

**Testimony of Mitch LaPlante, Ph.D., Associate Professor, University of California, San Francisco.**

Senate Finance Committee Hearing on "Home and Community Based Care: Expanding Options for Long Term Care" Tuesday Sept 25<sup>th</sup>, 2007 at 10am, Dirksen Office Building G-50

Chairman Baucus, Senator Grassley, and members of the Committee, I am honored to speak today on expanding the options low-income people with disabilities have to choose between living in an institution and living in the community. In our nation's history, deinstitutionalization occurred first for persons with mental illness in the 1960s. As a result of the Medicaid waiver program, a second wave of deinstitutionalization occurred in the 1990s for persons with intellectual and developmental disabilities. We appear to be entering a third wave of deinstitutionalization in which persons with physical disabilities and older persons can remain in the community instead of going to a nursing facility. As our population ages, we must find ways to provide home and community based services (HCBS) of sufficient quantity and quality so that individuals can choose where and how they will live.

The ADA protects the right of individuals to reside in the most socially integrated setting they desire and the Supreme Court Olmstead decision has reinforced this right. One of the goals of the Administration's New Freedom Initiative is to expand HCBS options. This is the right thing to do because many people with significant disabilities, regardless of age, want to avoid institutions and to leave an institution if they are placed in one. According to CMS data, about 20 percent of nursing home residents wish to live in the community.

Even though the Congress, the Executive, and the Supreme Court all agree people should be able to choose where and how they live, Medicaid, in its design, rules, and procedures favors placement in institutions over HCBS, what is known as the institutional bias. The key aspect is that institutional services are mandatory under the Medicaid program while HCBS are optional. Some states use their options, but many states do not. About 30 states use the PCS optional benefit which funds personal care services and attendants. In states that do not use the PCS option, PCS are only available if the state has a waiver that provides personal care. The fraction of a state's population that is provided personal care services (PCS) ranges from a low of 3 persons per 10,000 state residents in the lowest state to 84 persons in the highest state (Kitchener, Ng, Carrillo, Miller, & Harrington, 2007). Unlike the PCS benefit, the waivers are often restricted in who they will serve, and there are long waiting lists. While additional HCBS opportunities can be created through the Deficit Reduction Act (DRA) of 2005, these too are optional. This results in a continued significant bias towards institutions and individuals are not provided a real choice.

Given this situation, it is not surprising that there is unmet need for personal assistance among low-income persons. The fraction of persons who need help with 2 or more ADLs who have unmet need for personal assistance services and are in poverty was 31 percent among working ages and about 25 percent among those 65 and older. Unmet need is associated with a host of adverse consequences, such as injuries from falling, poor nutrition, and dehydration, which are unnecessary and add significant costs to the system (LaPlante, Kaye, Kang, & Harrington, 2004).

The Community Choice Act (S. 799) is a proposal for people with low incomes who have an institutional level of need, to help them avoid institutions, allow them to choose community services, and reduce unmet need. By making PCS a mandatory benefit, the Choice Act would greatly reduce the institutional bias. However, this idea has had an albatross around its neck since it was first introduced. The CBO estimated in 1997, for an earlier version of the bill, that new federal expenditures would be \$10-20 billion a year, if only a quarter of those who could be eligible obtained the benefit. I have to say frankly that estimate is inflated and erroneous. Based on research I and my colleagues have published (LaPlante, Kaye, & Harrington, 2007), we estimate a range from \$1.4 to \$3.7 billion depending on the rate of participation from 30 to 80 percent. Adjusting for inflation, it is about one-tenth the CBO estimate. The key difference between our estimate and the CBO estimate is the number of people who would be eligible. Measures of institutional need are typically based on having two or more of the basic activities of daily living, which include bathing, dressing, transferring, toileting, and eating. The CBO estimate included people who need help with a much broader set of instrumental activities including shopping for groceries or getting places outside of walking distance. However, someone who only needs help shopping for groceries or getting around is certainly not a candidate for an institution. Including these activities greatly inflated the CBO estimate.

There has been concern over a woodwork effect in that persons would obtain the benefit who otherwise would not have gone into an institution and their family members would have continued to help them without any cost to the government. Such individuals receive a tremendous amount of support from their families who often do everything they

can to keep them out of an institution at their own personal expense, including giving up work and careers. The CCA will not generate a large woodwork effect because it restricts the benefit to people with an institutional level of need. We estimate that 600,000 persons would be eligible, not several million.

I am concerned that the institutional need criteria are not specific. We know that some states use loose criteria, such as a physician's letter, while others use strict criteria, such as 3 or more ADL for determining institutional need (Tonner & Harrington, 2003; Tonner, LeBlanc, & Harrington, 2001). Institutional need criteria should be specified in the CCA, such as 2 or more ADLs, so that this does not become an Achilles' heel for the legislation.

While it is often claimed that HCBS are cheaper, the argument is rarely made that HCBS cost any more than institutional services. One study concludes that Medicaid could save \$44,000 by providing HCBS instead of a nursing home stay (Kitchener, Ng, Miller, & Harrington, 2006). Our ongoing research shows that the several states that have greatly expanded their HCBS programs in the 1990s have been able to reduce their institutional expenditures within 5 years. States that have established HCBS are ahead of the curve and controlling their costs. States that are reluctant to explore their options are behind the curve and experiencing increasing costs (Kaye, LaPlante, & Harrington, 2007).

I am aware that states do not like Medicaid mandates, but given ample options, many states apparently do not have the vision or wherewithal to rebalance their systems. Twenty states are not participating in Money Follows the Person two years after grants were first announced. I will mention again the 28:1 ratio in the fraction of the population

getting PCS across the states. It illustrates how much more some states are doing than others.

I have been able to touch on just a few points of a complex issue. I apologize if I have given some areas short shrift. However, it is my professional opinion that the CCA is socially and fiscally responsible legislation. It would replace a safety net that varies depending on which state a person lives in with one that is more uniform for all persons with significant disabilities, reducing that ratio from 28:1 to closer to 1:1 and it is likely to save money in the long run while improving people's lives. Given that the oldest baby boomers are 61 years old, there is not much time left to get rebalancing done. Until the institutional bias in Medicaid is remedied, choice will remain constrained.

## Citations

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