

TESTIMONY BEFORE THE MEDICAID COMMISSION

**Presented by Catriona Johnson, M.Sc.
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My name is Catriona Johnson and I testify today before you in both my professional capacity as a policy analyst with the National Disability Rights Network, but perhaps more importantly as the parent of a soon-to-be 14 year old with autism who is served by Maryland's Developmental Disabilities Medicaid Waiver. My testimony today combines my professional and personal knowledge and experiences, and I hope that it contributes something to the policy discussions that this Commission is undertaking.

The two areas that I will focus on today are 1) the legal right to long-term services and supports in the community, and 2) long-term care financing.

It is clear from this Commission's previous meetings that long-term care is an area in which you will be making recommendations, and I therefore ask that in shaping your recommendations that you keep the requirements of the American with Disabilities Act integration mandate, as interpreted by the U.S. Supreme Court in the *Olmstead v L.C. and E.W.* decision, front and central.

On June 22, 1999, the United States Supreme Court held in *Olmstead* that the unnecessary segregation of individuals with disabilities in institutions constitutes discrimination based on disability. The court ruled that the Americans with Disabilities Act (ADA) may require states to provide community-based services rather than institutional placements for individuals with disabilities when a state's own medical professionals reasonably conclude that an individual can reside in the community. Medicaid is affected by the *Olmstead* decision because it is the major source of public financing for long term services for people with disabilities. People with disabilities rely on long term care for the most basic needs such as getting out of bed, toileting, and use of a wheelchair. Services that are rarely high cost but in fact make the difference between institutionalization in a nursing facility and self-sufficiency in their own homes and workplaces. *Olmstead* established that state Medicaid programs must operate in compliance with the integration mandate of the ADA.

The current financing structure of Medicaid -- in which nursing home services are a mandated Medicaid state plan benefit and home-and community-based services are an optional benefit almost exclusively provided through capped Medicaid waivers -- has resulted in a system in which individuals with disabilities are too often forced to receive their care in nursing homes, even if the majority of these individuals desire to receive their services in their own homes and communities (usually for less cost). This Commission has the opportunity to recommend structural changes to Medicaid that would support the integration mandate of *Olmstead*, realigning services so that community-based services become the mandatory benefit and institutional care the waiver service. At the very least, each recommendation made by the Commission should be viewed through the lens of *Olmstead* to ensure that there are no

unintended consequences that result in the unnecessary institutionalization of individuals with disabilities currently living and working in the community.

The idea of providing home- and community- based services as mandated state plan services will probably make Governors and Medicaid Directors responsible for state budgets quake in their boots – and that is why, as a nation (and as a Commission) we must address broader long-term care financing issues. For if we do not, over the coming years policymakers will struggle to address significant health and long-term care issues, the results of which will have an effect on every American. According to the Bureau of the Census, the number of elderly people age 65 and older will increase by two and a half times between 2000 and 2050. The oldest seniors -- those over age 85 --will more than triple by 2050. These demographic changes are projected to use greater amounts of health care dollars than any generation before – in the area of long-term care alone, the Congressional Budget Office estimates that in 2004 over \$211 billion was spent, including over \$76 billion in donated care. Already States have begun to feel the impact of demographic trends and increasing health care costs.

Long-term care financing, and this Commission's recommendations, must therefore go beyond the scope of Medicaid and address broader long-term care financing options, including private long-term care insurance, long-term care partnerships, and the potential for a nationwide voluntary long-term care insurance such as proposed in S. 1951, the Community Living Assistance Services and Supports Act or CLASS Act.

While the purchase of private long-term care insurance is growing, it remains a small part of our long-term care financing system and of the 8.2 million policies sold, only approximately 7 in 10 are in force (Health Insurance Association of America, 2003). The fact is that for most low- and moderate- income Americans, the cost of long-term care insurance is unaffordable. The result is that a few individuals can privately fund their long-term services and supports, but the vast majority is reliant on Medicaid funding. Even with Long-Term Care Partnership Program, which is supposed to reduce the incentive to hide assets and increase the incentive to purchase private long-term care insurance, long-term care insurance is too costly for most individuals and many with disabilities and pre-existing conditions are unable to purchase such insurance due to eligibility requirements.

The goal should therefore be to diversify financing sources so that long-term care funding is derived from multiple sources thereby reducing dependence on Medicaid for most and using Medicaid-funded long-term supports and services for those low-income individuals with disabilities who are ineligible or cannot afford other long-term care financing mechanisms. The push towards increased use of private long-term care insurance through employer cafeteria plans and Long-Term Care Partnerships are steps in the right direction, but as stated, these alone will not address the cost barriers for most individuals with moderate and low incomes.

The CLASS Act or a proposal of similar scope would create a new national insurance program to help adults who have or develop functional impairments to remain independent, employed, and stay a part of their community. The CLASS Act as proposed is financed through voluntary payroll deductions of \$30.00 per month (with opt-out enrollment like Medicare Part B), and would help remove barriers to independence and choice (e.g., housing modification, assistive

technologies, personal assistance services, transportation) that can be overwhelmingly costly, by providing a cash benefit to those individuals who are unable to perform two or more functional activities of daily living. The large risk pool to be created by this program approach would make added coverage much more affordable than it is currently, thereby reducing the incentives for people with severe impairments to “spend down” to Medicaid. It will give individuals added choice and access to supports without requiring them to become impoverished to qualify. The CLASS Act or something like it is an important step in the evolution of public policy toward financing long-term care and giving individuals choices regarding the types of and location of long-term care services.

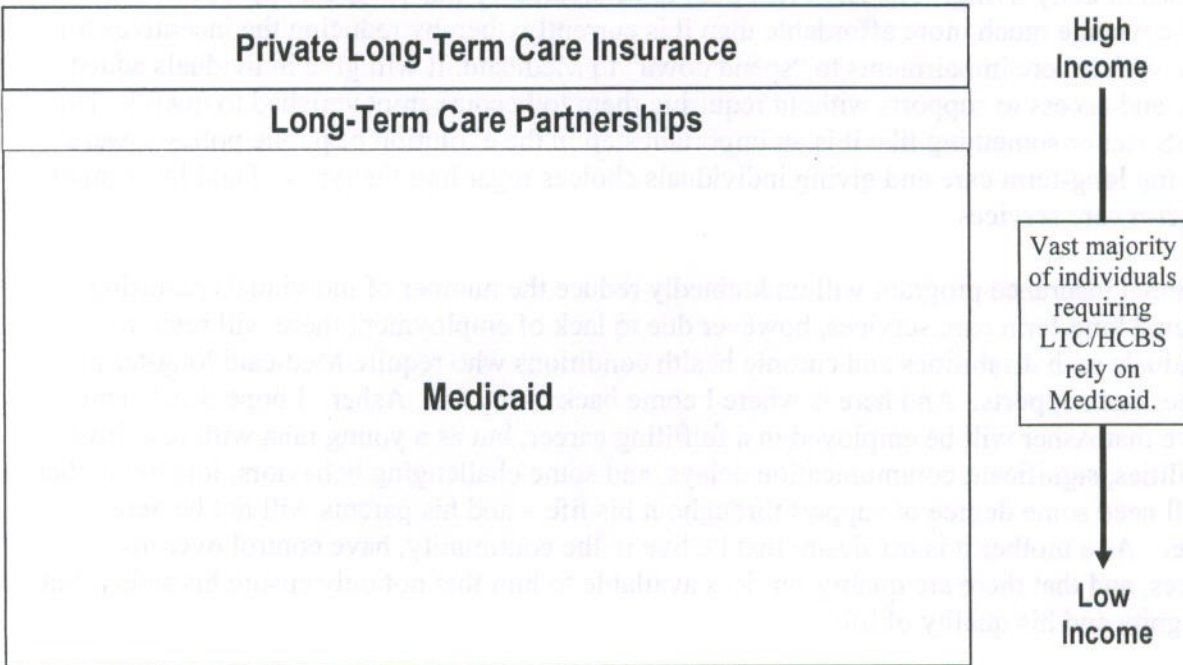
A national insurance program will undoubtedly reduce the number of individuals requiring Medicaid long-term care services, however due to lack of employment there will remain individuals with disabilities and chronic health conditions who require Medicaid long-term services and supports. And here is where I come back to my son, Asher. I hope dearly and believe that Asher will be employed in a fulfilling career, but as a young man with cognitive disabilities, significant communication delays, and some challenging behaviors, it is likely that he will need some degree of support throughout his life – and his parents will not be here forever. As a mother it is my desire that he live in the community, have control over his services, and that there are quality services available to him that not only ensure his safety, but his dignity and his quality of life.

I recognize much of this is dependent on how Medicaid, along with other long-term care financing mechanisms, are structured and funded. So I ask as a professional, and as a mother of a young man with a disability, that this Commission recommends diversified funding of long-term care, including some version of the CLASS Act, so that Medicaid remains to serve my son with a disability and others like him in their communities.

Respectfully Submitted on July 11, 2006

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CURRENT LONG-TERM CARE FINANCING SYSTEM



PROPOSED LONG-TERM CARE FINANCING SYSTEM

