



**CONSORTIUM FOR CITIZENS
WITH DISABILITIES**

October 10, 2007

Centers for Medicare and Medicaid Services
Department of Health and Human Services
Attention: CMS-2261-P
P.O. Box 8018
Baltimore, MD 21244-8018

Re: File Code CMS-2261-P

To Whom It May Concern:

We are writing to comment on the notice of proposed rulemaking (NPRM) with respect to Medicaid coverage of rehabilitative services that was published in the *Federal Register* on August 13, 2007. These comments are being submitted on behalf of the Consortium for Citizens with Disabilities (CCD). The CCD is the leading coalition of national organizations working together to advocate for national public policy that ensures the self determination, independence, empowerment, integration and inclusion of children and adults with disabilities in all aspects of society. CCD's membership consists of disability advocacy organizations, services providers, and other interested parties and covers the full spectrum of disabilities, including people with mental illness, people with developmental disabilities, children receiving foster care, people with physical disabilities, and other populations directly impacted by this proposed rule.

We are organizing our comments into major issues and concerns. Individual organizations, under separate cover, will also submit more detailed technical recommendations and section-by-section comments.

Major Issues and Concerns

The CCD has major issues with the proposed rule. We believe it is fatally flawed and should be withdrawn. We recognize that the proposed rule, in some cases, seeks to address legitimate policy issues. We welcome the opportunity to work in partnership with the Congress and the Administration to achieve consensus on appropriate policies and procedures to ensure that Medicaid beneficiaries receive the highest quality rehabilitative services, consistent with Title XIX of the Social Security Act, and to ensure that states operate their Medicaid programs to achieve the best clinical outcomes and in the most publicly accountable manner. We believe that this proposed rule prevents a necessary dialogue between federal officials, state Medicaid officials, other state officials (including individuals responsible for programs for people with mental illness, developmental disabilities, and child welfare), rehabilitative

services providers, and representatives of affected Medicaid populations. We are not aware of any meaningful effort by the Secretary of Health and Human Services or the Centers for Medicare and Medicaid Services (CMS) to work with affected stakeholders to address current policy concerns. Indeed, we have been troubled by dubious enforcement actions and audits by the HHS Office of the Inspector General (OIG) that have appeared more focused on limiting federal expenditures than improving the appropriateness or effective administration of services under the rehabilitative services (rehab) option. To the extent that policy changes are needed, we believe that the legislative process is the appropriate arena for addressing these issues. The following are major concerns:

1) Unjustified and unnecessary, the proposed rule would not further the purposes of Title XIX of the Social Security Act.

A central purpose of the Medicaid law is to provide rehabilitative services. Section 1901 of the Social Security Act reads,

“For the purpose of enabling each State, as far as practicable under the conditions in such State, to furnish... (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.”

Not only does the proposed rule not further this core goal of Medicaid, it erects new obstacles for Medicaid beneficiaries to receive medically necessary rehabilitative services. It does not justify the need for new rules and it does not provide a reasonable description of the impact of the proposed rule on Medicaid beneficiaries or rehabilitative services providers. The Regulatory Impact Analysis makes numerous assertions that are contradictory and appear intended to mask the impact of the proposed rule. For example, it states that, “the Secretary certifies that this major rule would not have a direct impact on providers of rehabilitative services that furnish services pursuant to section 1905(a)(13) of the Act.” In reality, the proposed rule would narrow the scope of services that providers have been providing under Medicaid, and imposes requirements that will have a significant financial and administrative impact on providers. The proposed rule also states that, “...because FFP [Federal financial participation] will be excluded for rehabilitative services that are included in other Federal, State, and local programs, it is estimated that Federal Medicaid spending on rehabilitative services would be reduced by approximately \$180 million in FY 2008 and would be reduced by \$2.2 billion between FY 2008 and FY 2012.” This would impose substantial increased costs on states that must change many of their administrative practices and that must either limit access to medically necessary services or increase state spending to provide services that were previously eligible for Medicaid FFP.

2) Contradicts Title XIX of the Social Security Act and exceeds the regulatory authority vested in the Executive Branch.

In several instances, we believe that the proposed rule exceeds the Executive’s regulatory authority and is inconsistent with Medicaid law.

a. The proposed rule would hinder access to prevention services.

We are troubled that the proposed rule could interfere with states' ability to deliver preventive services, authorized by section 1905(a)(13) of the Social Security Act, as defined by 42 C.F.R. § 440.130(c). Although the proposed rule ostensibly amends only 42 C.F.R. § 440.130(d), it creates the clear impression that numerous preventive services would be prohibited under section 1905(a)(13), even if they could be covered as preventive services.

Any revised rule should make clear that states can continue to cover preventive services including habilitation services and other services for people with intellectual and other developmental disabilities that meet the requirements of 42 C.F.R. § 440.130(c).

b. The proposed rule illegally imposes an intrinsic element test.

The proposed rule would deny FFP for services furnished, through a non-medical program as either a benefit or administrative activity, including services that are intrinsic elements of programs other than Medicaid, such as foster care, child welfare, education, child care, vocational and prevocational training, housing, parole and probation, juvenile justice, or public guardianship." This so-called "intrinsic element test" presents a barrier that could prevent Medicaid beneficiaries from receiving medically necessary Medicaid covered services that is not authorized by Title XIX of the Social Security Act. Indeed, we understand that the Administration proposed such a test in the legislative debate leading up to the enactment of the Deficit Reduction Act of 2005 (DRA, P.L. 109-171) and this test was explicitly rejected by the Congress (See July 7, 2006 letter to CMS Administrator Mark McClellan from Senators Harkin, Bingaman, and others). We oppose an intrinsic element test because it goes beyond the third party liability requirements of the Medicaid law as established by the Congress; we believe it is vague and could be applied to restrict services that are appropriately covered; and, it is arbitrary and could restrict access to Medicaid services even if no other program is available to provide coverage for otherwise Medicaid coverable services to Medicaid beneficiaries. This test has the potential to cause great harm to Medicaid beneficiaries who need timely and reliable access to Medicaid rehabilitative services.

c. The proposed rule does not fully comply with the EPSDT mandate for children.

We are very troubled by the potential impact of the proposed rule on children who are Medicaid beneficiaries. In particular, as drafted, we do not believe that the proposed rule complies with Medicaid's Early and Periodic, Screening, Diagnostic and Treatment Services (EPSDT) requirements. 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. We believe that the proposed rule must be re-drafted to include a restatement of the EPSDT requirement.

3) Implementation of the proposed rule would severely harm several Medicaid populations.

We believe that the proposed rule could severely restrict access to services and cause significant harm to several Medicaid populations:

a. The proposed rule would harm people with mental illness.

People with mental illness are primary recipients of Medicaid rehab option services. A recent report by the Kaiser Commission on Medicaid and the Uninsured found that in 2004, 73% of Medicaid beneficiaries receiving rehab option services had a mental health diagnosis, and they were responsible for 79% of rehab option spending. To the extent that the proposed rule significantly reduces federal spending on rehab option services, this results in a direct cut in services for beneficiaries with mental illness. By limiting access to effective community-based rehabilitative services, the proposed rule would place Medicaid beneficiaries with mental illness at risk for poorer health outcomes and this could lead to relapse or new episodes of illness. Such incidents typically result in increased utilization of high cost services such as emergency room care and inpatient care. The proposed rule does not alter Medicaid eligibility, it would simply restrict access to certain services—often those that are the most effective and the least costly. Therefore, we also worry that this proposal could lead to increased Medicaid spending if individuals are forced to get more costly, but less effective or appropriate services. In particular, we are concerned that the proposed rule could lead to increased hospitalizations that would be otherwise preventable, through the provisioning of community-based rehabilitative services.

It should be noted that given the high proportion of Medicaid beneficiaries receiving rehab option services who have mental illness, all of the harms and concerns raised in these comments should be considered to apply to people with mental illness.

b. The proposed rule would harm people with intellectual and other developmental disabilities

The proposed rule would severely harm people with intellectual disabilities (formerly called mental retardation) and other developmental disabilities in two major ways: it eliminates longstanding programs for providing day habilitation services to people with developmental disabilities, and it imposes a discriminatory and arbitrary exclusion from receiving many rehabilitative services for people with mental retardation and related conditions (a statutory term for people with intellectual and other developmental disabilities).

Elimination of FFP for habilitation services provided under the rehab and clinic options: In 2006, roughly \$808 million was spent on Medicaid clinic and rehab option services for persons with intellectual and other developmental disabilities. In the same year, it has been estimated that approximately 52,000 people with intellectual and other developmental disabilities received day habilitation services through the clinic and rehab options (Unpublished estimates, David Braddock, Coleman Institute for Cognitive Disabilities, University of Colorado). We believe that this proposed restriction contravenes the intent of the Congress to protect access to day habilitation services for people with developmental disabilities when it enacted Section 6411(g) of the Omnibus Budget Reconciliation Act of 1989 (OBRA '89, P.L. 101-239). This section reads:

(g) DAY HABILITATION AND RELATED SERVICES-

(1) PROHIBITION OF DISALLOWANCE PENDING ISSUANCE OF REGULATIONS- Except as specifically permitted under paragraph (3), the Secretary of Health and Human Services may not--

(A) withhold, suspend, disallow, or deny Federal financial participation under section 1903(a) of the Social Security Act for day habilitation and related services under paragraph (9) or (13) of section 1905(a) of such Act on behalf of persons with mental retardation or with related conditions pursuant to a provision of its State plan as approved on or before June 30, 1989, or

(B) withdraw Federal approval of any such State plan provision.

(2) REQUIREMENTS FOR REGULATION- A final regulation described in this paragraph is a regulation, promulgated after a notice of proposed rule-making and a period of at least 60 days for public comment, that--

(A) specifies the types of day habilitation and related services that a State may cover under paragraph (9) or (13) of section 1905(a) of the Social Security Act on behalf of persons with mental retardation or with related conditions, and

(B) any requirements respecting such coverage.

(3) PROSPECTIVE APPLICATION OF REGULATION- If the Secretary promulgates a final regulation described in paragraph (2) and the Secretary determines that a State plan under title XIX of the Social Security Act does not comply with such regulation, the Secretary shall notify the State of the determination and its basis, and such determination shall not apply to day habilitation and related services furnished before the first day of the first calendar quarter beginning after the date of the notice to the State.

In enacting this provision of law, the Congress was clearly intending to protect access to day habilitation programs for people with mental retardation and related conditions. In fact, a House of Representatives Committee Report accompanying this legislation stated, "In the view of the Committee, HCFA [Health Care Financing Administration, predecessor to CMS] should be encouraging states to offer community-based services to this vulnerable population, not restricting their efforts to do so." (Report of the House Budget Committee, "Explanation of the Commerce and Ways and Means Committees Affecting Medicare-Medicaid Programs," Sept. 20, 1989). It establishes that the Secretary may not deny FFP for habilitation services unless the Secretary promulgates a final regulation that "*specifies the types of day habilitation and related services that a State may cover...on behalf of persons with mental retardation or with related conditions.*"

In contradiction to the plain language of Section 6411(g) of OBRA '89, the proposed rule **does not** specify which day habilitation services that a state may cover. Instead, the proposed regulation would prohibit the provisioning of *any* habilitation services under paragraphs (9) and (13) of section 1905(a) of the Social Security Act. We believe that this NPRM exceeds the regulatory authority granted by the Congress and must be withdrawn. At a minimum, since the regulation does not comply with the OBRA '89 language, the Secretary would not have authority to deny FFP for habilitation services provided in those states with approved state plan coverage prior to June 30, 1989.

We also oppose the prohibition of coverage for habilitation services as a component of the clinic and rehab options on policy grounds. We believe the proposed rule represents a missed opportunity for the Secretary to specify the types of services that may be provided in a way that ensures that individuals receive the highest quality habilitative and rehabilitative services according to current standards of

treatment. The preamble of the proposed rule states that the rehab option is not a “custodial” benefit. We agree with the Secretary that state programs operated under the rehab and clinic options should set high standards for delivering active treatment and for innovating to develop programs for people with intellectual and other developmental disabilities that maximize their ability to attain, maintain, and retain their maximum ability to function, consistent with the original conception of rehabilitation, as found in section 1901 of the Social Security Act.

The preamble to the proposed rule also states that the Secretary intends “to work with those states that have habilitation programs under the clinic services or rehabilitative services benefits under their state plans to transition to appropriate Medicaid coverage authorities, such as section 1915(c) waivers or the Home and Community-Based Services State plan option under section 1915(i).” We take issue with the assertion that these are more appropriate coverage authorities. In particular, waiver programs operate as discretionary alternatives to their core Medicaid programs, which operate under their state plan. We believe that states should have the flexibility to continue operating habilitation programs under the longstanding options as part of their state plans.

Further, section 1915(c) waivers and the section 1915(i) option are not equivalent to the rehab or clinic options. Section 1915(c) waiver programs require individuals to meet a nursing facility level of care requirement, something that is not required for rehab or clinic option services. Further, the 1915(c) and 1915(i) coverage authorities have different financial eligibility standards. Most significantly, these coverage authorities do not extend an enforceable entitlement to services. Indeed, the disability community opposed aspects of section 1915(i) in the Deficit Reduction Act that permit enrollment caps and that do not extend an entitlement to services. Also, the Secretary has not issued regulations on this coverage authority, so it is not clear to us that additional constraints on the use of the option will not arise in the future. Nonetheless, this option was enacted to give states added flexibility and was not intended to supplant the rehab and clinic options by requiring states to shift to more restrictive coverage authorities. It should also be observed that the 1915(c) waiver programs are notable for their long and large waiting lists, something that is not permitted for clinic or rehab option services. In 2004, more than 206,000 people were on Medicaid waiting lists for community services, an increase of roughly 50,000 people in just two years. In some cases, average wait times to receive waiver services are more than two years (Kaiser Commission on Medicaid and the Uninsured, 2006). Shifting habilitation services to 1915(c) and 1915(i) coverage authorities will make access to habilitation services less secure and reliable.

We strongly recommend that the proposed exclusion of FFP for habilitation services under the clinic and rehab options not be implemented.

Discriminatory and arbitrary exclusion from receiving many rehabilitative services for people with mental retardation and related conditions: We strongly oppose the proposed rule’s definition of habilitation services [see section 441.45(b)(2)] as including “services provided to individuals with mental retardation and related conditions.” Coupled with the prohibition on habilitation services, this effectively excludes a population from services in violation of a fundamental principle of Medicaid, that medical assistance provided to one Medicaid beneficiary shall not be less in amount, duration, and scope than the medical assistance made available to any other Medicaid beneficiary [see section 1902(a)(10)(B) of the Social Security Act].

The proposed rule also states that, “Most physical impairments, and mental health and/or substance related disorders, are not included in the scope of related conditions, so rehabilitative services may be appropriately provided.” This policy would, at a minimum, create uncertainty that states can receive FFP for medically necessary rehab option services for people with mental retardation and related conditions. CMS policy appears to be that these individuals should receive services only through waiver programs (or the related 1915(i) option), and this is nonsensical in circumstances such as where a person with an intellectual disability has a knee replacement and needs services to regain physical functioning of the knee or where a person with epilepsy develops a substance abuse disorder. Further, this policy is likely to increase federal and state costs, as benefits for home- and community-based services (HCBS) waiver programs tend to be far more extensive than is generally provided under the rehab option.

Additionally, this population exclusion exposes a false premise that persons with intellectual disabilities and those with “related conditions” have achieved no prior capacity to function for which a rehabilitative service would be appropriately furnished under the rehab option. That sweeping assumption includes those defined by CMS elsewhere in regulations as having “related conditions” – people who have cerebral palsy, epilepsy, or any other conditions, other than mental illness, found to be closely related to mental retardation because it results in impairment of general intellectual functioning or adaptive behavior similar to that of people with mental retardation, with similar treatment needs; which manifests before age 22; is likely to continue indefinitely; and results in substantial functional limitations in three or more of the following areas of major life activities: self care, understanding and use of language, learning, mobility, self-direction, and capacity for independent living. This policy was not the result of Congressional action and preceded a period of significant progress in advancing the civil rights of people with disabilities. While the Americans with Disabilities Act (ADA) does not apply to federal administration of Medicaid, we believe that this policy violates, at a minimum, the spirit of the ADA, wherein the Congress was intending to impose a comprehensive national prohibition against discrimination on the basis of disability.

We urge the Secretary to rescind this constraint on rehab option services that is so blatantly stigmatizing and discriminatory to people with intellectual and other developmental disabilities.

c. The proposed rule would harm children receiving foster care

According to an Urban Institute analysis, 869,087 children were enrolled in Medicaid on the basis of receiving foster care in 2001, and 509,914 of these children were enrolled for Medicaid for the full year (Geen, Sommers, and Cohen, Urban Institute, August 2005). An analysis of Medicaid spending on these children found that 13.1% of Medicaid spending was for rehabilitative services. Prior research has shown that children receiving foster care have more health problems, especially mental health problems, than the general population or the population of poor children (Geen and others). As many as 80% of young people involved with child welfare have emotional or behavioral disorders, developmental delays, or other issues requiring mental health intervention (Farmer and others, *Social Service Review* 75(2):605-24). A Department of Health and Human Services (HHS) review found that only one state met federal standards for the provisioning of health and mental health services to children involved in the child welfare system (DHHS, 2005, “General Findings from the Federal Child and Family Services Review”). We are deeply concerned that the proposed rule will significantly harm Medicaid beneficiaries receiving foster care in two major ways: It could restrict access to Medicaid rehabilitative

services for children receiving foster care by determining that such services are intrinsic to other foster care programs, and it would eliminate coverage for therapeutic foster care services.

Restriction on access to Medicaid rehabilitative services for children receiving foster care by determining that such services are intrinsic to other foster care programs: Medicaid is the major provider of health and long-term services to children receiving foster care. The other federal programs that fund or support the child welfare system do not have primary responsibility for providing medical assistance services—this is Medicaid’s role. Ten percent of federal child welfare spending comes from Medicaid (*Profiles of Medicaid’s High Cost Populations*, Kaiser Commission on Medicaid and the Uninsured, December 2006). We are deeply concerned by the proposed intrinsic element test—and the rule’s specific invocation of services for children receiving foster care that would be un-coverable by Medicaid as a result of the proposed rule. There seems to be a perception that other funding components of the child welfare system should assume responsibility for medical assistance services currently provided by Medicaid. This is inconsistent with past Congressional action. In particular, the Title IV-E foster care program exists to help states provide safe and stable out-of-home care for children until the children are safely returned home, placed permanently with adoptive families, or placed in other planned arrangements for permanency (HHS Administration for Children and Families). The purpose of the IV-E program does not include medical assistance, and children in the IV-E program are entitled to Medicaid coverage.

As children eligible for Medicaid, these children are entitled to EPSDT services. However, under the proposed rule, FFP would not be available for rehabilitative services “furnished through” the foster care or child welfare system, “including services that are intrinsic elements of programs other than Medicaid.” This restriction on coverage of rehabilitative services is clearly in conflict with the EPSDT mandate. The fact that a service is “furnished through” another system such as the foster care or child welfare system has nothing to do with whether it should be covered by Medicaid. The reference to services “that are intrinsic elements of programs other than Medicaid” also is meaningless when considering whether a service should be covered for a Medicaid-eligible child. The proposed rule does not define “intrinsic element,” and this lack of definition is likely to lead to uncertainty for beneficiaries, their families, and health care providers as states grapple with figuring out what can and cannot be covered under this vague test.

The implementation of an intrinsic element test could make children receiving foster care unable to receive medically necessary mental and physical health services even when another component of the child welfare system is not available to shoulder Medicaid’s current responsibility for providing medical assistance services.

It would eliminate coverage for therapeutic foster care services: The proposed rule also prohibits the use of federal Medicaid funds for therapeutic foster care, designed for children with serious mental illness. For most children, therapeutic foster care — in which children are placed in a private home with foster parents who are specially trained to help them improve their condition — is an alternative to more costly care in a residential treatment program or psychiatric hospital (*Mental Health—A Report of the Surgeon General*, 1999).

d. The proposed rule would have an unclear impact on other populations

Due to data limitations, and the lack of a meaningful impact analysis by the Secretary, we are unclear how the proposed rule will impact other populations. Nonetheless, we remain concerned that the proposed rule could have serious negative impacts on other populations of Medicaid beneficiaries.

4) Implementation of the proposed rule would create an unreasonable barrier for states seeking to effectively deliver evidence-based practices and efficiently administer rehabilitation programs under Medicaid.

A major goal of Medicaid mental health treatment programs in recent years has been to re-orient the delivery of services to support recovery. Recovery is defined as a process of restoring or developing a positive and meaningful sense of identity apart from one's condition, and then rebuilding one's life despite, or within the limitations imposed by that condition. In a report issued in 2003, the President's New Freedom Commission on Mental Health recognized the importance of Medicaid services and urged that they be focused on recovery because this could have, "a powerful impact on fostering consumer's independence and their ability to live, work, learn and participate fully in their communities." This challenges many common conceptions of rehabilitation, as it suggests that the goal of treatment is not to cure or eliminate a condition, but it focuses the delivery of services on long-term management of a condition. Unlike individuals recovering from a physical injury in which intensive rehabilitation may be needed for a short, time-limited period, rehabilitative services needed by people with mental illness may be medically necessary over a lifetime.

Psychiatric rehabilitation services are designed to assist the recovery of adults with serious mental illness and children and youth with emotional, behavioral, and mental disorders. Such disorders cause significant deficits in functioning, including deficits in daily living skills, impaired social interactions and behavior, ineffective problem solving, a diminished ability to maintain relationships and a marked impairment in role function, including age-appropriate behavior and functioning in children.

We are deeply concerned that the implementation of the proposed rule would hinder state efforts to operate evidence-based treatment programs.

Starting in the late 1990s, the Robert Wood Johnson Foundation and other public and private funders, including the U.S. Substance Abuse and Mental Health Services Administration (SAMHSA), Johnson & Johnson, the West Family Foundation, and the John D. and Catherine T. MacArthur Foundation have funded the Dartmouth Psychiatric Research Center to operate an Evidence-Based Practice Project. The project has convened a consensus panel of a broad range of mental health practitioners and other stakeholders to review the evidence for various mental health practices. The panel identified the following practices for which there is a consensus that the practices were evidence-based and represented the best practices for the treatment of schizophrenia and severe mental illness:

- Assertive community treatment (ACT);
- Family psycho education;
- Illness management and recovery;
- Integrated dual disorders treatment;
- Medication management; and,
- Supported employment.

In June 1999, federal officials acknowledged through a State Medicaid Directors letter that Medicaid funds could be used to pay for ACT programs (See June 7, 1999 State Medicaid Director letter from Sally K. Richardson). The letter references an evaluation of the Schizophrenia Patient Outcomes Research Team (PORT) that was funded by the Agency for Health Care Policy and Research and the National Institute for Mental Health that found that,

“randomized trials have demonstrated consistently the effectiveness of these programs [ACT and a related program, Assertive Case Management or ACM] in reducing inpatient use among such high-risk patients. Several studies also support improvements in clinical and social outcomes. These studies suggest that both ACT and ACM are superior to conventional case management for high-risk cases.”

CMS has recognized all of these practices as promising practices and has confirmed (with certain restrictions) that these practices (or aspects of these practices) can be covered under the rehab option (*Medicaid Support of Evidence-Based Practices in Mental Health Programs*, Centers for Medicare and Medicaid Services, October 2005).

The proposed rule appears to continue disturbing CMS administrative practices to restrict flexibility in states use of various payment methodologies to pay for rehabilitative services. Several of our member organizations represent rehabilitative services providers in numerous states that have reported that CMS has tied approval of state plan amendments to the adoption of fee-for-service payment methodologies in which specific services are billed in discrete time increments, such as fifteen minute units of service. States and service providers need greater flexibility to use case rate payment methodologies, to pay daily rates, or use other payment methodologies. Current CMS restrictions are inconsistent with the efficient administration of the Medicaid program because such rigidity will lead to increased administrative costs. Further, numerous services providers report that many of the proven, effective, evidence-based practices cannot be efficiently administered without greater flexibility in using alternative payment methodologies. The Administration position also appears inconsistent with HHS policy to promote capitated managed care, and it does not recognize that per diem and other payment methodologies are used in other parts of the Medicaid program. For example, per diem nursing home payments are a much larger drain on the federal treasury, and we are not aware of any HHS policy to eliminate and transition away from per diem nursing home payments.

We do not ignore the federal responsibility to ensure accountability for significant federal resources that are being used to fund rehabilitative services. This is just one specific instance, however, where the Secretary should engage in a collaborative dialogue with states and rehabilitative services providers to maximize payment flexibility that leads to improved services, yet which also responds to federal obligations to ensure transparency and accountability.

5) Challenges efforts by states and school districts to effectively deliver health care services to children with disabilities in school settings.

The civil rights law, the Individuals with Disabilities Education Act (IDEA), entitles children with disabilities to a free, appropriate public education in conformity with an individualized education program (IEP). An IEP is developed for eligible individuals with disabilities and describes the range of services and supports needed to assist individuals in benefiting from and maximizing their educational

opportunities. The types of services provided under an IEP include services such as speech pathology and audiology services, and physical, psychological and occupational therapies. While IDEA confers rights to individuals and obligations on the part of school systems, it is not directly tied to a specific program or an automatic funding source. For years, the Federal government has failed to provide anywhere near the level of funding promised in the IDEA statute. States' ability to appropriately rely on Medicaid funds for Medicaid services provided to Medicaid-eligible children pursuant to an IEP helps defray some of the state and local costs of implementing IDEA. This, in turn, helps assure that children receive all of the services they have been found to need in order to meet their full potential.

The sources of funding available to fund services under IEPs have been a contentious issue in the past. Some time ago, HCFA attempted to limit the availability of Medicaid funding for services under IEPs. In 1988, the Congress addressed the issue in enacting the Medicare Catastrophic Coverage Act of 1988 (Public Law 100-360) in which it clarified that Medicaid coverage is available for Medicaid services provided to Medicaid-eligible children under an IEP. Under current law, the Social Security Act at section 1903 (c) reads,

“Nothing in this title shall be construed as prohibiting or restricting, or authorizing the Secretary to prohibit or restrict, payment under subsection (a) for medical assistance for covered services furnished to a child with a disability because such services are included in the child’s individualized education program established pursuant to part B of the Individuals with Disabilities Education Act or furnished to an infant or toddler with a disability because such services are included in the child’s individualized family service plan adopted pursuant to part H of such Act.”

Under separate cover, the CCD will comment on the NPRM issued on September 7, 2007 to restrict Medicaid coverage for school-based administration and transportation services. Our concern here is that, while the proposed rule does not explicitly restrict access to rehabilitative services in school settings, new requirements of this rule could be disruptive to schools and could make it more difficult to use the school environment to assure that children with disabilities receive the rehabilitative services that they need. In particular, we are concerned with new provider qualification standards that could restrict the ability of certain providers of services to serve children in schools. While we share the goal of ensuring that all rehabilitative services are of the highest quality and are only provided by providers who meet state credentialing standards, we are concerned that this rule would limit state flexibility to establish provider qualification requirements in school settings. Further, we are concerned that the any willing provider requirement could be disruptive to school efforts to serve children. We believe that the existing free choice of provider which guarantees parents the right to access medically necessary therapy and other services by other providers—outside of the school environment—is an appropriate way to protect parents’ right to access the Medicaid qualified provider of their choice. Again, the Secretary has not provided a policy justification for this new requirement, and we believe the net impact will be to make it less desirable for Medicaid programs to use school settings to provide essential rehabilitative services to children. The Congress could not have been clearer in its intent that it wants Medicaid to support the goals of IDEA; we believe that these narrow interpretations of the law are inconsistent with that intent.

For these and other reasons, we urge the Secretary to withdraw the proposed rule.

Thank you for the opportunity to comment on the proposed rule. For further information, please contact Marty Ford, Co-Chair of the CCD Long Terms Services and Supports Task Force (202-783-2229, ford@thepdc.org) or Kathy McGinley, Co-Chair of the CCD Health Task Force (202-408-9514, Kathy.McGinley@ndrn.org).

Sincerely,

1. ACCSES
2. American Academy of Pediatrics
3. American Association of People with Disabilities
4. American Association on Intellectual and Developmental Disabilities
5. American Music Therapy Association
6. American Counseling Association
7. American Network of Community Options and Resources
8. American Occupational Therapy Association
9. American Therapeutic Recreation Association
10. APSE – The Network on Employment
11. Association of University Centers on Disabilities
12. Autism Society of America
13. Autism Speaks
14. Bazelon Center for Mental Health Law
15. Council for Exceptional Children
16. Council for Learning Disabilities
17. Disability Rights Education and Defense Fund
18. Division for Early Children of the Council for Exceptional Children
19. Easter Seals
20. Epilepsy Foundation
21. IDEA Infant Toddler Coordinators Association
22. Inter-National Association of Business, Industry and Rehabilitation
23. Learning Disabilities Association of America
24. Mental Health America
25. National Alliance on Mental Illness
26. National Association for the Advancement of Orthotics and Prosthetics
27. National Association of Councils on Developmental Disabilities
28. National Association of County Behavioral Health and Developmental Disability Directors
29. National Association of Social Workers
30. National Association of State Head Injury Administrators
31. National Association of State Mental Health Program Directors
32. National Council for Community Behavioral Healthcare
33. National Disability Rights Network
34. National Down Syndrome Congress
35. National Down Syndrome Society
36. National Spinal Cord Injury Association
37. NISH

38. Paralyzed Veterans of America
39. TASH
40. The Arc of the United States
41. United Cerebral Palsy
42. United Spinal Association
43. World Institute on Disability