

Just Getting By: Unmet Need for Personal Assistance Services Among Persons 50 or Older with Disabilities

Introduction and Purpose

This In Brief summarizes key findings of the AARP Public Policy Institute issue paper, *Just Getting By: Unmet Needs for Personal Assistance Services Among Persons 50 or Older with Disabilities*, by Mary Jo Gibson and Saty Verma.¹ Persons with disabilities who do not receive all of the assistance they need with essential activities, such as bathing, dressing, and cooking, face daily challenges in doing simple things that people without disabilities take for granted. If their needs remain unmet, they are at risk for more severe disability, hospitalization, and institutionalization.

This report takes an in-depth look at unmet need for personal assistance services (PAS) among persons 50 and older with disabilities:

- the key factors associated with unmet need
- individuals' preferences for services
- changes they say would cause a major improvement in the quality of their lives.

The sample consists of 865 persons age 50 or older with difficulties with one or more of three activities, drawn from a nationally representative telephone survey of 1,102 persons 50 or older with disabilities conducted by Harris Interactive for AARP in September, 2002. Both univariate and multivariate analyses are used. Only results significant at 5% or less are reported.

Key Findings

- Almost three out of ten respondents (29%) reported having unmet needs for PAS:
 - over one-third of these (37%) received no help
 - nearly two-thirds (63%) received some -- but insufficient -- help.
- The primary reason for not receiving enough help was that it was "too expensive/can't afford it."
- Family members, predominantly spouses or adult children, were the primary sources of assistance. Only a small minority received help from paid sources (12%).
- Key factors increasing the likelihood of unmet needs when other variables were controlled included:
 - needing a way to pay for long-term services and equipment,
 - low income (less than \$15,000 per year compared with \$35,000 or more);
 - having a cognitive disability.

¹ For full report, see AARP Public Policy Issue Paper #2006-25.

In Brief written by Mary Jo Gibson, December 2006

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AARP Public Policy Institute, 601 E St NW, Washington, DC 20049

- Key factors in decreasing the likelihood of unmet needs included:
 - having coverage for both Medicare and Medicaid, called being “dually eligible”; and
 - living with and receiving unpaid help from a spouse, family member, or other informal caregiver
- The top changes that persons with unmet needs for PAS said would cause a major improvement in the quality of their lives were:
 - being able to pay for such assistance (71%);
 - having more control over who provides it (73%); and
 - having a known and trusted person available to help (73%) -- as well as
 - having better medical insurance (70%).
- Differences in the characteristics of the two groups with unmet needs were pronounced. For example, persons who received insufficient help were more likely to have very severe disabilities, live with a spouse or other family member, and have difficulty going out alone. Persons who received no help were more likely to have less severe disabilities, be unmarried or divorced, and live alone. The two groups’ preferences for services also varied.

Conclusions and Policy Implications

Expanding Home and Community-Based Services (HCBS): The findings underscore the need for states to accelerate their efforts to rebalance their Medicaid long-term care programs toward greater provision of HCBS services, especially in states that remain highly biased toward institutional services.

Increasing Consumer-directed Service models would give consumers more control over how, when, and from whom they receive services. Such models are gradually expanding in Medicaid and some state-funded programs.

Addressing Financial and Coverage Barriers. Preserving and strengthening programs for persons who are “dually- eligible” emerged as another clear policy implication of this study. In addition, aside from Medicaid and some state-funded programs, there are few sources of financial or other assistance for persons who need HCBS. (Medicare pays for only a limited amount of medically-oriented home health care.) The need for more and better financial options to pay for HCBS is pressing.

The results of this study raise many concerns about the ability of persons 50 and older with disabilities to pay for necessary long term services and supports and to find trusted and reliable formal caregivers. In addition, in a society that encourages sometimes overwhelming choice in goods and services by persons who can afford them, it is unsettling to find how many persons with disabilities have lost a great deal of choice regarding the most basic daily decisions and activities.