ANCOR American Network of Community Options and Resources
A National Network of Providers Offering Quality Supports to People with Disabilities

Public Comments to the Medicaid Commission
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Good afternoon. I am Suellen Galbraith, Director for Government Relations at the American Network of Community Options and Resources (ANCOR)—the national association of private providers of supports to more than 385,000 individuals with mental retardation and other disabilities nationwide. Today, I would like to focus my remarks on several broad points in reference to *long term care* or as ANCOR members refer to it—*long-term supports and services*.

As you know, this year marks the first year that members of the baby boomers turn 60. I figure that during the two hours set aside for public comment—660 individuals have turned 60. The Census Bureau estimates that 7,918 people will be turning 65 each day in 2006. So, the Commission's focus on long-term supports at this—and I hope—future meetings is both timely and important.

1. Demographics—Aging Baby Boomers—Rethink What That Means. The United States has not begun to prepare for this demographic dynamic. This challenge is not simply about *long-term care* and Social Security, pensions and other income maintenance efforts—its about housing, products and services, technologies, language, learning—every aspect of life. What will 77 million baby boomers like as their favorite drink, how will they prefer to shop, —malls, small stores, online, personal shoppers. **Included among the baby boom generation are individuals with life-long disabilities, family caregivers, and a workforce that has been providing a range of daily long-term supports and services.**

2. Do Demographics Define Destiny—Must It Be Gloom and Doom As Baby Boomers. Last week the Census Bureau issued a new report on the 65 and older population with the researchers reporting that for every dollar spent on health care for U.S. seniors, 65 cents is funded by Medicare and Medicaid, 19 cents comes from patient out-of-pocket spending and 12 cents is paid by private insurance. However, a major finding of the report is that there is some promising news—the percentage of people over age 65 who had a disability decreased from 26.2% in 1982 to 19.7% in 1999, and there "were signs the trend would continue. The signs of a healthier older population prompted the Director of the National Institute on Aging to state that the impact of aging baby boomers on Medicare and the government might not be as large as previously thought.

The lesson here may be that it's a mistake to compare Baby Boomers with their parents at the same ages and we need to be wary of holding *everything* constant—health status, education, work, and a host of behaviors and preferences. A report by Goldman Sachs—*60 Is the New* 65—the change in older people's presence in the workforce could raise national economic growth rates by a half a percentage point—**translating into an 11 percent increase in per capita incomes**. If the recent trend of the elderly and near-elderly working more continues, it could also improve the financial outlook for Medicaid and Medicare.

So, the point here is *Not My Father—or Grandfathers—Buick.* As Robert Reischauer, President of the Urban Institute and former head of the Congressional Budget Office states: *In the end, the nation will likely avoid the scariest budget scenarios and adjust to its new, grayer self in fits and starts, driven at least as much by changes in human behavior as by government policy. Changes take place gradually, and people and institutions change.*

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3. <u>Don't Make False Choices: Ask the Right Questions, Identify the Real Problems—The Real Issue—Lack of Comprehensive Approach to Long Term Care and Health Care In General</u>. How one frames a question or a problem determines not only the answer or solution, but how we go about search for an answer or solution. Many of us believe that the accurate focus on the question/problem to be identified rests not with Medicaid—but, with the broader issue of health care and long-term care in this country —the lack of comprehensive national approaches to both. We must also rely on **evidence-based research** in national reform and do the homework, the analysis, regarding **unintended consequences** of reforms.

Medicaid has worked, and worked well, for more than 40 years. However, Medicaid's success is now the source of calling for its reform. <u>It has become the default long-term supports and services program for the nation.</u> It has grown to providing needed health care and long term supports to 54 million people of all ages. **But, Medicaid is also being called upon to help address the health care needs of 45 million uninsured individuals. Medicaid supports the entire public and private health and long term care systems in this nation and it serves as an economic engine for states and local communities.** While some say that Medicaid spending is unsustainable, what is really unsustainable is the rising costs of health care in general—**health care costs that are unsustainable for America's workers, her low and moderate income families—including people with disabilities, and for America's employers—including providers of supports to people with disabilities**. As you heard from Diane Rowland from the Kaiser Family Foundation during the last meeting, when we look at long-term care, the absence of a comprehensive national policy approach is the real problem.

While the United States spends 16% of its GDP on health care, the industrial nations of Europe spend 11%—**that 5% difference equals $700 billion annually that we could spend on other priorities.** Imagine what this nation could do with $700 billion annually. We must look at all aspects of health care and long-term care—Medicare, Medicaid as well as income sources such SSI/SSDI, private savings, public cash assistance—as well as intersection with housing and disability policies.

<u>4.Focus on the Important, Not the Urgent.</u> In helping all of us take some steps toward some of the changes that may be needed, I am reminded with fuller appreciation now than several years ago of something former Minnesota Senator Durenberger use to say to many of us in the Coalition on Long Term Care. For several years in the 1990s, he headed this group of long term care aging and disability providers, consumers, family, insurance companies, hospital and specialty health, worker, and research organizations. Senator Durenberger use to remind us that Congress (as well as us) always focused on the urgent—and they (us) never got to the important. Many of us from that coalition are here today and will recall that frequent admonition. The lesson for me in this was and is—the bigger the issue, the more important it is, the more it demands your time and effort. I do not believe there is a short cut to address this important issue—we've been at it for a long time, in my professional career spanning from the Pepper Commission, to the Bipartisan Entitlement Committee in 1990s, to this Medicaid Commission, to the President's for a Medicare, Medicaid, Social Security Commission. Let's get it right, let's not short-change ourselves and reach for the quickest solution or seek those that merely look at financing.

<u>5.Take the Time to Establish Set of Principles or Values.</u> Again, borrowing from the experience of Senator Durenberger's Coalition on Long-Term Care (CLTC) —our coalition, composed of groups that frequently opposed each other on issues—took time to find *common ground* regarding long-term care reform. These principles were **based on core values** of the coalition. In 1999, 1999, CLTC developed a set of *Pillars of Reform* which I believe are worth repeat:

- **Every American must be assured access to needed long term care services.**
- **A wholly new, stand-alone, comprehensive financing system for long term care is neither practical nor likely at this time and hence long term care financing reform should be initiated on existing structures.**

- **The social commitment to long term care must be in the form of a public/private system built on the principles of social insurance and private insurance.**
- **Professionals, paraprofessionals, and direct support professionals are critical to quality care and must be recognized and valued by the system.**
- **Public assistance must be maintained and improved to provide a full range of services and supports to those who are not otherwise covered.**

We agreed upon a set of basic principles which would shape the development of an ideal long-term care system. All efforts to enact change were to incorporate and reaffirm basic principles in the following areas:

- *Independence*
- *Choice*
- *Role of Families*
- *Access*
- *Eligibility*
- *Financing*
- *Accountability*
- *Standards*
- *Coordination*
- *Efficiency*

CLTC took the following positions:

- **Medicaid as a safety net must be available to those who need long term care but have no other source of financial assistance, and it must expand the choices available for long term care.**

- **A new social insurance cash payment benefit with appropriate eligibility and benefit level standards and requirements must be based on the level of functional need and provide a minimum floor of protection in a way that is sufficiently flexible to best help individuals with disabilities and their families meet their unique circumstances.**

Motivated by concerns over the current state of long term care and in agreement on the need to pool long term care risk, CLTC calls for a national dialogue on reforming the financing of long term care. The system must:

- **Be a public/private long term care system;**
- **It must assure access to care [services and supports];**
- **Support individual preferences and family caregivers; and**
- **Build on the current financial security framework…..AND**
- **Must be financed by a clear national commitment based on principles of social and private insurance.**

I have attached the principles from Citizens for Long term Care's white paper on *Defining Common Ground.*

I believe a good first step at building upon these principles is the bipartisan **Community Living Assistance Services and Supports (CLASS) Act (S. 1951) introduced by Senators DeWine and Kennedy**. The aim of the CLASS Act is the building of a long-term support system available to all Americans by establishing a voluntary private mechanism—the purchase of long-term care insurance—to augment limited public programs that require a poverty threshold as the entrée to supports. By creating a risk pool of Americans across the nation, premiums will be more affordable to all—including working individuals with disabilities.

- **The Alliance for Full Participation**—a partnership of ten national organizations dedicated to enhancing the lives of individuals of all ages with intellectual and other developmental disabilities who

need comprehensive health and long term supports across their lifespan, developed a statement of principles ***Going Forward, Medicaid Policy Must***, in the summer of 2005. I have attached those principles as well as a set of ***Medicaid Facts.***

5. Reform Calls for Public Discussion and Education. We must engage the broader public in a real discussion about long term supports and services. We need to engage a range of publics—beyond federal and state policy makers—including beneficiaries and their families, providers, and media. We need to find effective ways to make the work of this Commission and the opportunity for public comment, meeting schedules, etc. more widely known. We need to *educate* the public on the issues facing long term supports and service, but we need to engage the public in determining our nation's values and principles (social responsibilities) that form the foundation for our long term supports and services.

6. Reform Includes Investments in Our Systems—investments which initially may add to the costs of Medicaid and our long term supports system—but which eventually will have reduce the overall rate of growth in spending. We must recognize that the operation of effective and responsive service delivery systems requires state and local capacity to meet the needs of people with disabilities. And, we must build in ways to ***account*** **for benefits and savings accrued**—even those outside of savings derived only from Medicaid.

- **Reimbursement Rates.** When it comes to reimbursing providers, for instance, Medicaid is stingier than either Medicare or commercial insurance. Compensation cuts have become of the most expedient means for saving dollars. However, by low-balling compensation, the program e4nds up reducing the number of providers willing to provide Medicaid supports and services.

- **Recruitment and Retention of Workforce.** We must contribute to the quality and effectiveness of services through the development of a fairly compensated, well-trained, stable community workforce and a sufficient supply of qualified providers—be they employees of agencies or independent providers —family and friends that are selected and controlled by individuals with disabilities.

- **Investments in CMS and State Implementation, Evaluation, and Analysis.** There has not been the investment in Medicaid that there has been in Medicare. We must make investments in the evaluation and analysis of innovations and how successes can be replicated in other states. We must invest in analysis of desired outcomes and evidence-based research—not assumptions and anecdotes.

- **Investments in the Private System of the Delivery of Supports and Services.** In recognizing the value and efficiencies in providing supports in the home and community and person-centered services, we must provide a parallel shift in the financing to match the preferences and desires of people with disabilities. Far too many of federal and state dollars are directed to public delivery and publicly (both state and local) operated systems of long term supports and services.

- **Investments in Housing.** The lack of safe, affordable and accessible housing is a major barrier to expanding home and community services and supports. People with disabilities receiving monthly SSI payments as their source of income needed to **spend 106.9 percent of their monthly income** ($676—more than the entire SSI monthly SSI payment of $564 in 2004) in order to rent a modest one-bedroom unit priced at the HUD Fair Market Rent. As reported in *Priced Out in 2004—The Housing Crisis for People with Disabilities*, this is an significant increase since the first report in 1998.

- **Investments in Technologies, Including National Electronic Health Care Records.**

6. Recommendations Drawn from Lessons and Experience. Drawing upon lessons of the past, recommendations for values and principles underlying reform must include the following:

- **Transparency at all levels of government.**

- **Inclusion of all stakeholders in policy and evaluation—including people with disabilities, family members, and providers of supports and services.**
- **Reliance on evidence-based analysis, not assumptions.**
- **Build a system that recognizes different populations, different needs and preferences that change over a life time.**
- **Eliminate the cost to Medicaid of nearly 7 million dual-eligibles' long-term supports and supports—these costs should be born either by reforms to Medicare or new financing programs.**

7. Recommendation that the Commission invite a formal presentation by Dr. David Braddock **of the Coleman Institute for Cognitive Disabilities, The University of Colorado.** Dr. Braddock, drawing upon his studies the *State of the States in Developmental Disabilities*, can provide useful information on the trends in the growth and funding of public and private supports for people with mental retardation and other disabilities. Dr. Braddock can talk about the waiting list for individuals with mental retardation and developmental disabilities. (over 76,000 in 36 states in 2004) and more than *711,000 aging caregivers*. A copy of his most recent study released in 2005 is submitted. I might also add that the focus of the Coleman Institute is technologies for people with cognitive disabilities.

Principles to guide long term care

Upon its inception in 1999, Citizens For Long Term Care member organizations agreed upon a set of basic principles which would shape the development of an ideal long term care system. We believe that all efforts to enact change must incorporate and reaffirm our basic principles.

Independence

Services should promote individual dignity, maximize independence and self-sufficiency, and be provided in the least restrictive setting possible, and reflect the overwhelming preference of individuals to remain at home.

Choice

People should be able to choose from a full range of home, community-based, facility-based health and social services so they can get the types of services that will meet their individual needs and preferences.

Role of Families

The central role families play in planning for and providing long term care should be recognized and supported.

Access

People of all ages and income levels should have access to long term care services and supports.

Eligibility

Eligibility for services should be based on functional criteria and social needs that take into account cognitive, physical, and behavioral limitations and the need for support, supervision, or training.

Financing

Costs should be spread broadly and progressively, so that out of pocket costs are affordable. This goal may involve tax policy, Social Security, Medicare, Medicaid, private health insurance and pensions, social services and housing policies. Both public and private financing mechanisms should be strengthened toward this goal.

Accountability

Systems for assuring the quality of care should be built into all long term care programs. These systems should assure quality and value based on outcomes and consumer protections enforced through appropriate government regulations.

Standards

The highest standards of professionalism and quality are essential for caregivers and systems. This must be supported by thorough training, appropriate supervision and fair compensation.

Coordination

Systems should coordinate services for people with multiple needs that change over time, providing a seamless continuum of care.

Efficiency

Incentives and controls in public and private programs must maximize quality and control costs.