PAS Center for Personal Assistance Services
September 2012 Research Brief

PAS Workforce and Informal Caregivers: State of the Research

Unprecedented demand for both publicly-funded and private-pay personal assistance services (PAS)—also known as "home care" services—is being fueled by demographic trends, consumer preference, and fiscal concerns. The home care and personal assistance industry is adding jobs faster than any other U.S. industry, and two PAS occupations—personal care aides and home health aides—are projected to be the two fastest growing occupations in the country over the next decade.

The PAS workforce is one of the largest workforces in the country, conservatively totaling today nearly 2.3 million.[1] PAS workers provide essential paid long-term services and supports to significant numbers of the 11 million Americans who are community-residing and live with functional limitations due to aging, physical disabilities, developmental and intellectual disabilities, and chronic illnesses.[2] Although the intrinsic rewards of this work can be high, these workers often receive low wages, few benefits, and work under demanding physical and emotional conditions that require ongoing responsibility and judgment as well as emotional commitment and flexibility. Injury rates are high, and in general formal training requirements are quite limited with many workers receiving no training at all. One consequence of these problematic employment conditions is high turnover which in turn undermines workforce stability and continuity of care.

At the same time, millions of unpaid caregivers provide the bulk of personal assistance to those living with functional limitations. The family caregiving "system" is increasingly stressed as the population of adults over age 65 grows at three times the rate of the population of family members available to care for them, primarily spouses and adult children aged 45 to 64 years old. As these informal caregivers age, they are at increasing risk of needing supports themselves, and are less likely to be able to provide unpaid care at the same rate as they have in recent decades. Growing caregiving responsibilities are pressuring increasing numbers of women to retire early or move from full-time to part-time work, and the adverse health impacts of overburdened caregivers, in the opinion of experts, now constitute an "emergent public health issue."[3]

This brief provides an overview of the current state of knowledge regarding both the paid PAS workforce and the country's immense population of informal caregivers. It highlights research progress achieved in the past five years but also identifies gaps in our knowledge as well as considerations for future research.

Understanding the PAS Workforce

During the past five years, considerable progress has been made in identifying and tracking the basic demographic and employment characteristics of the PAS workforce. Online data resources centers created by the PAS Center and PHI now provide easy public access to tabulated annual survey data from the American Community Survey, the Annual Social and Economic Supplement of the Current

Population Survey, and employment and wage estimates available from the Occupational Employment Statistics program of the Bureau of Labor Statistics.

As a result of this data collection and related analyses, a clear national profile of the PAS workforce has emerged. Table 1 shows that most workers are female and members of minority groups or Hispanic. About 60 percent have no more than a high school education.

Table 1: Demographic Characteristics of Personal Care Aides, 2010

Median age(years)	44
Gender	
Female	84.3%
Male	15.7%
Race/Ethnicity	
White only, non-Hispanic	48.6%
Black only, non-Hispanic	23.9%
Spanish, Hispanic, or Latino	19.1%
Other or mixed, non-Hispanic	8.4%
Single parent, grand-parent, or caretaker	19.9%
Citizenship/Foreign Born	
Native	79.7%
Foreign born	20.3%
Education: High school or less	59.4%

Source: PHI analysis of March Supplement data from 2011 Current Population Survey.

At the regional and state levels, elements of this national workforce profile vary markedly. For example, while nationally an estimated 20 percent of personal care aides are foreign born, in California and New York, up to half of the workforce is foreign-born. And in these two states, much higher proportions of personal care aides are non-white (roughly 70 percent in both California and New York) compared to the nation as a whole.[4]

Table 2 shows that most personal care aides work part time and have low earnings. A third have no health coverage and half live in households that receive one or more forms of public assistance.

Table 2: Employment & Income Characteristics of Personal Care Aides, 2010

Labor force participation in home & personal care	
Year round, full time	42.4%
Part time	57.6%
Of which, involuntary part-time	44.1%
Individual annual earnings, mean	$15,971
Individual annual earnings if full time, full year	$24,355
Family poverty status	
<1.00	25.9%
<2.00	53.7%
Health insurance	
Uninsured	33.8%
Employer provided, private	36.7%
Other private	9.2%
Public insurance	20.2%
Household public assistance	
Any	50.9%
Medicaid	41.2%
Food and nutrition assistance	38.1%

Source: PHI analysis of March Supplement data from 2011 Current Population Survey.

The data collection activities of the PAS Center and PHI provide a wealth of state-level data for further analysis. The PHI State Data Center is an online resource center dedicated to providing state level data on PAS workers and also nursing aides.[5] At the PAS Center, extensive state workforce data can be found at the "Caregivers and PAS Workers Project."[6] A complementary annual resource provided by the PAS Center and PHI is a chart book providing a ten-year profile of wages (nominal and adjusted for inflation) for personal care aides.[7] In recent years, over two-thirds of states report

average hourly wages for personal care aides below 200 percent of the Federal Poverty Level for individuals in one-person households working full time, a level low enough to qualify households for many state and federal assistance programs.

Two further projects devoted to improving our descriptive knowledge of PAS workers merit attention. The first is CMS's State Profile Tool Grant Program.[8] Seven states have been awarded supplemental funding to enable them to assess their long-term support systems and, in particular, to field surveys designed to collect data on agency-employed and participant-directed PAS workers providing services under public programs. These data collection efforts follow the minimum data set recommendations made in a national white paper issued by the CMS-funded National Direct Service Workforce Resource Center.[9]

Finally, one of the key policy issues facing states and the federal government is how to organize and improve training standards for PAS workers.[10] There are no federal training standards, but some states have instituted limited training standards for at least some groups of these aides. However, within a given state, these standards can vary widely across different programs.

A multi-year PHI research project has been collecting and analyzing information on state training requirements for personal care aides. Findings will be released in Fall 2012. The timing of this PAS Center project aligns with a federal demonstration program—the Personal and Home Care Aide State Training (PHCAST) Program—currently underway in six states. These states are developing core competencies, piloting training curricula, and creating certification programs for PAS workers. Funded under the Affordable Care Act of 2010, PHCAST is the first federal initiative dedicated to improving training for PAS workers. Evaluations are being conducted in each state and will be complemented by a national evaluation.

For example, the PAS Center is conducting the evaluation of the California PHCAST project. A partnership of three community colleges and two personal care aide employers developed a competency-based 100 hour curriculum offered in both an online and classroom format. To date, nearly 500 participants have completed the training. Future challenges include linking trainees with employment opportunities, and working with state or national entities to establish certification.

Informal and Unpaid Caregivers

Estimates of the number of family caregivers nationwide vary enormously, from 7 million up to 54 million, or from 3 percent of individuals to 27 percent. This range is indicative of the fact that there is as yet little consensus on what kind of caregiving is to be measured or for what care-recipient populations. For example, in order to designate someone as a care provider, should the interpretation be left to the care respondent, and should the criteria be the provision of <u>any</u> personal care or support services including "unskilled help" or, alternatively, the provision of regular "skilled" help? Furthermore, should the survey be drawn from a representative sample of households or should individuals with disabilities be sampled? These remain some of the unresolved, but critical, measurement issues in this field.[11]

What do the most recent national surveys say about the *incidence* of different types of caregiving? A recent study analyzing the 2004 National Long Term Care Survey finds that at least 90 percent of older people receiving care in the community received family care, either alone or in combination with "formal (skilled) care."[12] However, the number of older people living in the community who received only formal services almost doubled from 210,000 in 1984 to 410,000 in 2004. Also, in both 1999 and 2004, 53 percent of older people and/or their families reported making payments for

home care, with most payments being for "unskilled" help with daily activities.

Researchers analyzing the 2005 Survey of Income and Program Participation report that 89.9 percent of community-residing individuals who are unable to perform two or more ADLs report relying on family, friend or other unpaid help while 22.5 percent relied on paid helpers. For individuals living alone, 49.2 percent reported relying on paid help.[2]

Researchers have stressed that caregiving experiences and outcomes can vary in important ways across racial and ethnic groups.[13] At the same time, there has been a virtual explosion of research addressing the adverse health impacts for over-burdened caregivers.[3] Finally, new thinking on "informal caregivers" is underway that emphasizes the opportunity to engage family caregivers as important care partners who, with training and support, can contribute to reducing unnecessary hospitalizations and improving patient outcomes.[14]

Reframing the "Home Care and Personal Assistance Industry" and Service Delivery Systems for PAS

Nearly all PAS workers in the United States are employed not by local and state government but by private households and organizations. While many of these entities are reimbursed with public funds, the make-up of these various employment arrangements is important to understand because they ultimately determine working conditions for PAS workers.

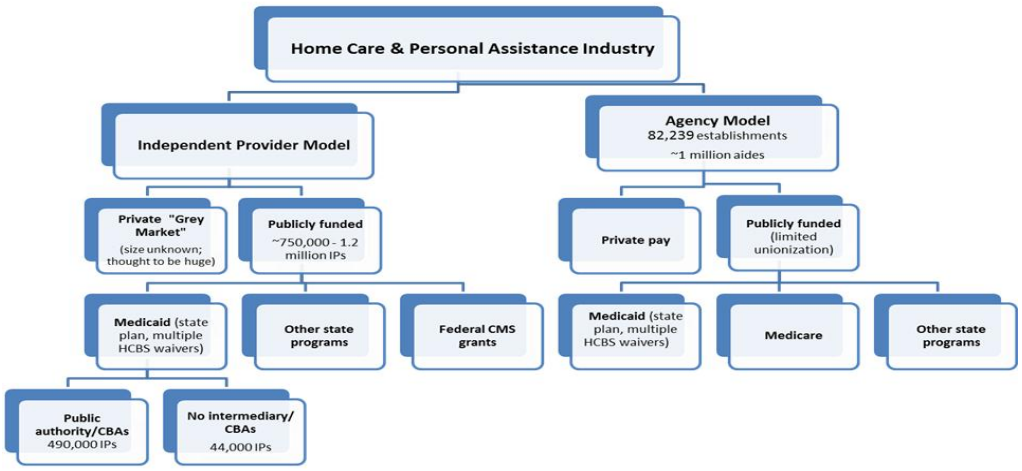
Over the last five years, progress has been made in understanding important changes that have occurred in the organizations and agencies that employ PAS workers. Advances have also been made in identifying the variety of arrangements under which PAS services are provided to persons with functional limitations. Up until recently, the assumption was that the principal agencies employing "home care" workers were located in the industry called "Home Health Care Services"—one of several industries making up the larger Health Care sector. But recent research supported by the PAS Center has challenged this outdated notion, establishing that an industry located in the Social Assistance sector—Services for the Elderly and Persons with Disabilities—is now a major employer of PAS workers.[1516] This sub-industry contains many home care or private-duty companies specializing in providing non-medical home care, including fast-growing chains of for-profit franchises providing non-medical home care services.

In its recent economic analysis of proposed regulatory changes to the companionship services exemption of the Fair Labor Standards Act—an exemption that currently prevents large numbers of PAS workers from receiving federal wage and hour protection—DOL embraced this updated industry framework.[17]

Service delivery systems for PAS have been evolving in response to substantial shifts in demand, but they are also shaped by the fractured and siloed funding coming primarily from Medicaid. Figure 1 below provides a schematic of PAS service delivery systems.

Research is needed to examine how states vary in their mix of participant-directed services and agency-delivered services, and how workforce and care outcomes may be connected to that variation. Ideally, such research would allow for differences in types of agencies (home health care vs. non-medical companies, and not-for-profit vs. for-profit) as well as types of participant-directed options (*e.g.,* with or without fiscal intermediaries and/or collective bargaining).

Figure 1



From: Seavey & Marquand (2011)

Research on PAS Workforce Outcomes

Compared to research on the nursing aide workforce that works in nursing care facilities, there is much more limited peer-reviewed research examining associations with PAS workforce-related outcomes such as worker satisfaction, supply, retention, turnover and consumer satisfaction and care quality. The modest size of the existing research notwithstanding, three strong themes have emerged:

1) Wages and health care coverage play a critical role in determining the adequacy and stability of the home care workforce, and lower wages are associated with higher turnover and lower quality of care;

2) Lack of training and poor supervisory support is associated with higher injury rates, lower job satisfaction, higher turnover intent, and lower care quality; and

3) Other employer practices such as balanced workloads, regular schedules, and opportunities for advancement are also associated with positive workforce outcomes such as higher job satisfaction and lower turnover intent.

Examples of key findings from studies developing the above themes include the following:

Wages, health insurance and turnover

- A near doubling of wages for home care workers in San Francisco County over a 52-month period was associated with an increase in the annual retention rate of new workers from 39 percent to 74 percent. This improved retention translated into a 57 percent decrease in the turnover rate for new workers.[18]

- In Wyoming**,** the average wage of experienced direct-support workers increased from $7.38 to $10.74 over a three-year period beginning in 2001. Over the same period, full-time staff turnover declined from 52 percent to 32 percent.[19]

- A statewide study of home care workers in Maine found that a 20 percent wage increase for agency-employed home care workers can be expected to reduce turnover by 28 percent.[20]

- Among PAS workers in Illinois' Community Integrated Living Arrangements (community-based group residences services for people with developmental disabilities), higher worker turnover increased state-reimbursed training costs, the number of workers engaged in training, and the cost of workers' compensation to the agencies. A wage subsidy is recommended in order to reduce turnover, and it is estimated that increasing annual compensation for workers in the range of 24 to 31 percent would have cut the turnover rate by a third.[21]

- In California, providing health insurance increased the probability of PAS workers remaining in their jobs for at least one year by 21 percent.[22]

Training

- Using the National Home Health Aide Survey, researchers found that aide perceptions of poor training and poor supervisory support were significantly related to higher risk for workplace injuries, and that injured aides had lower job satisfaction, higher turnover intent, and poor employment and care quality perceptions.[23]

Other employer characteristics affecting workforce

- A Better Jobs Better Care study[24] investigated how the job perceptions of the direct-care workers related to their intent to leave their job. A total of 3,039 workers from 50 nursing homes, 39 home care agencies, 40 assisted living facilities and 10 adult day services in five states participated in the survey. Researchers found that the perceived lack of opportunity for advancement along with the perception of work overload were significantly related to intent to leave, particularly among home care agency and skilled nursing home staff.

- A statewide study of home care workers in Maine found that unreliable schedules and irregular hours correlate with lower rates of job satisfaction and higher rates of intent to leave.[25]

Challenges and Research Gaps

To date, the main emphasis of research in the PAS workforce field has been establishing a reliable data foundation for investigating the descriptive characteristics of the traditionally agency-employed PAS workforce. This research provides a strong basis for identifying the analytical research issues most central to the challenge of developing adequate, stable PAS workforces across the country. In particular, research is needed that explores the associations between state policies, the workforce policies and practices of employer agencies, and PAS workforce outcomes (*e.g.,* retention, turnover, job satisfaction, earnings).

Workforce Size. One of the biggest challenges to sound research and policy making in the PAS workforce field is that, existing federal and state surveys notwithstanding, the PAS workforce is heavily undercounted. For example, PHI estimates that there are roughly 800,000 PAS workers who are employed as "independent providers" (IPs) in participant-directed public programs (in which those receiving PAS hire and manage workers) and that the vast majority of these workers are not captured by establishment surveys conducted by the Occupational Employment Statistics program. Furthermore, state Medicaid agencies typically do not collect data on how many IPs are employed in their programs, and CMS does not require that this information be reported. Additionally, the staffing assumptions used by BLS in their employment projections appear to result in a vast undercount of the number of PAS workers who are either self-employed or work directly for households.[26] An important consideration is that significant numbers of PAS workers are thought to work directly for consumers and

their families under private pay arrangements that often go unreported.

Injury risks for PAS workers are also thought to be significantly underestimated, in part because independent providers are largely ignored.[27]

Non-traditional PAS workers. A critical research gap in the PAS workforce field is our limited understanding of non-traditional PAS workers—that is, IPs in public pro-grams and PAS workers in the so-called "grey market." As participant direction grows as a delivery option, we need to learn more about the intersection of family caregiving and paid caregiving, including qualitative research that helps us understand the roles and self-perception of unpaid and paid family caregivers. Today every state has at least one employer authority program offering the participant the opportunity to select and hire their own worker. All but 18 states have or are developing programs that allow veterans to direct their own PAS.[28]

There is a small but growing literature examining non-traditional PAS workers, much of it relying on data from the California In-Home Supportive Services (IHSS) Program. Findings include the following: a) Paid IHSS family caregivers have the potential to add significantly to the PAS workforce by continuing as PAS providers;[29] b) Allowing spouses, parents, and other relatives to be paid IHSS providers resulted in fewer hospital and nursing home admissions and lower average Medicaid expenditures,[30] and there were no differences in health-related outcomes for recipients using relative- vs. non-relative providers;[31] c) In the MI Choice Medicaid Waiver Program, a majority of family caregivers (57 percent) do *not* live with the participant they support and a significant proportion of paid family members would like training, particularly on clinical topics and in communications skills;[32] and d) In the Los Angeles area IHSS program, abuse from consumers, unpaid overtime hours, and caring for more than one consumer as well as work-health demands predict less satisfaction whereas job security and union involvement have a direct positive effect on job satisfaction.[33]

Training. Another topic deserving of further research is training for PAS workers. Policy makers have an interest in understanding how investments in home and community-based services workforce training and development influence satisfaction, supply and retention of frontline workers in home care. In addition, research is needed to identify and explore the interest that non-traditional PAS workers and self-directing consumers have in acquiring skills and information.

Future Challenges. In addition to the research gaps and challenges identified above, two new frontiers confront the PAS workforce field. The first is the role that PAS workers and family caregivers could play in new models of integrated care. The regular hands-on contact of PAS workers with their clients make them well positioned to identify changes in a client's condition and take preventive action to avoid costly institutional care. With support and training, PAS workers and other caregivers also have potential to improve outcomes by participating in team approaches to chronic disease management, assisting with transitions from one care setting to another, and providing support and information to family caregivers. CMS has recently funded new studies in this area through the Center for Medicare and Medicaid Innovation (CMMI).

The second frontier concerns the rapid movement to managed long-term care systems across the country, and the challenge of identifying contracting standards and performance indicators related to access to community-based care, and workforce adequacy and quality. These standards need to be identified for contracts between states and managed care organizations (MCOs), and also for contracts between MCOs and provider agencies.

Conclusion

While much has been accomplished in recent years, further research on the PAS workforce at this time could not be more important. Expanding state-based delivery systems for long term care services and supports is predicated on the availability of an adequate, stable PAS workforce and research can contribute important learnings regarding the workforce impact of state policies, and employer employment practices and working conditions.

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Endnotes

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