

**Unmet Need for Personal Assistance Services:
What Do We Know and What Do We Need to Know?**

Testimony

For the

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Unmet Need for Personal Assistance Services:

What Do We Know and What Do We Need to Know?

The national Center for Personal Assistance Services (PAS) was established by the University of California, San Francisco (UCSF) in 2003, as a Rehabilitation Research and Training Center (RRTC) funded by the National Institute on Disability and Rehabilitation Research.

The Center's faculty is among the nation's leading researchers in disability and PAS, with over 15 years of research and policy experience, numerous academic publications, a previous track record of NIDRR funding for a national center for disability statistics, and teaching experience in disabilities studies. The Center is collaborating with faculty members at the University of Maryland, the University of Michigan, and West Virginia University, as well as with the Topeka Independent Living Resource Center, InfoUse, the Paraprofessional Health Care Institute, and the Institute for the Future of Aging Services. We have a Blue Ribbon Advisory Committee of PAS users, disability advocates, business leaders, independent living center leaders, and academics who provide guidance to the project.

We are conducting 4 large research projects:

- (1) Formal and Informal PAS - to study the relationship between formal and informal PAS and care-giving support, and the role of assistive technology (AT) in complementing PAS;
- (2) Home and Community Based PAS - to study home and community PAS, including state and federal policies and programs, barriers and new models to eliminate barriers to formal and informal PAS, and best practice models in states and in the home and community;
- (3) Workforce PAS - to study the PAS workforce and workforce development that reflects geographic diversity and addresses PAS workforce recruitment, retention, compensation and benefits; professional training, development and networking for PAS providers; and crossover issues between disability and aging providers; and
- (4) Workplace PAS - to study workplace PAS and evaluate models to eliminate barriers to formal and informal PAS and AT in the workplace and identify best practice models in the workplace.

In addition, we are providing training, dissemination, and technical assistance relative to PAS. For the findings from our studies, see our website at www.pascenter.org. Overall, we are focusing our research on expanding access to high quality PAS in the U.S.

Research on Met and Unmet Need for Personal Assistance Services

We have been studying the extent of met and unmet need for personal assistance services in the U.S. An analysis of the 1994-97 National Health Interview Survey on Disability (NHIS-D) examined the met need for personal assistance services (PAS) in ADLs and IADLs. We found that 3.2 million people received an average of 17.6 hours of paid help per week and 11.7

million received an average of 30.7 hours of unpaid help per week.¹

Another study of the NHIS-D 1994-97 data examined the unmet need for services. This study found that 912,000 individuals who were at or below the federal income level to qualify for Supplemental Security Income needed additional help with two or more activities of daily living (ADLs) that they did not receive.² Individuals with unmet need for personal assistance with 2 or more of the 5 basic ADLs have a shortfall of 16.6 hours of help per week compared to those whose needs are met. The relative shortfall is twice as great for persons who live alone as for those who live with others.

The study found that individuals who did not get all the help they needed experienced adverse consequences, especially for those who live alone. The adverse consequences included discomfort, weight loss, dehydration, falls, burns, and dissatisfaction with the help received. Those with unmet need are 10 times as likely to go hungry because no one is available to help them eat as those whose needs are met, 20 times more likely to miss a meal because of lack of help with shopping, 5 times as likely to lose weight unintentionally, and almost three times as likely to fall because no one was around to prevent their falling. As a result, these people are at risk of being forced to leave their homes and move into institutions, such as nursing homes.

The causes of unmet need are many. Informal helpers, such as family and friends, may have to balance other responsibilities that limit the amount of help they can provide. People without informal help depend largely on formal assistance, if affordable and available. Such public services remain biased toward institutional living.

Inadequate Public Programs for Personal Assistance Services

Several major problems are related to unmet needs for home and community based services. The first is the limited state Medicaid funding for home and community based services in many states. Our studies of states show shortfalls in available Medicaid home and community based services across states and many states have long waiting lists for services.^{3 4} Only 26 states provide personal care services under the state plan option and the amount and type of these

¹ LaPlante, M.P., Harrington, C., and Kang, T. 2002. Estimating Paid and Unpaid Hours of Personal Assistance Services in Activities of Daily Living Provided to Adults Living at Home. *Health Services Research*. 37 (2):397-415.

² LaPlante, M. P., Kaye, H. S., Kang, T., and Harrington, C. 2004. Unmet need for personal assistance services: estimating the shortfall in hours of help and adverse consequences. *J Gerontol B Psychol Sci Soc Sci*. 59(2):S98-S108.

³ Kitchener, M., Ng, T., and Harrington, C. Medicaid 1915c Home and Community-Based Services Waivers: A National Survey of Eligibility Criteria, Caps, and Waiting Lists. Home Health and Community Services Quarterly. In press.

⁴ Kitchener, M. and Harrington, C. 2002. Variations In Home and Community Based Waiver Programs. San Francisco, CA: University of California.

services are often limited.⁵ Second, many states restrict eligibility and benefits to keep the costs of home and community based services low. Third, many states report limited availability of individuals to provide personal assistance services (PAS). Fourth, low wages and benefits often result in high personnel turnover rates and difficulties in recruiting and retaining PAS workers resulting in shortages of workers.⁶ While assistive technology can be of critical importance to individuals who need PAS, the more fundamental problem in unmet need is the lack of available public PAS services and workers. These factors all result in wide variation in the availability of personal assistance services for individuals with low incomes both across and within states.^{7 8}

Cost Estimates for Providing Additional Hours for Unmet Need

Our study, using data from the NHIS-D for 1994-97, estimated the costs of expanding access to paid PAS, which appears crucial in reducing unmet need among those who live alone. If the estimated shortfall in hours were to be provided through public funds, the cost of eliminating unmet need among people who live alone with low-income ranges from \$1.2 to \$2.7 billion, a relatively small amount. The cost of meeting the needs of people who live with others ranges from \$2.2 to \$7.1 billion.⁹

On the positive side, the study finds that 93 percent of the need for assistance is being met, largely by family members and friends. Previous research, by looking only at the prevalence of unmet need for PAS, creates a false impression that unmet need is a large and costly problem to resolve. In fact, only 6.6% of all needed hours of help are unmet among adults needing help in two or more ADLs.

A more recent estimate, using data from the 2002 Survey of Income and Program Participation (SIPP), found that 1,167,000 individuals who were at or below the federal income level to qualify for Supplemental Security Income needed help with two or more activities of daily living (ADLs). Subtracting out the hours of care for those individuals who receive paid help by Medicaid, we found that the costs of providing additional hours to individuals who need additional care would range from between \$3.9 and \$15.6 billion, depending upon the assumptions about the percent of eligible individuals who would actually request additional

⁵ Harrington, C., Carrillo, H., Wellin, V., Norwood, F., and Miller, N.A. 2001. Access of Target Groups To 1915(c) Medicaid Home and Community Based Waiver. *Home Health and Community Care Services Quarterly*. 20 (2): 61-80.

⁶ Harrington, C., A.J. LeBlanc, J. Wood, N. Satten, and C. Tonner. 2002. Met and Unmet Need for Medicaid Home and Community Based Services in the States. *Journal of Applied Gerontology*. 21 (4):524-550.

⁷ Harrington, C., H.Carrillo, V. Wellin, N. Miller, and A.J. LeBlanc. 2000b. Predicting State Medicaid Home and Community Based Waiver Participants and Expenditures, 1992-1997. *The Gerontologist*. 40 (6):673-686.

⁸ Kitchener, M. and Harrington, C. Medicaid Community-Based programs: A Longitudinal Analysis of State Variation in Expenditures and Utilization. *Inquiry*. 2004; 40(4): 375-389

⁹ LaPlante, M. P., Kaye, H. S., Kang, T., and Harrington, C. 2004. Unmet need for personal assistance services: estimating the shortfall in hours of help and adverse consequences. *J Gerontol B Psychol Sci Soc Sci*. 59(2):S98-S108.

services. We estimate that the costs would mostly likely to be at the lower end of the range.¹⁰ About half of this would be federal costs and half would be state costs to the Medicaid program. This does not take into account possible savings if adverse consequences of unmet need are averted.

Even a modest amount of unmet need can jeopardize a person's ability to live independently. Unmet need likely increases the chances of an individual being prematurely institutionalized or being hospitalized, and reduces an individual's participation in society. These are large costs that, if avoided, would offset the cost of providing the additional help that is indicated. The reduction, if not the elimination, of unmet need for help is a financially achievable goal for the nation and one that long-term policy should focus on.

New Disability Studies Are Needed

New data on the actual paid hours of care received, hours of care needed, and additional hours of care needed by individuals with a range of levels of disability are greatly needed. The best approach would be to develop a national disability survey, like the National Interview Survey on Disability (NHIS-D), which should be conducted on a regular basis. Since the most recent study was conducted in 1994-97, we lack more recent data to understand the current needs of individuals with disabilities. Without this type of comprehensive information, it is difficult to assess the current need for additional services and to make cost estimates. The need to measure the nation's progress in services persons with disabilities who need personal assistance services is greatly hampered by the lack of on-going data. Such disabilities statistics should be considered vital statistics that would be available on a regular basis.

Another issue is that personal assistance services are provided to individuals with low incomes at the state level. Accurate disability statistics on met and unmet need should be collected from large enough samples that state-level estimates can be made. We believe that Interagency Committee on Disability Research should take a leadership role in ensuring that the nation has adequate information to identify met and unmet needs for personal assistance services in order to inform public policies.

¹⁰ LaPlante, M.P, Kaye, H.S., and C. Harrington. 2004. *The Cost of MiCassa*. San Francisco, CA: Center for Personal Assistance Services.