# Personal Assistance Services Advisory Committee ANNUAL REPORT

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# **Personal Assistance Services Advisory Committee**

The Personal Assistance Services Advisory Committee (PASAC) was created during the 2005 Legislative Session under House Bill 1542 (HB 1542), Maryland Quality Home Care Services Act. The purpose of the Advisory Committee is to provide guidance to the Governor, General Assembly, and the Maryland Department of Disabilities (MDOD) on personal assistance services, including:

- Development of standards for the training of personal assistance workers;
- Feasibility of establishing a referral system of individual providers;
- Feasibility of establishing a registry for personal assistance workers; and, the
- Need to offer competitive and reasonable compensation levels for providers of personal assistance services.

The Committee is to be composed of twenty-one members: eleven individuals with disabilities who have previously received or are currently receiving personal assistance services and ten representatives from State agencies, advocacy organizations, and local offices of government (see Appendix A). Currently, the PASAC is being reconstituted to reflect a broader representation of individuals with meaningful personal and professional experience with the delivery of personal assistance services in Maryland. The designated terms of prior committee members have expired and therefore the task of seating a fully functioning board is a primary goal. MDOD is taking preliminary steps to identify and appoint new members, who will be tasked with reviewing prior PASAC recommendations and to use current information and data to continue to address the infrastructure needed to improve personal assistance service availability and delivery in Maryland.

### **Overview of Personal Assistance Services**

#### What are Personal Assistance Services (PAS)?

Personal Assistance Services refer to help provided to people with disabilities to assist them with tasks essential for daily living. These tasks include bathing, dressing, ambulating, toileting, eating, and shopping. PAS help people with disabilities to fully participate in activities at home, work, and in the community<sup>1</sup>. PAS is also referred to as attendant care and personal care services (PCS).

<sup>&</sup>lt;sup>1</sup> Center for Personal Assistance Services Bulletin, January 2009, Volume 6, Issue 1

#### What is a Provider Registry?

A Provider Registry is a community resource by which individuals, social workers, service coordinators, case managers, and/or family members have access to a centralized listing of available personal assistance service workers. Providers can be skilled or non-skilled, depending on the needs of the individual and the level of assistance required. Provider registries are typically the starting point for individuals interested in identifying personal assistance service workers and promote a person-centered model of service delivery.

# Overview of Personal Assistance Services in Maryland

#### Maryland Personal Assistance Service Programs:

- Maryland Department of Disabilities (MDOD), Attendant Care Program
- Department of Health & Mental Hygiene (DHMH), Medical Assistance Personal Care (MAPC) Program and Medicaid Waiver Programs such as Living at Home and Older Adults
- Department of Human Resources (DHR), In-Home Aide Service
- Department of Aging (MDoA), Senior Care

All public programs providing personal assistance services may provide, at a minimum, assistance with bathing, eating, dressing, mobility, toileting, light household chores, food shopping, meal preparation and some transportation. Each of the publicly funded programs providing personal assistance services differ in terms of eligibility determination requirements (e.g. severity of disability, income, and age), type or amount of assistance provided (e.g. financial reimbursement, hourly and/or weekly caps), and programmatic processes (e.g. self-directed vs. specified level of worker training and screening) (See Appendix B).

#### How many people in Maryland need Personal Assistance Services?

According to the most recent data available (2005) an estimated 120,000 people in Maryland, or 2.4% of the population ages 5 and over, have difficulty independently performing self-care activities also known as activities of daily living.

The majority (110,000) are adults. Maryland's demographic data follows<sup>2</sup>:

#### Age:

5-17	10,000
18-64	59,000
65+	51,000
Total	120,000

#### **Ethnicities**

White	78,000
African American	37,000
Other	5,000
Total	120,000

#### Family Income

In poverty*:	25,000
Above poverty:	95,000
Total	120,000

<sup>\*18,000</sup> of the 25,000 receive Supplemental Security Income (SSI). Medicaid coverage is automatically given to individuals receiving SSI.

# **Summary of PASAC Findings**

In an effort to determine the feasibility and likely success of establishing a provider registry in Maryland, PASAC members reviewed existing registries from other states. A questionnaire was developed and used to ensure consistency in the collection and evaluation of the information gathered. General findings included:

- Funding for initial registry development came from grants awarded by the Centers for Medicare and Medicaid Services (CMS), dedicated State funds, and/or private contributions and ranged from \$100,000 to \$1,000,000;
- The majority of registry systems were designed with the assistance of a consultant and third party software;
- All states used disclaimers to address liability issues regarding criminal background checks and provider training requirements; and

<sup>&</sup>lt;sup>2</sup> Maryland Disability Data Table from the 2005 American Community Survey compiled by The Center for Personal Assistance Services. Statistics are based on tabulations of public use data from the Census Bureau's American Community Survey (ACS) for 2005. Because it is a household survey, people living in institutions such as nursing facilities are not included.

 All states reported positive feedback from both providers and users of the registries and that the registries proved to be a useful tool for individuals seeking personal assistance workers.

#### **Spotlight on Massachusetts**

The Committee also noted that the model developed in Massachusetts was worthy of further consideration. That provider registry, known as Rewarding Work Resources, Inc, began as a pilot project as part of a comprehensive workforce development program through the Massachusetts Department of Developmental Services. The project initially focused on the recruitment of direct support professionals for provider agencies supporting people with intellectual and developmental disabilities. The original funding was provided through a grant sponsored by the University of Massachusetts Medical School, Center for Health Policy and Research, and the New England States Consortium Systems Organization and cost approximately \$100,000 the first year. Initial funding included the cost of marketing, outreach to prospective workers, and the construction of the infrastructure (call center and website), and database components. The website and database were developed in collaboration with a web development company to ensure information security and automation. Continuing costs for the annual operation of the database, marketing, and outreach have not exceeded \$100,000 per year. The registry has proven to be a great resource for provider agencies, support coordinators, case managers, senior citizens, individuals with disabilities and their families.

Today, Rewarding Work Resources, Inc. is organized as a 501 (c) (3) nonprofit organization and is a collaborative effort between four states (Connecticut added in 2004, New Jersey added in 2005, and Rhode Island added in 2006). The Rewarding Work Website and recruitment campaign have been cited as a promising practice by CMS and was recently redesigned to enable older people and individuals with disabilities and chronic diseases to hire personal assistants and other health-related staff directly. The four states share a common database and use a zip code search which enables individuals to find providers within 10 miles of their homes. In addition, individuals who live along state lines are able to access potential providers from neighboring states, thereby expanding their pool of qualified applicants.

# **Summary of PASAC Recommendations**

The Committee offered recommendations which, if implemented, would better position Maryland as a state where individuals with disabilities have improved access to community-based personal assistance services, meaningful choices in the delivery of these services, fair wage compensation for personal assistance workers, and quality services from providers whose training meets standards appropriate to their specific needs.

#### Access

Currently, individuals who need personal assistance services in Maryland have limited or no access to a centralized, reliable location from which to begin looking for service providers. Although some programs offer provider lists to participants, they are typically program specific and don't include a comprehensive listing of available workers across the state. As a result, only individuals who are enrolled in a particular program, such as Medical Assistance Personal Care or a Medicaid Home and Community-Based Waiver program, have access to a list of potential providers. Individuals who may not qualify for a publicly-funded program or are private pay citizens do not have access to a reliable method for locating personal assistance providers.

A review of established registries in other states found that such an undertaking could be accomplished cost effectively with outcomes that are universally accepted by both individuals with disabilities and provider agencies. Marylanders with disabilities as well as personal assistance providers would benefit from the implementation of a registry of available and qualified providers. This approach would not only allow for a more persondirected method for locating personal assistance services but would also assist individuals to lead more independent lives in the communities in which they live.

#### Compensation

The Committee identified varying levels of compensation paid to providers for the delivery of personal assistance services by skilled, non-skilled, independent, and agency providers. Broad variations were also noted among providers with the same skill level or for performing comparable services. Compensation discrepancies among State programs should be addressed and should include identifying ways to provide a fair and livable wage for tiered care services (skilled and non-skilled) and identify potential benefits (e.g. health care insurance, workman's compensation) for independent self-employed providers using both employment and consumer-directed models. Not only will this provide the State with a pool of eligible and trained providers, it will also increase the reliability of service delivery in the community.

## **Next Steps for the PASAC**

Though the current fiscal environment and ongoing budget cuts will likely prevent significant change in this area for the foreseeable future, the Committee recommends that Maryland conduct a comprehensive review of the Medical Assistance Personal Care Program (MAPC). This review will result in a better understanding of how limited resources and low wages to personal care providers has resulted in lack of quality services, diminishing provider pools, and gaps in community services for the individuals who need them. Armed with this information, Maryland should consider similar reviews for IHAS, Senior Care, and other PAS services available in the State. Additionally, the State agency representatives to the committee, shall work collaboratively to address proper utilization of personal assistance services and avoidance of inappropriate duplication of the same.

Maryland should also engage in a dialogue with Massachusetts and the other states working with Rewarding Work Resources to determine feasibility of Maryland partnering with those states. By joining an established system, cost savings and other efficiencies may result.

#### APPENDIX A

Personal Assistance Services Advisory Committee Members

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# APPENDIX B MARYLAND PERSONAL ASSISTANCE SERVICES FLOW CHART

