



October 10, 2007

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

Dear Sir(s) or Madams:

The Council for Exceptional Children (CEC) is the largest professional organization of teachers, administrators, parents, and others concerned with the education of children with disabilities, gifted and talents, or both. CEC is writing in response to the August 13, 2007 *Federal Register* announcement requesting public comment on the Notice for Proposed Rule Making for Coverage for Rehabilitative Services under the Medicaid program.

CEC is gravely concerned about the devastating impact that the proposed CMS regulations for the rehabilitation services option will have on the welfare of children with disabilities. The elimination of these reimbursements would inevitably shift the financial responsibility for rehabilitation claims to individual school districts and early childhood providers across the nation. The Administration estimates that the elimination of the reimbursement for the Medicaid rehabilitation services option will provide a savings of \$2.29 billion over the next five years. However, there is no corresponding increase in funding for the federal special education law, the Individuals with Disabilities Education Act (IDEA), that will enable schools and early childhood providers to make up for the reduction in Medicaid reimbursements for rehabilitation services option provided to children with disabilities.

### **Major Issues and Concerns**

CEC 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 We believe it is fatally flawed and should be withdrawn.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 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 that have mental illness, all of the harms and concerns and 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." 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 maximizes 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.

**4) Challenges efforts by states, school districts, and early intervention providers to effectively deliver health care services to children with disabilities in school/early childhood settings.**

The civil rights law, the Individuals with Disabilities Education Act (IDEA), entitles children with disabilities to a free, appropriate public education and early intervention services in conformity with an individualized education program (IEP) and an individualized family service plan (IFSP). An IEP/IFSP 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/developmental opportunities. The types of services provided under an IEP/IFSP 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/early intervention providers, 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/IFSP 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/IFSPs have been a contentious issue in the past. Some time ago, HCFA attempted to limit the availability of Medicaid funding for services under IDEA. 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/IFSP. 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.”

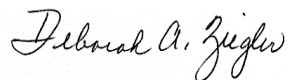
Our concern here is that, while the proposed rule does not explicitly restrict access to rehabilitative services in school and early childhood settings, new requirements of this rule could be disruptive and could make it more difficult to use the school and early

childhood environments 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 and early childhood settings. 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 and early childhood settings. Further, we are concerned that the any willing provider requirement could be disruptive to 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/early childhood 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/early childhood 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 allowing the public to provide comments on Medicaid Program; Coverage for Rehabilitative Services and for considering CEC’s recommendations. If you need additional information please contact Deborah Ziegler, Associate Executive Director for Policy and Advocacy Services at [debz@cec.sped.org](mailto:debz@cec.sped.org) or 703-264-9406, or Dan Blair, Senior Director for Policy and Advocacy Services at [danb@cec.sped.org](mailto:danb@cec.sped.org) or 703-264-9403.

Sincerely,



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Associate Executive Director  
Policy and Advocacy Services