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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American Network of Community Options and Resources
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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.*

Recommendation: Establish a set of short-term and long-term recommendations. ANCOR calls attention

to the original text of the Medicaid statute that establishes Federal appropriations for the Medicaid program, keeping in mind that the program was designed to assist individuals of limited income and to provide those services that help individuals and their families **attain or retain capability for independence or self-care.**

- Title XIX of the Social Security Act: SEC. 1901. *[42 U.S.C. 1396]* For the purpose of enabling each State, as far as practicable under the conditions in such State, to furnish (1) medical assistance on behalf of families with dependent children and of aged, blind, or disabled individuals, **whose income and resources are insufficient to meet the costs of necessary medical services, and (2) rehabilitation and other services to help such families and individuals attain or retain capability for independence or self-care,** there is hereby authorized to be appropriated for each fiscal year a sum sufficient to carry out the purposes of this title. The sums made available under this section shall be used for making payments to States which have submitted, and had approved by the Secretary, State plans for medical assistance.

Recommendation: <u>Medicaid must remain the safety net</u> for those individuals who need long term care but have no other source of financial assistance.

Individuals with disabilities, their families, and providers have advocated since the 1980s for a system of long-term supports based on community integration. While efforts of the original so-called *Chafee bill* to create a mandatory community supports provision that eliminated the focus on institutions met with resistance, these efforts led Congress in 1990 to enact the Community Supported Living Arrangements Services (CSLA), amending the Medicaid program (Section 1930 [42 U.S.C. 1396u]).

- SEC. 1930. *[42 U.S.C. 1396u]* (a) COMMUNITY SUPPORTED LIVING ARRANGEMENTS SERVICES.—In this title, the term "community supported living arrangements services" means one or more of the following services meeting the requirements of subsection (h) provided in a State eligible to provide services under this section (as defined in subsection (d)) to assist a developmentally disabled individual (as defined in subsection (b)) in activities of daily living necessary to permit such individual to live in the individual's own home, apartment, family home, or rental unit furnished in a community supported living arrangement setting:
  (1) Personal assistance.
  (2) Training and habilitation services (necessary to assist the individual in achieving increased integration, independence and productivity).

(3) 24-hour emergency assistance (as defined by the Secretary).
(4) Assistive technology.
(5) Adaptive equipment.
(6) Other services (as approved by the Secretary, except those services described in subsection (g)).
(7) Support services necessary to aid an individual to participate in community activities.

Although CSLA ended up being a pilot limited to eight states and focused only on assistance to individuals with developmental disabilities, multiple efforts have continued for more than 25 years to end the institutional bias in the Medicaid program. More recently, the Deficit Reduction Act of 2005 took significant steps forward, but did not go far enough. The institutional bias in Federal Medicaid policy and financing must be eliminated with home and community-based services authorized as a mandatory part of each state's plan and adequate financing to support this policy emphasis.

Recommendation: Amend Section 6086—Home and Community Based Services Option—of the Deficit Reduction Act of 2005 and authorize states to provide long-term supports based on 300% of FPL and include services and supports available under the current 1915(c) home and community-based waiver (HCBS) option—including the category of "other."

Recommendation: Medicaid must eliminate the program's *institutional bias* and authorize states instead to provide as the program's primary mechanism the provision of mandatory state plan long-term supports based on individualized, person-centered home and community supports that offer flexible and expanded choices for supports that span lifetime needs of a diverse population.

Creating a Vision

In a previous Commission meeting, Governor Sundquist stated that the Commission ought to deal with the *big picture* and should lay out a *vision* for the Commission's final report. ANCOR supports that approach.

Recommendation: Establish a set of principles based upon a core set of values for long-term supports.

In previous ANCOR public comments, we provided the Commission with examples of three sets of principles:

1. **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.**
2. Principles adopted in **1999by Senator Durenberger's Citizens for Long Term Care** that include *common ground* reached by numerous consumer, insurance, professional, wide variety of long-term care provider organizations that should 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*

3. **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 in the summer of 2005—***Going Forward, Medicaid Policy***. Those principles were provided to the Commission at its March meeting.

The Big Picture

Recommendation: The Commission would provide a great service by providing a framework that reflects the big picture—the context of current health care and long term supports.

In addressing the issue of the long-term sustainability of Medicaid, **we can not overlook the bigger picture—the sustainability of our nation's overall health and long-term care systems**. What is really unsustainable is the **rising costs of health care in general**—health care costs that are unsustainable for America's workers, low and moderate income families—including people with disabilities, and for America's employers—including providers of supports to people with disabilities.

- While the United States spends 16% of its GDP on health care, the industrial nations of Europe spend 11% of their GDP—**that 5% difference equals $700 billion annually that we could spend on other priorities.** Governor Bush asked during last Commission's meeting, I would like to know what it is that France is doing differently. Whether it is France, Germany or other industrial nations, what can we learn from other nations?
- According to a report published May 9th in the journal *Health Affairs*, the **U.S. Health Care Spends the highest among industrialized Countries.** For the report, researchers from John Hopkins University and Princeton University examined data from the Organization for Economic Cooperation and Development and found that the U.S. spent $5,635 per person on health care in 2003 -- two-and-a-half times the $2,280 average among industrialized countries. U.S. spending was 48% higher than Norway, which was the second-highest spender per capita at $3,807. Researchers said that the U.S. spends more than other nations in large part because of higher prices for health care goods and services.
- The same study found that the U.S. government outlays for health IT totaled $125 million in 2005, compared with $1 billion in Canada, $1.8 billion in Germany, and $11.5 billion in the United Kingdom. On a per capita basis those outlays computed to 43 cents in the United States compared with $193 in the United Kingdom.
- As you previously heard from Diane Rowland from the Kaiser Family Foundation, when we look at long-term care, the absence of a comprehensive national policy approach is the real problem.

Medicaid has worked, and worked well, for more than 40 years. However, Medicaid's success is now the source for the calls for reforms and improvements that bring the program into a different environment in the 21st century rather than the context of the 1960s. It has grown to be the program that provides needed health care and long term supports to 54 million people of all ages. It 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.

Reduce the Burden and Fiscal Pressure on the Medicaid Program

In the absence of a comprehensive national policy for long-term supports, Medicaid will remain the largest payer for long-term care.

Recommendation: Eliminate the cost to Medicaid of nearly 7 million dual-eligibles long-term supports and supports, Medicare premiums, and Medicare co-payments. These costs should be born either by reforms to Medicare and/or creation of new public and private long-term care financing mechanisms.

Expand the Financing *Pie* for Long Term Supports

In 1999, Citizens for Long Term Care established the following *Pillars of Reform* for addressing a comprehensive national approach to long-term care:

- **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.**

Recommendation: The Commission should include a set of recommendation based on the need for a comprehensive national approach to long-term supports—an approach that reduces the pressure on Medicaid as the single, largest funder of long-term care services—that expands the *pie* for financing long-term supports.

Recommendation: As Citizens for Long Term Care recommended in 1999, we must create a new social insurance cash payment benefit with appropriate eligibility and benefit level standards and requirements based on the level of functional need that provides 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.

Recommendation: A good first step forward 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.

Recommendation: Establish a public/private mandatory social insurance program for long-term care based upon private contributions similar to payroll deductions for Medicare and Social Security.

Social Security Cash Assistance

To be eligible for Social Security disability benefits, a person must be unable to engage in substantial gainful activity (SGA). A person who is earning more than a certain monthly amount (net of impairment-related work expenses) is ordinarily considered to be engaging in SGA. The amount of monthly earnings considered as SGA depends on the nature of a person's disability. The Social Security Act specifies a higher SGA amount for

statutorily blind individuals; Federal regulations specify a lower SGA amount for non-blind individuals. The monthly SGA 2006 SGA level for blind individuals is $1,450, while the monthly SGA level for non-blind individuals with disabilities is $860.

Nearly 7 million individuals of all ages with disabilities rely on Supplemental Security Income (SSI). The maximum SSI payment in 2006 is $7,240.56, with the average SSI payment in February at $449.10. Yet 100% of the 2005 FPL for an individual was $9,570. Therefore, SSI payments are well below the FPL. Individuals relying on SSI incomes have very limited incomes to meet the challenge of community integration—housing, food, transportation, and supports.

Recommendation: The Commission should recommend an increase in the SGA level for non-blind persons with disabilities to that of blind individuals.

Recommendation: The Commission should recommend an increase in the level of maximum SSI payment to <u>at least reflect 100%</u> of the federal poverty level coupled with annual cost-of-living increases.

<u>Information and Other Technologies</u>

A new study reported in the *New York Times* on May 12th says that the United States is up to a dozen years behind other developed nations in adopting health information technology systems. Yet the nation spends two-and-a-half times more per capita on health care than the median country among the 30 nations belonging to the Organization for Economic Cooperation and Development (OECD), the study notes. Led by Johns Hopkins health policy professor Gerard F. Anderson, the study compares spending patterns for various aspects of health care in addition to health IT. The authors state that to the extent that technology saves money, the lack of a national information technology network "could exacerbate the position of the United States relative to countries that are [health IT] leaders.

The *Washington Post* reported on May 15th that: Defense, intelligence and homeland security remain powerful growth engines for information technology contractors, but companies also are bulking up their health-care operations.

> "Many countries have subsidized the application of [health IT] with public funds, on the condition that those systems can interconnect," the study authors said. "The United States has begun to do so in recent years as well; although so far on a much more modest scale." Government outlays for health IT totaled $125 million in the United States in 2005, compared with $1 billion in Canada, $1.8 billion in Germany, and $11.5 billion in the United Kingdom. On a per capita basis those outlays computed to 43 cents in the United States compared with $193 in the United Kingdom. Government outlays for health IT totaled $125 million in the United States in 2005, compared with $1 billion in Canada, $1.8 billion in Germany, and $11.5 billion in the United Kingdom. On a per capita basis those outlays computed to 43 cents in the United States compared with $193 in the United Kingdom. The U.S. could shorten the time it takes to implement health IT "if it can learn from these countries' experiences.

Work attracting private companies' interest ranges from improving the efficiency of Medicare and Medicaid systems to sharing health records and using advanced technologies to spot and track emerging health threats. The Health and Human Services Department is devoting resources toward this effort with a contract that will be used to develop prototypes for a nationwide health information network architecture that would let disparate systems exchange electronic health records. However, adoption of health information technology systems requires substantial and extended financial commitment across public and private sectors.

Recommendation: As a means of addressing the sustainability of Medicaid, as well as the rising costs of health and long term care, the Commission should include five-year and ten-year recommendations outlining the pubic and private commitment needed to develop a nationwide health information network

Creating the Climate for Change—a Call to Engage the Public in Extended Dialogue

There is no short cut to address this important issue of long-term supports. We've been at it for a long time, spanning from the Pepper Commission, to the Bipartisan Entitlement Committee in 1990s, to this Medicaid Commission, to the President's call for a Medicare, Medicaid, Social Security Commission. Let's get it right, let's not short-change ourselves and reach for the quickest solution.

This effort must include extensive public discussion and engage America in identifying the public and private responsibilities and financing mechanisms to address the 21st century challenges in long-term supports. ANCOR included such a recommendation in its public testimony in 2001 following President Bush's directive under the New Freedom Initiative.

Recently on *Meet the Press,* Newt Gingrich recommended that the nation take a couple of years of public discussion to address the challenges of developing a comprehensive national approach to health and long-term care. ANCOR encourages that kind of broad public engagement in public discourse.

Motivated by concerns over the current state of long term care and in agreement on the need to pool long term care risk, Citizens for Long Term Care in 1999 called 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;**
- **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.**

Recommendation: The Commission must help the nation focus on the need for a comprehensive national policy approach to long-term supports by reporting on the need for an extended period of public discussion.

Quality Enhancement

Section 6086—Home and Community Based Services Option of the Deficit Reduction Act of 2005 includes a major step forward by establishing for the first time in federal statute a provision to address quality enhancement in regards to home and community supports. However, the lack of a common taxonomy in identifying and defining *quality* that establish performance excellence is a major challenge to measuring performance and establishing national benchmarks.

ANCOR has recently launched *Performance Excellence Program* to define key outcomes and key processes to support these outcomes spanning a range of home and community supports. This three-part initiative includes: (1) a performance metrics benchmark pilot to establish markers (eight major categories with 66 individual quality markers) that will help individuals with disabilities and their families assess community living and work support services; (2) a quality markers framework with an on-line community of practice; and (3) a quality values statement and pledge.

ANCOR's efforts are in addition to those undertaken by the Health Research Strategies Institute, the National Association of State Directors of Developmental Disabilities Services, and other public and private entities.

Recommendation: ANCOR urges the Commission to adopt a recommendation regarding the development of quality outcomes for long-term supports—outcomes that include participant satisfaction—regardless of where the long-term supports are provided.

Recommendation: The Commission should recommend that the development of these quality outcomes must include participation by Medicaid participants and providers as well as a review of the past and current efforts by public and private entities to develop such outcomes.

Reform Includes Investments in Multiple Systems

Investments which initially may add to the costs of Medicaid and our long term supports system or other federal and state programs—but which eventually will reduce the overall rate of growth in long-term care spending are needed. 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.

- **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. ANCOR urges the Commission to include recommendations that address the crisis in recruitment and retention of long-term care direct support workers. **To that end, ANCOR organized a bipartisan approach (Direct Support Professionals Fairness and Security Act, H.R. 1264) that creates an incentive for states to increase the wages of Medicaid private long-term care direct support professionals.**

- **Investments in CMS and State Implementation, Evaluation, and Successful Innovations.** 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.

ANCOR Recommendations

Recommendation: Establish a set of short-term and long-term recommendations. ANCOR calls attention to the original text of the Medicaid statute that establishes Federal appropriations for the Medicaid program, keeping in mind that the program was designed to assist individuals of limited income and to provide those services that help individuals and their families **attain or retain capability for independence or self-care.**

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Recommendation: Reform Includes Investments in Multiple Systems

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