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Subcommittee on Health

Helping Families with Needed Care: Medicaid's Critical Role for
Americans with Disabilities

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The Arc of New Jersey is the largest statewide advocacy organization in New Jersey for individuals with intellectual and other developmental disabilities and their families. We serve over 18,000 member families statewide, and advocate on behalf and along side of more than 200,000 individuals with developmental disabilities in New Jersey. The Arc of New Jersey is a chapter of The Arc of the United States which includes more than 140,000 members affiliated through more than 850 state and local chapters across the nation, whose mission, like our own, is to advocate for the rights and full participation of all children and adults with intellectual and developmental disabilities.

The Arc of New Jersey thanks Chairman Pallone and distinguished members of the Subcommittee on Health for recognizing the concerns of individuals with intellectual and other developmental disabilities and their families.

Our comments today will focus on pending federal legislation that will impact individuals with developmental disabilities as well as recent rule proposals made by the Centers for Medicare and Medicaid Services (CMS) that will have a potentially catastrophic impact on individuals with intellectual and other developmental disabilities three of which are most alarming: case management and targeted case management services, the rehabilitative services option, and school based services and transportation.

Medicaid is a critical safety net for low income children and adults with disabilities. Medicaid works and it is the critical life line for our country's most vulnerable populations. However, improvements need to be made and Congress must address the harmful actions CMS is taking that will likely sever this critical line for many.

For children with all types of disabilities, access to the Early and Periodic Screening, Diagnosis and Treatment (EPSDT) benefit, with its variety of screenings, services, and therapies, can often make a major difference in their lives. Access to these critical services is what enables them to lead healthy and more active lives; avoid additional disabilities; continue to live at home with their families; and make it through school. Children with disabilities also receive educationally related services such as occupational, physical, or speech

therapies through Medicaid that help them succeed in school. These children can then grow up within their own communities and can get jobs and be contributing members of society.

Medicaid works and is the critical life line for our country's most vulnerable populations. With that said, the recent CMS rules discussed below could sever access to critically-needed services for many of the individuals who so desperately need them.

For many people with intellectual (formerly referred to as mental retardation) and other types of disabilities, Medicaid generally is the only source of funds for them to live and work in their community with friends and families and avoid costly and segregated nursing homes or institutions.

For people with epilepsy, mental illness, HIV, and a variety of other conditions, Medicaid is very often the only source of access to essential prescription drug coverage.

For people with a variety of physical disabilities, such as spinal cord injuries, traumatic brain injuries, cerebral palsy, or amputations, Medicaid usually is the only way they can get access to durable medical equipment like wheelchairs or prosthetic devices, as well as assistive technology.

CMS Rule Proposals

Optional State Plan Case Management Services

Case management services are a critical Medicaid benefit that help millions of low-income children and adults with disabilities gain access to necessary services. Forty-nine states plus the District of Columbia provide targeted case management services to some populations of adults with disabilities and all states, in compliance with the Early and Periodic Screening, Diagnosis and Treatment (EPSDT) mandate, provide medically necessary case management services to children.

CMS has published an interim final rule (Optional State Plan Case Management Services, Federal Register, December 4, 2007) which goes well beyond the policies established by the Congress in the Deficit Reduction Act of 2005 (DRA). This rule needs to align with the statutorily-enacted policies of the DRA. According to CMS's projections, the interim final rule would save \$1.28 billion over five years, an impact well

above the \$760 million in savings projected by the Congressional Budget Office (CBO) when scoring the policy changes enacted by Congress in the DRA. This difference in the estimated impact on Medicaid spending itself is one indication that the rules go beyond what Congress intended.

Current Medicaid policy allows states to provide case management and targeted case management services to assist in the transition of a Medicaid beneficiary from an institution to the community. Federal reimbursement is available for case management provided during the last 180 days of the stay in the institution. This policy was issued in response to the U.S. Supreme Court's decision in L.C v. Olmstead, which found that the Americans with Disabilities Act requires states to provide services to individuals in the most integrated community settings that are appropriate to beneficiaries' needs. The interim final rule reduces federal reimbursement from 180 days to 60 days – an insufficient time, in many cases, to transition from an institution to the community.

Moreover, the interim final rule seriously undercuts the Bush Administration's Money Follows the Person Initiative. Transitioning people into the community is a difficult and complex process. It is necessary to assess an individual's support needs, arrange for Medicaid services, identify and obtain safe, affordable, and accessible housing, and arrange for other non-Medicaid services and supports. It is not reasonable to restrict case management services to a 60-day period.

Additionally, the provision in the interim final rule that providers can only be paid for transition case management services once an individual has successfully transitioned into the community undermines the system in place to provide necessary transitional services. This policy limits the pool of providers to those who could shoulder the financial delay and risk in order to serve as case management providers. The Arc of New Jersey is concerned that some case managers may be especially effective at providing case management services, and they may have unique capacities to work with certain populations yet they will be unable to serve as case managers because they do not have the financial resources to bear the risk that they will not be paid for

the services they provide. This will create a very real problem in New Jersey where community provider agencies are already underfunded and have not received sufficient cost of living increases in over a decade.

The Arc of New Jersey is also deeply concerned that CMS is imposing new restrictions that will limit access to medically necessary case management services to Medicaid-eligible individuals. We believe that these policies were not authorized by the Congress and will be extremely harmful to Medicaid beneficiaries.

The rules would also limit state flexibility by prohibiting a state from providing a beneficiary with more than one case manager even when the complexity of the beneficiary's condition demands the expertise of more than one program. In most cases, having one case manager would be beneficial to avoid duplication. However, if a beneficiary has multiple conditions, a single case manager may not be able to coordinate housing, health care, and social needs across multiple systems.

A central principle of the federal-state partnership to operate Medicaid is that states must follow federal guidelines but retain broad flexibility in establishing payment rates and determining payment policies. Disregarding this precept, the rules restrict state flexibility to determine payment methodologies in a way that could make Medicaid payments less efficient.

The rules would prohibit states from making fee-for-service payments for case management services in any way other than paying for units of service that do not exceed 15 minutes. States often use case rates, per diem rates, or other payment methodologies to pay for case management.

The DRA includes a list of activities that may not be included in case management under Medicaid, because they are services that are part of the foster care services delivered by child welfare agencies. While this is a policy established by the Congress, the interim final rule goes substantially further and would prohibit federal Medicaid funds for *all* case management services provided by child welfare and child protective services agencies and contractors of these agencies, regardless of whether the contractors are qualified Medicaid providers.

All children in Medicaid are eligible for case management services when the services are medically necessary. Some states provide medically necessary case management services to children with disabilities in school settings as part of a free and appropriate public education. The interim final rules would allow the provision of case management for children with disabilities in schools only when case management is designated as a required service in the child's Individualized Education Program or an infant or toddler's Individualized Family Service Plan. The rule specifically disallows the provision of case management when it is part of a child's plan under Section 504 of the Rehabilitation Act.

Taken together, these proposed limitations on case management services will have a significant impact on the ability of individuals with developmental disabilities to access critically-needed services.

Coverage for Rehabilitative Services

CMS's proposed rule (Coverage of Rehabilitative Service, Federal Register, August 13, 2007) is unnecessary and would not further the purposes of the Medicaid program. A central objective of the Medicaid program is to provide rehabilitative services. Not only does the proposed rule not further this core goal of Medicaid, it creates new obstacles for Medicaid beneficiaries to receive medically necessary rehabilitative services. This proposed rule would narrow the scope of services that providers have been providing under Medicaid, and impose requirements that will have a significant financial and administrative impact on providers.

We believe that the proposed rule would severely harm people with intellectual and other developmental disabilities in two major ways: 1) it eliminates longstanding programs for providing day habilitation services to many people with developmental disabilities by removing those services from the rehabilitative option and transferring them to a waiver thus capping the services; and 2) it imposes a discriminatory and arbitrary exclusion from receiving many rehabilitative services for many people with mental retardation and related conditions (a statutory term for people with intellectual and other developmental disabilities). These services

enhance the independence of people with intellectual disabilities and are critical to enabling them to move from institutions into the community.

In addition, The Arc of New Jersey believes that the proposed rule does not fully comply with Medicaid's Early Periodic Screening, Diagnosis, and Treatment (EPSDT) mandate for children and would have a serious impact on children who are Medicaid beneficiaries. The EPSDT mandate requires that all Medicaid beneficiaries under age 21 must receive all necessary services listed in section 1905(a) of the Social Security Act to correct or ameliorate physical or mental illnesses and conditions, regardless of whether those services are covered under a state's Medicaid plan. CMS failed to include the EPSDT requirement, which if omitted could prohibit children from receiving services.

Elimination of Reimbursement under Medicaid for School Administration Expenditures and Costs Related to Transportation of School-Age Children between Home and School

CMS published a final rule on December 28, 2007 which is attempting to address legitimate policy issues in the proposed regulation, however, The Arc of New Jersey believes that the final rule constitutes bad fiscal and social policy. The "savings" to the federal coffers, \$3.56 billion over 5 years, will be miniscule compared to the impact on those school systems which rely on appropriate Medicaid reimbursement to serve children with disabilities. Worse, the ultimate losers in this policy shift will be the children since we have no confidence that the school systems will come up with the lost funds to maintain the level of service they now provide. Thus vital related services will disappear based on funding availability, not service need. Knowing the value of related services for many special education students, this rule will likely actually result in greater need for Medicaid services and expense in the future since services not delivered to children can exacerbate their disability and result in more costly treatment in adulthood.

This new rule would usurp current and previous guidance provided by CMS to school systems. There is no basis for this rule – except to make a tiny dent in the federal deficit on the backs of poor children with disabilities – which in fact, will have a disproportionate impact on minority students who are overrepresented in special education.

While there may be a small number of school systems which are inappropriately billing Medicaid, the solution to this problem is not to punish all school systems by curtailing legitimate transportation and administrative expenses. The solution should be to eliminate the abuse by systematic enforcement of the current rule and guidance school system by school system, something we don't believe that CMS has seriously attempted. Rather than implementing its own policies, CMS instead chooses cut \$3.6 billion over five years, thus imposing a huge and insurmountable burden on the schools. The vast majority of school systems affected by these cuts will have only one option: reduce services to the children. This proposed policy flies directly into the face of the Bush Administration's New Freedom Initiative which promises more, not less, services to make children and adults with disabilities more independent.

The local school is often the first and only avenue for families to learn about Medicaid and the services it offers. Yet this discriminatory rule would seriously damage the inter-relationship between schools and Medicaid, particularly for those school systems that have never violated a Medicaid rule or guidance. If the Congress does not act to extend the moratorium or pass legislation to fix CMS's proposed policy changes children with disabilities may not receive necessary services. Many children receive speech, language, hearing, occupational, and physical therapies. This rule could either totally eliminate or drastically reduce these services. In addition key personnel could possibly be eliminated including the therapists that provide those therapies previously mentioned, as well as school nurses, social workers, classroom aides, bus drivers and special education teachers. School buses will be less accessible affecting student with the most serious disabilities. School districts and parents could be pitted against one another if school authorities offer fewer services because of funding cuts.

The Arc of New Jersey would be remiss, if we failed to recognize the efforts and leadership of Chairman Dingell for his sponsorship, and Subcommittee Chairman Pallone's co-sponsorship, of H.R. 1017 or the Protecting Children's Health in Schools Act of 2007. The provisions of this bill would provide a common sense fix without unduly harming school systems that have never violated Medicaid policy and students with

disabilities who are doing their best to learn and become more independent. We urge the Congress to act immediately on this legislation.

In addition, The Arc of New Jersey would like to thank Chairman Pallone for his leadership in securing a six month moratorium on the rehabilitative services and school based services/transportation regulations in the “Medicare, Medicaid and SCHIP Extension Act of 2007.” We also urge members of this Committee and the Congress as a whole to either extend the moratorium to include the recently proposed Medicaid regulations addressing case management and targeted case management for at least 12 months, or pass legislation, such as H.R. 1017 to fix the policy changes embodied in the proposed Medicaid regulations being discussed today.

Pending Federal Legislation

Despite the proposed Medicaid rules, the Congress has before it legislation that will positively impact individuals with disabilities and The Arc of New Jersey is grateful for the opportunity to discuss three of those bills. In particular, The Arc of New Jersey thanks Chairman Pallone for sponsoring H.R. 3001, better known as the “Community Living Assistance Services and Supports Act” or “CLASS Act.”

Community Living Assistance Services and Supports Act (CLASS Act)

Many, if not most, Americans who have or develop severe functional impairments can only access coverage to services necessary for them to maintain their independence through the Medicaid program. In order to access critical services through the Medicaid program, individuals are forced to “spend down” assets, and to be blunt, impoverish themselves.

The CLASS Act provides an alternative to impoverishment and sole reliance on the Medicaid program. It creates a national insurance program to help adults who have or develop functional impairments so that they may remain independent, employed, and a part of their community. This legislation, funded through a modest voluntary payroll deduction, would help remove barriers to independence and choice that can be costly beyond imagination, by providing a cash benefit to those individuals who are unable to perform two or more functional activities of daily living such as communicating, taking medications, household management and basic money

management. The CLASS Act would allow individuals to access supports and services without requiring them to become impoverished to qualify for Medicaid.

The Act will also provide savings to individual states. As we all know, many states, including New Jersey, are facing soaring debt and limited revenues. If a person is eligible for benefits through the CLASS Act as well as long term services under Medicaid, CLASS Act benefits could be used to offset the costs to Medicaid, therefore producing savings for a state's Medicaid program.

Community Choice Act

The second piece of important legislation which The Arc of New Jersey supports, is H.R. 1621 or the Community Choice Act sponsored by Congressman Davis. This legislation would amend Medicaid to mandate state Medicaid plan coverage of community-based attendant services and supports for certain Medicaid-eligible individuals.

The support available under this bill would include services to assist individuals in accomplishing activities of daily living (ADLs), instrumental activities of daily living (IADLs), and health-related tasks through hands-on assistance, supervision, or cueing. Services must be provided in a home or community setting based on a written plan.

States would be required to establish a Development and Implementation Council to work with the state in developing and implementing the state plan amendment necessary in order to provide the services. The Council must have as a majority of its members people with disabilities, elderly individuals, or representatives of such individuals, and must collaborate with providers and advocates. Services must be made available statewide and must be provided in the most integrated setting appropriate for the individual.

With an emphasis on person-centered planning and self-directed services, the Community Choice Act is a critical piece of legislation for individuals with disabilities. The Medicaid program receives great attention for its cost. A major cost driver to the Medicaid program is nursing home care which is a mandatory service in the Medicaid program. Many individuals living in nursing homes do not want to be there nor would they need to

be there if attendant services and supports were available in a community based residential setting. The Community Choice Act is a step in the right direction for both the Medicaid program and individuals requiring long term supports.

Direct Support Professionals Fairness and Security Act

Another important piece of legislation is H.R.1279 or the Direct Support Professionals Fairness and Security Act of 2007 and we want to thank Congresswoman Capps for her sponsorship of this legislation. Direct support professionals are the keystone to the service delivery system for our most vulnerable populations.

Direct support professionals are personal care assistants, home care aides, or staff in community residential supports programs who assist people with disabilities with medications, preparing and eating meals, dressing, mobility, and their most intimate needs. Yet, there is a crisis in the availability of professionals to provide these direct supports. Many workers find that they can earn higher hourly wages, and receive better benefits, in far less demanding jobs. As a direct result, people with disabilities experience a revolving door of direct support workers causing trauma to the individual and their family.

Self-advocates, families, advocates, and service providers have worked for decades to ensure successful community living for all people with disabilities. When there is safety, security and stability in community based services and supports, people do better. We are all too familiar with the impact on quality of care when staff are provided with low wages and no benefits and high staff turnover results. It is also important to note that workers in the least desirable service setting - state-run institutions - are typically paid higher wages and receive better benefits than their counterparts providing highly valued community-based services and supports.

In short, this legislation would amend the Medicaid program to provide funds to states to enable them to increase the wages paid to targeted direct support professionals in providing services to individuals with disabilities. The program is designed as an option to states and would provide enhanced federal medical assistance percentage (FMAP) for five years to states to increase wages. It is designed to increase wages and eliminate the gap between wages paid to private employees and wages paid to public employees in the state.

The Administration and many in Congress are looking for ways to limit the Medicaid program. However, without enactment of this legislation, people with disabilities who need direct supports will continue to be made more vulnerable by the failure of the system to pay direct support professionals a living wage with critical health care and other benefits. This legislation is also in line with the Administration's New Freedom Initiatives intended to remove barriers to community living for people with disabilities.

Despite our fiscal constraints, community provider agencies continue to utilize cost efficient business practices to stretch dollars and provide quality services to vulnerable populations. Currently, the social services non-profit industry in New Jersey is nearly \$1 billion in size, employs more than 8,000 people and engages and relies on the services of approximately 20,000 volunteers. In addition, community provider agencies have had to rely more and more on unstable sources of funding including fundraisers and private donations. Community provider agencies continue to provide essential services based on their commitment to their mission and values – the needs of New Jersey's most vulnerable populations must be met, crises notwithstanding. However, it is unclear how long they will continue to be able to do so.

Revisions to Deficit Reduction Act of 2005

While there is no specific piece of legislation pending, we believe that it is critical that Congress make some adjustments to the new Section 1915(i) home and community based services option which was enacted as part of the DRA (Section 6086, Expanded Access to Home and Community-Based Services for the Elderly and Disabled). Section 1915(i) establishes a new option for states to provide home and community-based services (HCBS) without states needing to use a waiver process and, with the requirement that states establish stricter eligibility (level of care) criteria for institutional services than for community-based services, for the first time, states will be able to offer services to people who would not otherwise qualify for the institutional services. However, there are some barriers to full implementation by the states and concerns of consumers which need attention.

Section 1915(i) allows states to provide, under the new option, a few, but not all, of the services now covered under HCBS waivers. Section 1915(i) limits services to people with incomes below 150 percent of the federal poverty level. Further, Section 1915(i) allows states to cap the number of people to be served under the new HCBS Medicaid option, to provide these services in limited geographical areas of the state, and to maintain waiting lists for these services. Currently HCBS waiver beneficiaries who do not meet any new criteria established by the state in the future would have grandfather protection for as little as only one year.

To ensure that the HCBS option can provide optimal coverage for home and community-based services, we urge that the provision be amended to achieve the following:

- Remove the authority for states to cap services and maintain waiting lists;
- Allow states to provide the full range of services that can currently be provided under the HCBS waiver, including other services approved by the Secretary;
- Remove the limit on coverage of people with incomes up to 150 percent of poverty and allow the full range of income eligibility allowed for people in facility-based settings; and
- Eliminate the states' ability to limit services to certain sections of the states.

In conclusion, The Arc of New Jersey supports all three bills discussed above and improvements to the new home and community-based services option. We urge the Congress to act swiftly to pass legislation which would relieve the pressure on our Medicaid system and ensure employees and their families are covered by an affordable, premium-based long term support insurance program, can live in the community while receiving necessary attendant services, and assist states in the recruitment and retention of direct support professionals. We also strongly urge you to extend the current rehabilitative services option and school based services/transportation moratorium adding the interim final rule on case management and targeted case management, or to pass legislation to fix the policy changes embodied in these rules. We look forward to working with you, Chairman Pallone, and other members of this Subcommittee to better the health, safety and wellbeing of individuals with developmental disabilities, their families, and those that provide support services.

Summary

In addition to underscoring the importance of Medicaid to children and adults with intellectual and other developmental disabilities, The Arc of New Jersey will focus on pending federal legislation that will impact individuals with developmental disabilities as well as recent rule proposals made by the Centers for Medicare and Medicaid Services (CMS).

CMS Rule Proposals

Optional State Plan Case Management Services

CMS has published an interim final rule (Optional State Plan Case Management Services, Federal Register, December 4, 2007) which goes well beyond the policies established by the Congress in the Deficit Reduction Act of 2005 (DRA) and will have several deleterious effects on individuals with developmental disabilities.

Coverage for Rehabilitative Services

CMS's proposed rule (Coverage of Rehabilitative Service, Federal Register, August 13, 2007) is unnecessary and would not further the purposes of the Medicaid program. A central objective of the Medicaid program is to provide rehabilitative services. Not only does the proposed rule not further this core goal of Medicaid, it creates many new obstacles for Medicaid beneficiaries to receive medically necessary rehabilitative services.

Elimination of Reimbursement under Medicaid for School Administration Expenditures and Costs Related to Transportation of School-Age Children between Home and School

This new rule would usurp current and previous CMS guidance to school systems. There is no basis for this rule – except to make a tiny dent in the federal deficit on the backs of poor children with disabilities – which in fact, will have a disproportionate impact on minority students who are overrepresented in special education. To address CMS' policy concerns, Congress should pass the Protecting Children's Health in Schools Act of 2007, which would provide a common sense fix without unduly harming school systems that have never violated Medicaid policy and students with disabilities who are doing their best to learn and become more independent.

The Arc of New Jersey strongly urges Congress to:

- 1) Extend the recently passed 6-month moratorium on Medicaid's Rehabilitative Services and School Based Services/Transportation for at least 12 months and include provisions of the interim final rule on case management/targeted case management; or pass legislation, like H.R. 1017, that would fix the policies in these regulations
- 2) Pass the: Community Living Assistance Services and Supports Act (CLASS Act), Community Choice Act, Direct Support Professionals Fairness and Security Act of 2007 and make improvement to the Deficit Reduction Act of 2005.