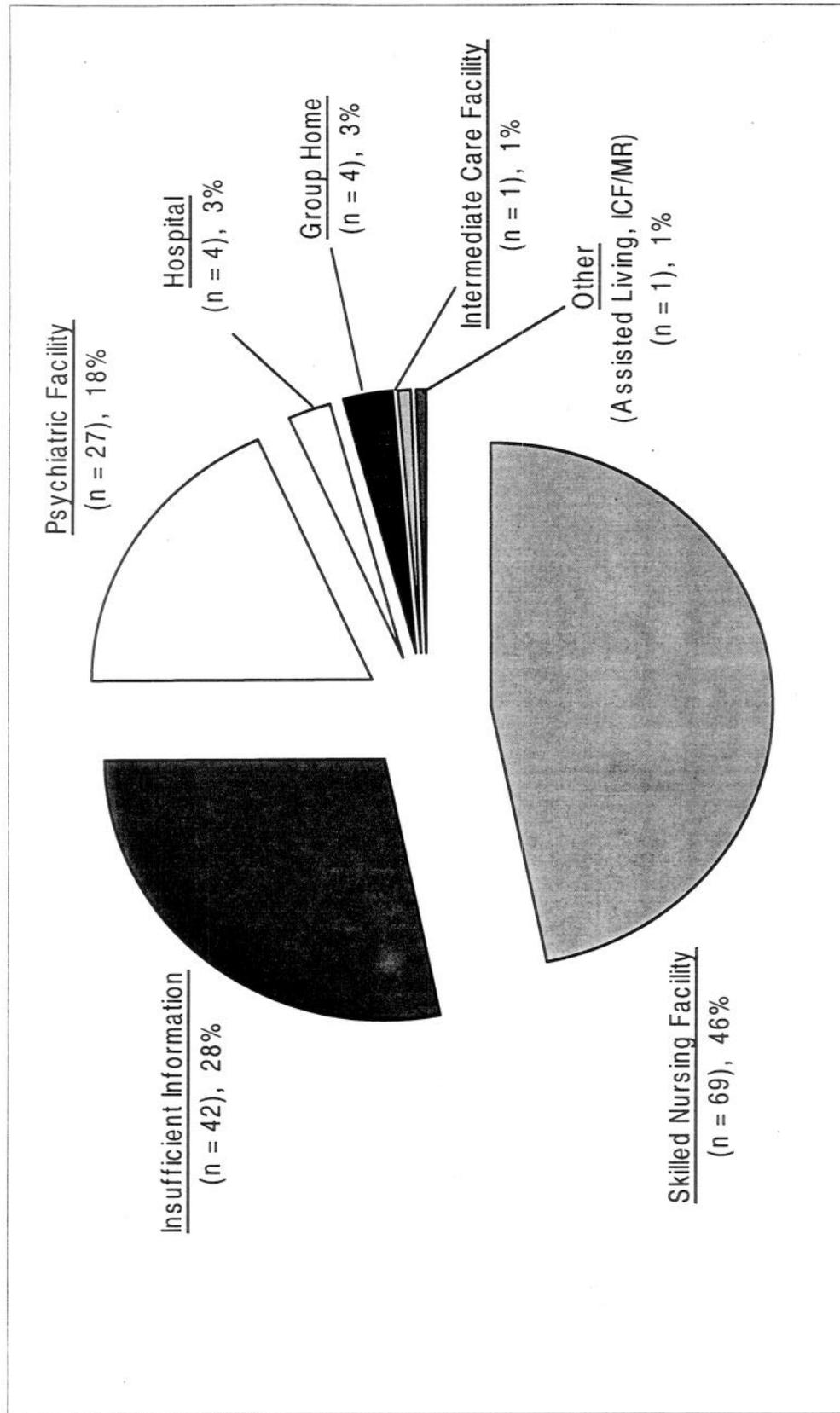
6. Institutional Placement Institutionalized Complainants (n = 228)



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

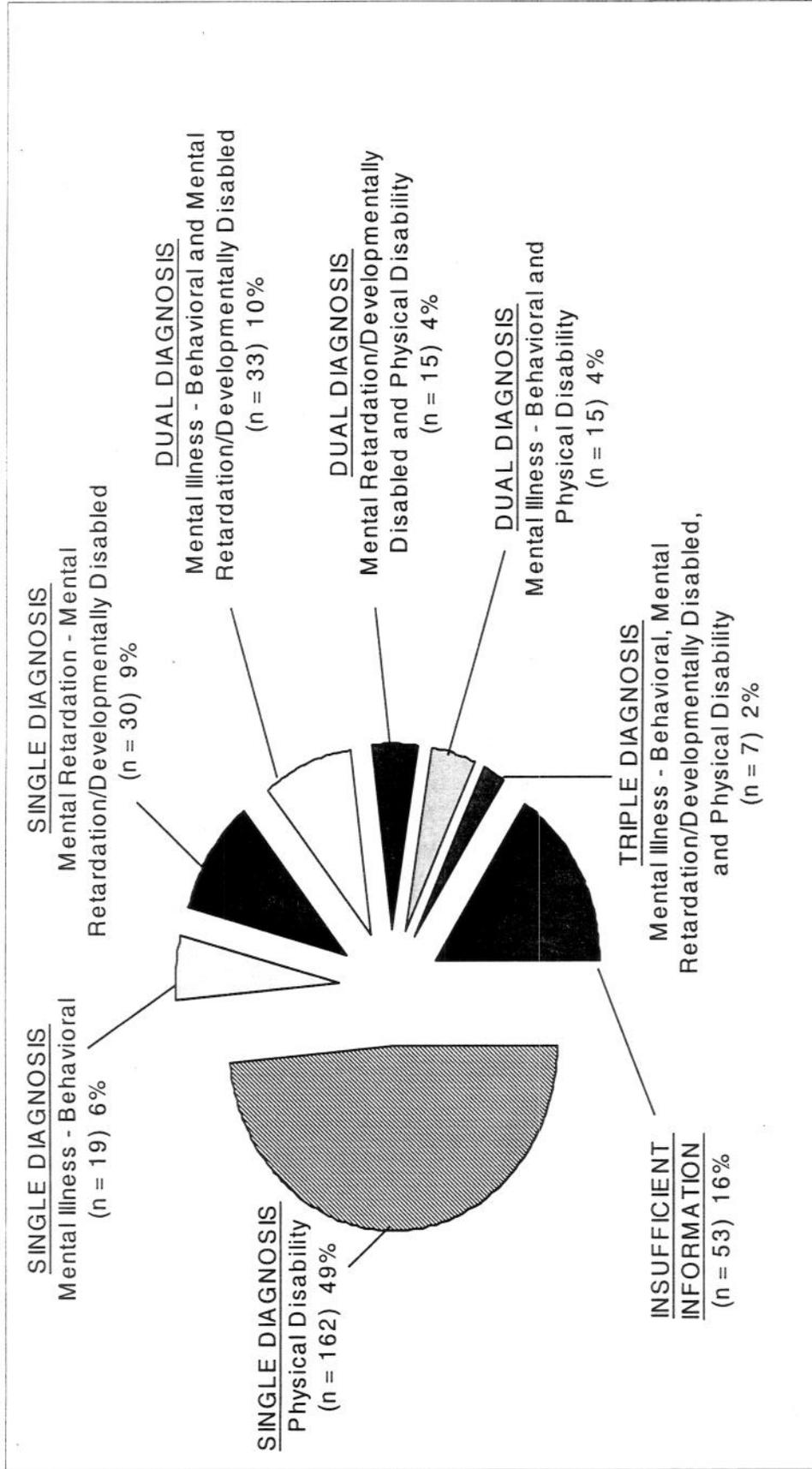


8. Institutional Status of Complainants Ages 22 - 64 Institutionalized Complainants Ages 22 - 64 (n = 148)

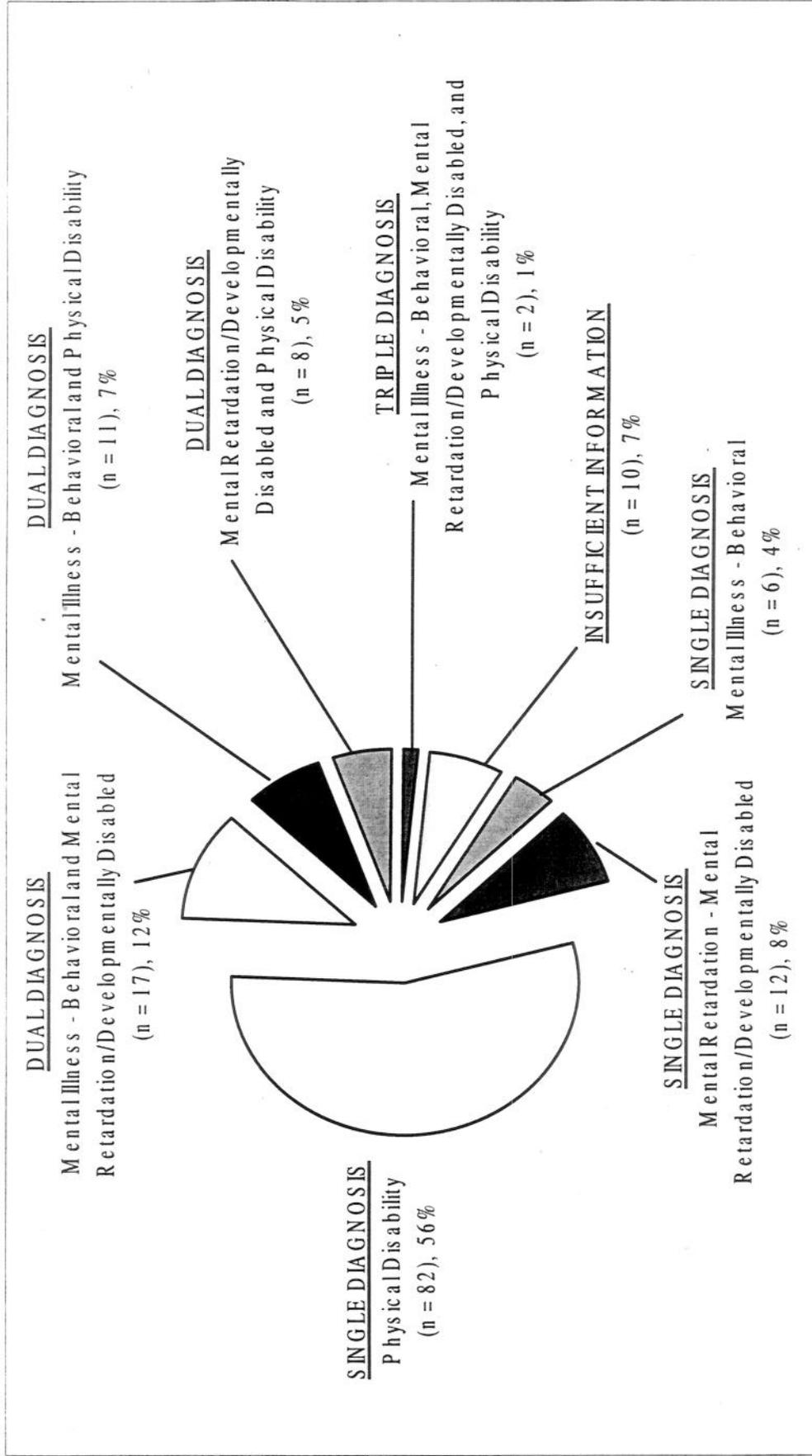


9. Nature of Complainant's Disability

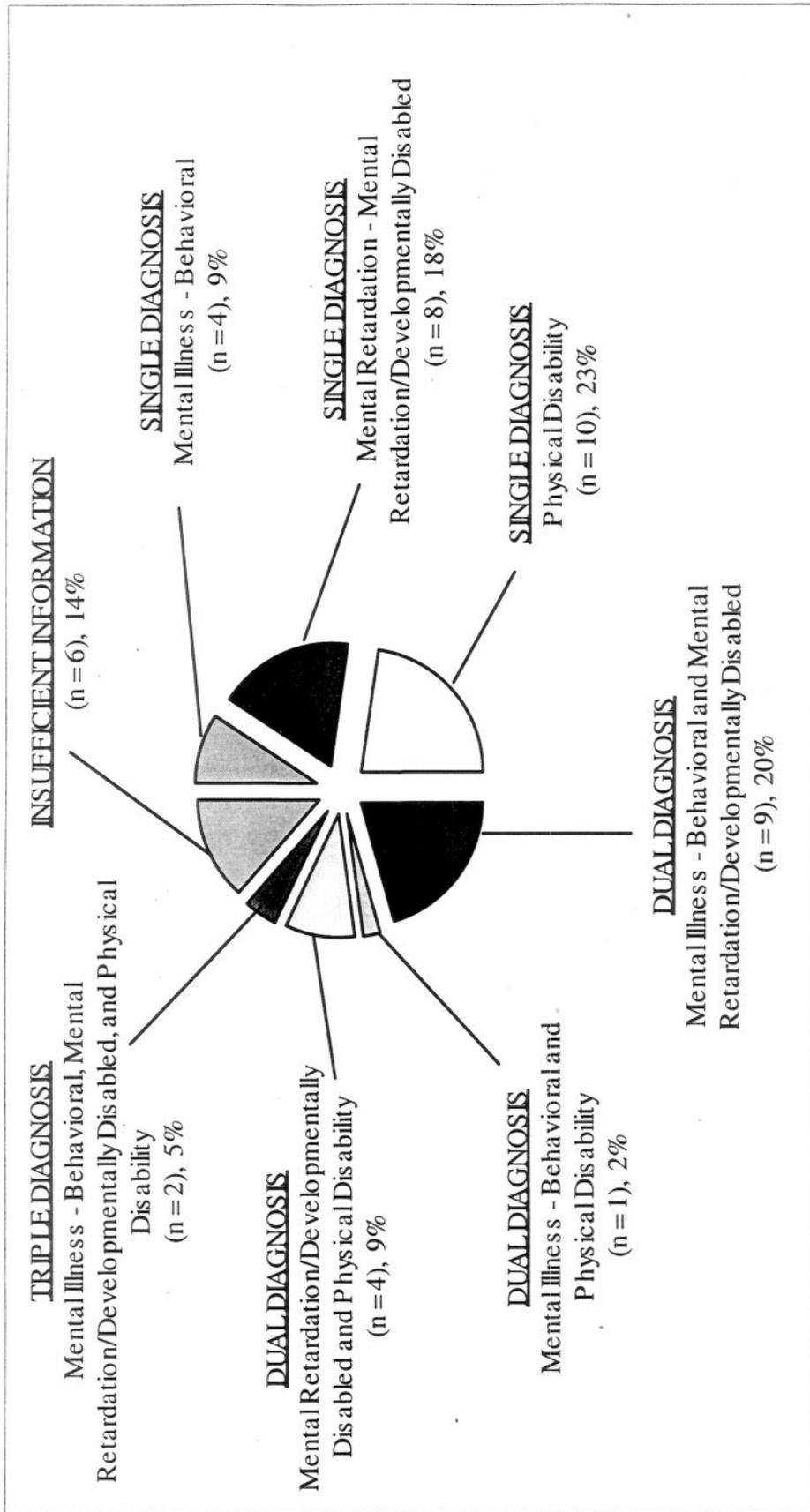
Number of Complainants (n = 334)



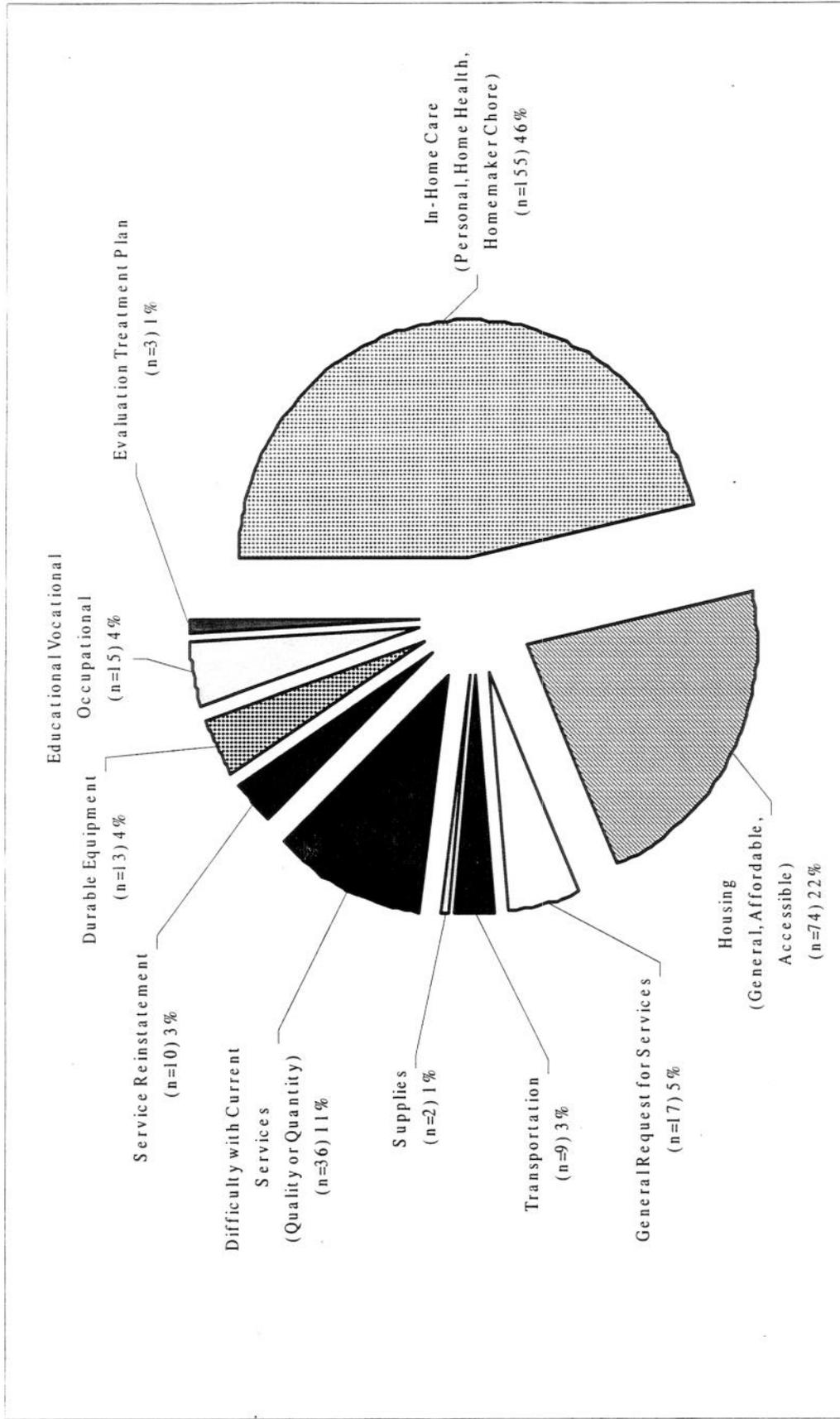
10. Complainants by Disability Ages 22 - 64 Complainants Ages 22 - 64 (n = 148)



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)

