NATIONAL COUNCIL ON INDEPENDENT LIVING (NCIL)

Testimony to the Medicaid Commission by Executive Director John Lancaster
November 16, 2006

Chairman Sundquist, Chairman King, distinguished members of the Medicaid Commission, thank you for this opportunity to comment before you begin your deliberations on the final commission report. My name is John Lancaster. I am NCIL's Executive Director

The National Council on Independent Living is a consumer driven membership organization whose mission is to advance independent living and the rights of people with disabilities. Centers for Independent Living have been pioneers in nursing home transition. We all look forward to the day when every person can choose where we want to live. We also are a voice for consumer choices and safeguards to ensure that individuals with disabilities have full and equal access to health care that meets their needs and responds to their preferences

LONG TERM CARE: Two months ago, many in this room heard the Commissioners build an apparent consensus to do away with the institutional bias that treats nursing home care as an entitlement, while restricting the access of hundreds of thousands of persons with disabilities to home and community based services through waiting lists, caps and other mechanisms. I had hoped to be here today to congratulate the Commission on a job well done. Although we appreciate the attention to and emphasis on home and community based services and the mention of the relevance of housing to this issue, we are sorry to say that the decisive action we had hoped for is lacking and the Chairman's mark breaks little, if any, new ground. Indeed we are particularly disappointed to have to note that the Commission's long-term care recommendations involving home and community based services seem limited to increased utilization of provisions of the Deficit Reduction Act. Now is the time for decisive action. We support Commissioner Gillenwater's proposed amendment to long-term care recommendation #2 and agree that Sec. 1905(a)(4)(A) of the Social Security Act [42 U.S.C. 1396d] should be amended to ensure that individuals should be entitled to long-term care in the setting of their choice as is already available in several states. Massachusetts, Wisconsin and several other states have already taken this step. The Commission should do so as well in its final report.

Sadly, the Chairman's Mark does not even mention the $1.75 billion Money Follows the Person program, which NCIL views as the most promising HCBS provision of the Deficit Reduction Act. Some 37 states applied to obtain funding to rebalance their long-term care systems and to help transition individuals with disabilities from institutional to community settings. This is a best practice and a model for replication – a crucial cornerstone of Dr.McClellan's legacy at CMS – not something to be glossed over.

Instead, the commission report places reliance upon cash-and-counseling and the HCBS State Plan option – despite their significant limitations. We understand why the Commission would be inclined to place increased reliance on the HCBS option – as it gives the states some of the flexibility that they are requesting. But that flexibility that states are getting is not to the benefit of consumers. Section 6086 that would permit states to set enrollment caps, maintain waiting lists, and waive the requirement that services be provided statewide as a part of their HCBS state plan options. Since nursing home services ARE provided statewide, and there are no waiting lists or enrollment caps on institutional care, the HCBS state plan option actually perpetuates the institutional bias rather than eliminating it. Furthermore, the state plan option is limited to individuals with 150% of the federal poverty level, depriving states of needed flexibility. Since there is a lack of accessible, affordable housing, this maximum resource level poses a significant barrier to seniors and persons with disabilities wishing to live in the community. Furthermore, such resource limits pose an additional barrier to initiatives and efforts to move persons with disabilities into the workforce.

We also wish to caution you about cash-and-counseling. Although we welcome self-direction and consumer control, fixed or capped budget allotments worry us because they are inflexible in the face of changing circumstances or resource intensive conditions. Would capped monthly payments be adequate to meet the needs of persons who rely on ventilators and live in their homes? What would happen to individuals with fixed monthly payments if their condition, regimen of care, or service provision costs changed in midstream? Since to date, cash-and-counseling has only been done on a demonstration basis, these important questions remain unanswered. Accordingly, we urge you to follow the Hypocratic Oath and "first do no harm!"

MANAGED CARE AND THE NEED FOR AN ACCESSIBLE MEDICAL HOME

NCIL implores the Medicaid Commission to reconsider its utilization of a medical home model that promotes an unfettered expansion of Medicaid managed care devoid of essential consumer input and safeguards. We understand that the Commission places great faith in the powers of the market and competition. And under normal circumstances and with typical markets we would tend to agree. But acute and long-term care for persons with disabilities is anything but an ordinary market. If any label would describe the market, it is probably dysfunctional. To put it in economic terms, demand for long-term and acute care services among persons with disabilities is inelastic – if you need care, you either get the care – or deal with serious adverse consequences often of a life or death nature. This is NOT a commodity that people can do without! Furthermore, the focus on the bottom line often comes at the expense of the delivery of the highest quality of care, meaning that the products offered by the managed care industry have, by and large, distinctively failed to meet the needs preferences of consumers with disabilities! An instructive article by Barbara Martinez in yesterday's Wall Street Journal, entitled *In Medicaid, Private HMOs Take a Big, and Profitable, Role*, sounds an important cautionary note about the serious dangers posed by excessive reliance on managed care in addressing the needs of beneficiaries with disabilities and chronic conditions. When a market is dysfunctional and fails to meet the essential needs of consumers, that is the

proper time for government intervention to structure the market and set essential standards.

The commission report refers to a Medical Home and that model raises interesting parallels for the disability community. Housing is another industry that has signally failed to offer products that meet the needs of persons with disabilities. Despite the demographics and the advocacy homebuilders often refuse to address the demand of consumers for housing with zero-step entrances and wide door thresholds that persons with disabilities require. We tell them "If you build it, we will come," but without government intervention in the form of ordinances or state law, progress in creating an adequate supply of accessible housing has been painfully slow.

So if you require, or push consumers with disabilities to use the medical home model, you need to make that medical home "Accessible," so that they can utilize it. This requires that providers be required to have accessible facilities and examination equipment, and be equipped to communicate with all beneficiaries. This further requires that providers must develop and train their personnel to ensure the delivery of culturally competent care for persons with disabilities. States also need to consult with consumers, disability advocacy organizations and MCOs both in advance of implementation and on an ongoing basis after the program is implemented. Provider networks must be adequate, especially to ensure that people with disabilities can get care from appropriate specialists, including those with whom they have existing relationships. Payments to providers must be adequate to ensure that a provider network including all necessary specialists and capable of delivering timely and accessible quality care can be recruited and retained. Other vital safeguards and indispensable guarantees must be built into the system that I do not have time to describe in detail. This is why I implore you to support Commissioner Gillenwater's Quality and Care Coordination Recommendation #2, which will provide for an accessible medical home that meets the needs of consumers with disabilities and bring order to what is now a dysfunctional market. Considerable scholarly research including the work of the California Health Foundation and George Washington University's School of Public Health & Health Services supports this recommendation and NCIL strongly urges its adoption!

This Commission has the opportunity to stand up for Medicaid beneficiaries with and without disabilities by ensuring the delivery of long term care in the setting of consumers' choice and by implementing safeguards that will ensure that Medicaid beneficiaries receive will be able to access high quality health care services that truly address their needs. To achieve these worthy objectives I urge support for the aforementioned amendments. Thank you.