DISABILITY POLICY COLLABORATION

A Partnership of The Arc & United Cerebral Palsy

August 16, 2005

STATEMENT TO MEDICAID COMMISSION

The Arc of the United States and United Cerebral Palsy (UCP) appreciate this opportunity to outline our views on generating short-term Medicaid savings and look forward to providing you more detailed comments on our views regarding long-term Medicaid reforms in the future.

The Arc is the national organization of and for people with mental retardation and related developmental disabilities and their families. UCP is a nationwide network of organizations providing advocacy and direct services to people with disabilities and their families. Many chapters of The Arc and affiliates of UCP provide services to people with developmental and other disabilities through their state Medicaid plans.

We urge the Commission to reject the Administration's proposal to clarify the definition of rehabilitation services in a manner that would result in restricted use of the services.

The rehabilitation services state plan option is used in some states to provide day rehabilitation or habilitation services or day activities programs to people with mental retardation, cerebral palsy, and other developmental disabilities. Theses services are also available through the more comprehensive service of intermediate care facilities for people with mental retardation or related conditions (ICFs/MR). They are also available in some states through the home and community based services waiver program.

Habilitation is a critical service for people with developmental disabilities in that it provides supports, services, and training to teach individuals to achieve self-determination and independence, productivity, and full citizenship through greater mental, physical, and social development. For certain Medicaid beneficiaries – those with severe cognitive disabilities – the issues may not be medical restoration of a lost skill or function but the need for lifelong support to attain or retain necessary skills or functions.

We believe that the purposes of these services are directly in line with the purposes of the Medicaid program. As stated in Section 1901 of the Social Security Act, the funds made available for the Medicaid program are for the purpose of enabling each 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..."

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We particularly urge the Commission to focus on the second purpose of the Medicaid program: "rehabilitation and other services to help such families and individuals attain or retain capability for independence or self-care". Those services that are often thought to have exceeded the medical purpose of the program are, in fact, well within the second stated purpose of the Medicaid program for helping individuals attain or retain capability for independence or self-care.

The Administration's proposal for clarifying the definition of the rehabilitation option appears to limit the states' ability to use the option to only the most restrictive, medically supervised approaches to rehabilitation, even though many states have provided rehabilitation services more broadly for years. Since states have clearly found that the broader approach meets a need that states wish to address, the Administration's proposal is puzzling. It becomes all the more puzzling if you consider that, in the absence of the broader rehabilitation option, states could continue to cover such services for some people in the ICF/MR setting. Therefore, for those individuals in need of intensive daytime rehabilitation/habilitation services, they might be pushed back toward the more expensive and unwarranted institutional model. It seems penny-wise/pound-foolish to restrict a service that states are currently using in lieu of a more expensive approach.

We urge the Commission to reject this narrowing of the rehabilitation option. In addition, we continue to urge the Commission to reject recommendations that will hurt beneficiaries through cuts in services or eligibility or increases in co-payments.

Again, the Medicaid program serves millions of people nationwide, with a growth rate for health care services lower than that of the private sector. The real issues are the failure of our current system to address the health care needs of people with a wide variety of needs. Medicaid has served the nation well in taking up the slack for the failures of our private health care system and our otherwise non-existent long term care system.

Medicaid is not the problem - it has provided many vulnerable people with severe disabilities and complex needs with their only solutions. We should be looking to improve Medicaid's ability to serve its beneficiaries and to repair what ails the rest of our health and long term care systems.

As this Commission turns its attention to the longer-term recommendations for Medicaid this fall, we have several recommendations for improving the program for people with disabilities. They include:

- Maintaining the individual entitlement to a full range of Medicaid health and long term supports and services for all eligible children and adults with disabilities;
- Creating an option for home and community services and redirecting any institutional savings to community long term supports and services;
- Creating an option for families of children with disabilities to buy into Medicaid if private health insurance is not available or does not meet their needs;

- Removing the institutional bias from the system and amending the Medicaid formula for cost-sharing with the states to provide greater fiscal incentive for supporting individuals in the community rather than in institutions;
- Establishing an incentive program of increased federal match for states that commit to eliminating the wage differential between workers in community services and workers in government-run services by increasing wages and benefits of community workers; and
- Ensuring that states set and update rates to reflect the actual costs of providing Medicaid funded services and supports, including direct support worker wages and benefits and reimbursement rates and fees for health practitioners and clinical specialists.

We would be happy to provide more information on these and other possible improvements to the Medicaid program.

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