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Testimony of
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On
Health Reform in an Aging America
Before the
Special Committee on Aging
United States Senate

March 4, 2009



Chairman Kohl, Senator Martinez and Members of the Committee, Good morning.

I am Henry Claypool, the Washington Liaison for PHI – which promotes *quality care through quality jobs* within the eldercare/ disability services system. PHI works with a wide range of providers, consumer groups and labor to strengthen the front-line workforce – Home Health Aides, Certified Nurse Aides, Personal Care Attendants – and with the American Geriatric Society is the co-convenor of the new national *Eldercare Workforce Alliance*. My testimony today reflects only the views of PHI, however, and not that of the Alliance.

Thank you for inviting me to testify today to share my perspective on the importance of addressing long-term services and supports in health reform efforts. My comments are also informed by my own personal experience. I am a former Medicaid beneficiary and I continue to rely on supports provided by direct-care workers. I have used this personal experience to inform policy making in various roles within state and federal government. I am acutely aware of the critical role long-term services and supports (LTSS) play in maintaining one's health. I define long-term services and supports as those needed when ability to care for one self has been compromised by a chronic illness, disability or aging. Core long-term services are those that provide assistance in routine daily activities such as bathing, dressing and preparing meals.

I use the term, “long term services and supports” rather than “long term care” for two reasons. First, I believe it better captures what those of who rely on the assistance of others need and want. Second, the term “long-term care” has become synonymous with nursing home or other forms of institutional services. In fact, over 80 percent of people with significant disabilities across the age-span live in their homes or other community-based settings. The number of long-term residents of nursing homes, intermediate care facilities for persons with intellectual and developmental disabilities and mental health institutions has declined dramatically over the past several decades, which requires a shift in how Americans think and talk about this sector of the country's health care system.

I. INTRODUCTION

The nation appears poised to consider – and hopefully enact – comprehensive health reforms to provide health insurance to the nearly 50 million Americans who currently are uninsured as well as another estimated 25 million who are “underinsured.” The “underinsured” are made up of individuals who like myself have insurance coverage that is insufficient to meet all of their health care needs. We have an important opportunity in our nation to improve the lives of

uninsured and underinsured Americans by better streamlining, organizing, and integrating how we provide health care and related services. The conventional wisdom seems to be that all of the ills of our health care system can be remedied by addressing the issues of the uninsured and bringing about increased cost efficiencies through increased comparative effectiveness research. These are vital and necessary prerequisites for moving forward. However, I do not believe that limiting the scope of the health reform agenda to these issues will be sufficient to meet the challenge facing the American people today.

To truly meet this challenge, I believe we also must rethink and retool how we as a nation design, finance, and deliver long-term services. Health Reform must move beyond making improvements in access to acute care services and embrace interventions that improve access to on-going services and social supports that allow individuals with limitations in activities of daily living to lead better and healthier lives. People who use long-term services tend to be extensive users of health care as well. As such they are a major cost driver of the health care system. We simply cannot achieve efficiencies and cost savings in our health system unless and until we adopt and effectively implement a comprehensive approach to managing their needs.

For example, if one looks solely at Americans with Medicare over age 65, the cost to the program for treating the medical needs of those with functional limitations is three times that of a beneficiary without long-term care needs. If we do not include this population – which consumes a significant share of our nation’s health care resources – Congressional efforts to address the growth rate of medical costs is likely to fall far short of its goal.

As with the acute care system, each of the major payers in our health system – private insurance, Medicaid, and Medicare – plays distinct roles in financing and delivering long-term services and supports. Medicare provides limited post-acute care through its skilled nursing facility benefit and its home health care benefit, accounting for slightly less than one-quarter of total long-term care spending. Direct out-of-pocket care spending by individuals and families accounts for 22 percent of spending.

The overwhelming majority of people who need long-term assistance and supports relies primarily on unpaid help from family and friends. This is not only for older Americans but for both children and adults who have significant disabilities as well. When such natural supports are either not present or not sufficient to meet their daily needs, however, many of these Americans and their families must turn to Medicaid. For example, most people who require extensive nursing home stays, or on-going assistance to live in their communities, exhaust

their savings and become eligible for Medicaid. As a result, Medicaid is the largest single funding source in the U.S. for both institutional- and community-based long term services. Medicaid now accounts for 40 percent of total long-term services and support spending.

While it is reasonable to ask individuals to bear as much of the cost of their services as possible, we know that long-term service costs can quickly overwhelm most individuals and families. This is especially true of younger adults who have not built up a nest egg to rely on for financial support.

For working aged adults with sufficient resources or employer-sponsored benefits, private insurance can play a role. Some individuals have access to short-term disability insurance which can provide critical support following an injury. A smaller number of Americans have access to long-term disability insurance that provides an income support base for individuals who lose their ability to work due to disability. A smaller number of Americans have purchased private long-term care insurance.

The value of these insurance products varies immensely. However, if designed well and indexed for inflation, they may hold the potential to provide important support for some individuals who, due to disability, need access to long-term services and supports. It may be obvious, but it is important to note, however, that people who have already developed a disability are unable to purchase private long-term care insurance.

I would now like to offer several recommendations on financing reforms to make more community-based long-term services and supports (LTSS) available to Americans as well as approaches for building workforce capacity to meet the demand for community living services.

II. REFORM LTSS FINANCING BY STRENGTHENING MEDICAID AND CREATING A NEW PUBLIC INSURANCE OPTION

A starting point for thinking about how to improve access to LTSS is to recognize that Medicaid is the anchor of our national financing system for these supports and services. As noted above, Medicaid pays for 40% of long-term services spending in the United States and 46% of institutional or nursing home care. Medicaid is intended to assist low-income individuals with very few assets and is not available to everyone who needs LTSS. Individuals must meet both financial and functional eligibility criteria to qualify for these services.

At its inception, Medicaid was not intended to play such a large role in financing and delivering long-term services, but has come to this because of the convergence of a dearth of other financing sources for long-term services, and the high cost of long-term services and supports, which is quickly impoverishing for most Americans.

The Medicaid program makes critical LTSS available to thousands of Americans with disabilities across the age-span that receive life-sustaining support from the program. For example, persons with mental retardation and developmental disabilities rely on Medicaid for supervision and cueing services. Persons with mental illness may need supervised housing or help with medication management. Persons with spinal cord injuries and traumatic brain injuries need environmental modification for wheelchairs and other assistive technology as well as personal care services. Persons with Alzheimer's disease and dementia need long-term services due to decreasing mobility and cognitive functioning that comes with aging. They also rely on supervision and cueing services as well as transportation. And finally, persons with neuron-degenerative conditions need help with personal care.

Medicaid covers both community-based and institutional long-term services and supports, but access to community-based services is often limited as witnessed by the growing number of people on waiting lists for services (332,000 in 2007). Historically, differences in functional and financial eligibility criteria between nursing home and community-based settings have steered people with long-term services needs into institutional settings. This "institutional bias" within the Medicaid program counters consumer demand for greater access to community-based services, and contributes to inequities in eligibility across the states. While Medicaid is effective in helping many people live meaningful lives as an integral part of their community, for many others, some institutional or nursing home services are the only option available when the need of long-term services and supports arises.

Access to Medicaid long-term services should be provided in the most appropriate setting that can meet the needs of an individual, whether in an institution or the community. So long as Medicaid beneficiaries are limited to \$2,000 in assets, making financial arrangements for the goods and services needed to maintain a residence in the community will be very difficult, and in many cases only possible with assistance from friends and family members. To accomplish this, asset limits for community-based services must be increased at least to the levels that a spouse is permitted to retain when their partner enters a nursing home. In other words, there must be parity in asset limitations between

those seeking to receive nursing home care, and those seeking to receive home- and community-based services.

Another complication created by the institutional bias in Medicaid is that the amount of community-based services that a beneficiary might receive varies from state to state and often within a state. Even though where an individual lives should not have such a significant effect on his or her ability to participate in community activities, attend religious services, seek an education, or pursue vocational goals – unfortunately, for people with Medicaid who need assistance with activities of daily living, this variation in service options is too often the case.

To strengthen our country’s financing for LTSS and increase the availability and accessibility of community living services, I recommend that Congress work with President Obama to enact comprehensive LTSS reforms such as those envisioned in the Community Choice Act and the CLASS Act

1. Advance the Community Choice Act

As you know, Senator Harkin has long sponsored legislation that would address the institutional bias in Medicaid and give those in a need a real choice of community-based or institutional services. The most recent iteration of this legislation– the Community Choice Act – would advance this vital aim by providing states with additional federal resources to make community living services a mandatory part of the Medicaid benefit. In so doing, it would offer people that need such assistance a real choice between living in an institution or their community – enabling states to better meet their civil rights obligations under the Americans with Disabilities Act to provide people with disabilities with services – including Medicaid LTSS – in the most integrated setting appropriate to their needs.

The cost to the federal government associated with this proposal has been cited as a barrier to its enactment in the past. There is evidence, however, that the original estimates relied on assumptions that are now out-dated. By using recently compiled data regarding states’ spending on personal assistance services, a more refined estimate from the Congressional Budget Office may allow policy makers to better weigh the benefits associated with allocating resources toward making access to community-based personal assistance services an entitlement

If the estimated cost of the Community Choice Act continues to discourage legislators from adopting this approach to address the need to make more community-based personal assistance services available through the Medicaid

program, an alternative approach should be included as part of health reform. Such provisions could include providing financial incentives to states to increase the availability of community-based personal assistance services and supports over a five- to ten-year period. The federal government could establish a series of annual benchmarks to set a target for each state to measure progress toward providing a level of personal assistance services that would support an increased number of beneficiaries to live in their homes and communities.

Providing, for example, a states with a modest increase in their FMAP over a prolonged five- to ten-year period could help advance four key objectives:

- It could help states to measurably reduce and gradually eliminate service access disparities that currently exist within states, across different groups of beneficiaries, and throughout the country.
- It could provide states with a federal funding commitment to expand access to such services and to sustain such access even during one or more economic downturn. This is necessary to address the chilling effect that the countercyclical nature of Medicaid has upon state policy makers' decision-making that affects community living services in both good times and bad.
- It could provide states with the time they require to rebalance their LTSS systems and begin to realize some of the cost efficiencies and savings that can result from doing so.
- Such an approach also could provide the states and the federal government the time needed to experiment with and arrive at a consensus on what a fair and sustainable division of labor and funding responsibility for Medicaid LTSS should be.

States' participation in such a program could be voluntary. However, if a state refused to participate or take good-faith effort to make meaningful progress in rebalancing its LTSS system, it could be compelled to comply with the integration requirements of the ADA and the Olmstead decision.

2. The CLASS Act

Another important component of health reform should be the inclusion of Senator Kennedy's Community Living Assistance Services and Supports (CLASS) Act. Designed as a program that would pay for itself through premiums, the CLASS Act would allow Americans to enroll in a broad-based public insurance program to prepare for the eventuality that they might experience an inability to perform certain activities of daily living. This program would help individuals and families safeguard their financial future against the

economic devastation and hardships that often accompany the loss of certain functional abilities.

Employed individuals would pay monthly premiums; there would be a vesting period; and there would be no exclusions based on health or disability status. People would be eligible for cash benefits based on functional need - not diagnosis. Benefits could be used to purchase assistance based on the individual's and family's circumstances. This insurance plan would provide access to long-term services and supports without the need to "spend down" to become eligible for Medicaid; as a result, beneficiaries would not need to become impoverished for life to have their needs met.

The CLASS Act would have the added effect of slowing the demand for Medicaid services by the number of Americans that were able to meet their needs with the distributions from this program. Individuals could supplement their coverage with private insurance, if desired. If enacted, this program could eventually help thousands of Americans take steps to close crucial gaps that currently exist in the nation's health care system. Acting now will make this an option in the not too distant future.

III. BUILD LTSS WORKFORCE CAPACITY

Addressing long-term care program design and financing is only part of the answer. As you have recognized, Mr. Chairman – and as underscored in the Institute of Medicine's 2008 report, *Retooling the Health Care Workforce for an Aging America* – equal attention must be paid to building and strengthening the workforce needed to provide these services. Thank you for your leadership on matters related to the direct care workforce. We also appreciate your efforts, along with Senator Wyden, to include investments in our nation's direct-care workforce in the Economic Recovery legislation.

More specifically, your legislation, the Retooling the Health Care Workforce for an Aging America Act, originally introduced last December and reintroduced at the beginning of this Congress, would address a number of issues confronting the home- and community-based workforce today. PHI is pleased to support this legislation.

As you therefore well know, Mr. Chairman, the eldercare/disability services workforce is an invisible giant. Many do not recognize just how large this workforce is. According to PHI's analysis of data from the U.S. Bureau of Labor Statistic, the direct-care workforce – which includes home health aides, personal care aides and certified nurse aides among others – now numbers 3,000,000, and

demand for these jobs is projected to grow to 4,000,000 by the year 2016. At 4,000,000 workers, this workforce will outnumber teachers who educate our youth; nurses; and law enforcement and public safety officers.

Two direct-care worker occupations in particular—Personal and Home Care Aides and Home Health Aides—are expected to be the second and third fastest-growing occupations in the nation, increasing at rates of about 50 percent from 2006 to 2016.

As our country invests in providing greater choices for receiving eldercare/disability services and expanding the availability of community-based services, we must support the workforce to meet the growing demand this creates. I have called for an enhanced federal financial effort to end the institutional bias in Medicaid but *a complementary effort by the federal government must be extended to address the workforce capacity challenges that our nation faces in the realm of LTSS.*

Further we must recognize that the direct-care workforce – deployed in hundreds of thousands of homes and tens of thousands of facilities around the country every day – is a tremendously valuable, yet underutilized, asset in our health care infrastructure. We absolutely must seek ways to leverage this resource toward our reform goals of improving access, promoting quality, increasing efficiency, and controlling costs.

In order to provide services and supports to an increasing number of Medicaid beneficiaries in home- and community-based settings – and to develop service delivery systems that are more cost efficient and effective in promoting positive health outcomes – our country must make advancements in three areas:

1. Improve direct-care worker compensation
2. Upgrade training for direct-care workers
3. Explore new health management practices that target behavior/habits/daily activities of people with chronic conditions and the direct care staff that work with them.

1. Improve direct-care worker compensation

Our long-term care system faces a huge recruitment and retention challenge – one made more difficult by the poor quality of many direct-care jobs. In 2007, most direct-care workers earned just over \$10 an hour. This is only two-thirds of the median wage for all US workers, which is about \$15 an hour. With wages this low, it should come as little surprise that over 40 percent of direct-care worker households rely on some type of public benefit such as Medicaid or food stamps in order to make ends meet.

But not all direct-care jobs are the same. Direct-care workers who work in nursing homes generally have a higher hourly wage than their counterparts providing services in the community. In fact, if we look back over the last decade – at a period of time when the federal government and states have been trying to rebalance our long-term care system to provide greater access to community-based services – our payments to workers have gone in the opposite direction. Over the last eight years, when adjusted for inflation, wages for Nursing Aides, Orderlies and Attendants have seen a modest increase in their real wages while real wages for Home Health Aides and Personal and Home Care Aides have actually declined.

Access to health insurance is also a critical concern for direct-care workers. While two-thirds of Americans under age 65 receive health coverage through their employer, only about half of direct care workers have employer-based coverage. Community-based workers are particularly affected. Nearly one-third of home care aides have no health coverage.

Providing decent paying jobs and health benefits for direct-care workers is the key to ensuring quality of life and quality of care for millions of Americans with disabilities and chronic illnesses. Without competitive compensation for direct-care workers, consumers will be forced to go without needed services, and quality of care will continue to be undermined by turnover as direct-care workers leave the field for higher paying less demanding occupations.

Community-based workers support clients with complex service needs – individuals who could only have been served in nursing homes years ago – and most of these workers are doing so without the benefit of on-site support from supervisors or peers. If we truly wish to end the intuitional bias in Medicaid, we must pay workers in the community the same as those who work in institutions. By doing so, we will bring real choice to workers who may prefer to work with people in their homes or other community settings.

Finally, in the area of setting better compensation policies and standards for direct-care workers, policy makers are hampered by a lack of ongoing, reliable state-based information about the wages and benefits that are financed with public dollars. Indeed, most states are unable to identify how many workers are employed in delivering public LTSS. The federal government can play an important role in encouraging states to collect and publicly report a “minimum data set” of information on their direct-care workforces across the full range of eldercare / disability service settings.

2. Upgrade training for direct-care workers

The training that direct-care workers receive is important and needs to be relevant to the worker's experience, knowledge base and responsibilities. Mr. Chairman, as your bill recognizes, our training programs for direct-care workers have not kept pace with the changes in our eldercare / disability service system.

In many states, the only training that is available for direct-care workers is Certified Nurse Aide (CNA) training programs, which primarily prepare workers to assist older adults in nursing homes – and as the IOM report on the eldercare workforce noted, even this CNA training is outdated and should be re-designed to meet the service needs of today's far more complex long-term service and support consumers. In addition, the IOM report called for an increase in the minimum federally mandated training requirements from the current 75 hours to at least 120 hours.

However, even less public policy attention is paid to teaching how to provide services to consumers living in their homes or other community settings, or to younger consumers with disabilities. Training standards for personal care workers vary widely between states, and even between programs within states. In fact, in many places these workers have no training opportunities at all.

Many advocates from the disability community have strong opinions about training and training requirements. This may be due to a negative experience having hired workers who have gone through a poorly designed training course that provided little information on how to interact with a person who has significant disabilities. Bad experiences with poor-quality training have led some beneficiaries, particularly those in consumer directed or self-directed personal assistance programs, to seek the opportunity to train, as well as hire, their own workers.

We submit, however, that best-practice forms of training are now available that prepare workers explicitly for working within a consumer-directed model, and that these, more "relationship-based" forms of training can directly support the aspirations of self-directed consumers to in turn further train, employ and supervise their direct-care workers.

Consistent with the direct-care worker training provisions of your bill S. 245, we must upgrade current training programs and expand their relevancy to a greater range of workers. We can enhance the content of entry-level and advanced training for direct-care workers by identifying the competencies required for workers to provide quality services to long-term care consumers in any setting.

Training would also be improved by developing competency-based curricula designed around a system-wide review of the skills and knowledge needed to provide quality services to address the physical, emotional, and cognitive needs of older Americans and individuals with disabilities. Finally, training should include a greater emphasis on communication and interpersonal problem-solving skills to strengthen service and support relationships, ensure delivery of person-centered services, and coordinate with family caregivers.

3. Explore new health management practices that target the behavior, habits, and daily activities of people with chronic conditions and the direct-care staff who work with them.

As I noted earlier, I believe that it is critical that health reforms embrace interventions that improve access to on-going services, as well as social supports that allow individuals with limitations in activities of daily living to lead better and healthier lives. People who use LTSS tend to be the cost driver of the health care system, and we cannot achieve efficiencies and cost savings in our health system unless and until we embrace a comprehensive approach to managing their needs.

The direct-care workforce is ideally positioned to help manage chronic conditions, ensure compliance with medication and health care regimens, and introduce wellness and prevention education, thus resulting in better health status for consumers and lower medical costs for our health care system. Recent efforts to involve home care workers in monitoring the chronic health conditions of the individuals they are serving have great promise as a building block for new disease management practices.

While monitoring certain health statistics (*e.g.*, blood pressure, blood sugar level, adherence to medication regiment) are critical functions that can be performed by direct-care workers, changing the behaviors that bring on many chronic conditions may present the greatest challenge to lessening the impact of these conditions on overall health status. Since the root cause of many chronic health conditions is human behavior, it is important to explore how direct-care workers might support healthier behavior of the people they serve.

By providing a mix of education and modest incentives, direct-care workers may be able to support certain health-related behaviors, and thus certain conditions, that are acquired or exacerbated by poor eating habits, lack of physical activity, and social isolation. For example, providing a direct-care worker with a basket of produce to prepare a meal for their client, along with a video on food

preparation, may create a learning experience for both the consumer and the worker.

Since direct-care workers themselves often come from communities where the incidence of certain chronic conditions is high, it may make sense to think of the worker and the consumer as a health dyad where resources could be focused to change behavior and improve health status of the two, together.

In closing, I would like to thank the committee for its efforts to ensure that long-term services and supports are included in health reform. The Americans that rely on these crucial services are often people with multiple chronic health conditions. Without a concerted effort to address simultaneously the acute and long-term services needs of this population, efforts to curb the growth in cost of health care overall may unintentionally result in undermining access and quality within our nation's long-term care system.