264-2

It is imperative that CMS withdraw, revise and re-issue the regulations proposed under Section 441.45(b)(2), with greater clarity as to the implications for children and adolescents with special needs who are currently receiving necessary medical services (BHRS) here in Pennsylvania.

As written, these proposed regulations raise questions as to whether the federal government will use them to force Pennsylvania to restrict these vital services for our children.

It is also urged that CMS provide opportunity for public comment.

Sincerely,

[signature]

Address: 1895 Rte 212
Quakertown PA 18951

✓ Parent

✓ Professional

____Other ____________________

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October 8, 2007

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

To Whom It May Concern:

Reference: File Code CMS 2261-P

As a concerned citizen and Executive Director of Threshold, Inc., I write to submit the following comments on the proposed new regulations to govern Medicaid's rehabilitation service category that were recently published in the August 13, 2007 Federal Register (Volume 72, Number 155). Threshold operates a psychosocial rehabilitation program based on the Clubhouse Model for adults in Durham, NC, with a severe mental illness. Established in 1985 by concerned parents, Threshold is committed to facilitating personal well-being and community involvement through meaningful work and relationships.

I commend CMS for undertaking to attempt to "provide for important beneficiary protections such as a person-centered written rehabilitation plan and maintenance of case records," as is stated in the summary in the Federal Register. As a taxpayer, I think it is important that to ensure the fiscal integrity of the Medicaid program. The proposed rule changes are comprehensive and would significantly affect the public provision of services to children and adults with serious mental disorders and people with physical or developmental disabilities. As I understand it, the net effect of the changes would be to save the federal government an estimated $180 million in one year and $2.2 billion over a five-year period. However, the states and localities would see none of those dollars, which means they would have to either reduce services or pick up the slack for the lost federal revenue. I believe the proposed rules will do more harm than good, and I urge you to reconsider the sweeping changes you are about to make. I offer the specific comments concerning the proposed rules below.

Non-covered services: 441.45(b)

This section appears to introduce an entirely new concept into Medicaid, one that conflicts with current federal statutory requirements. It denies Medicaid coverage for covered services to covered individuals if such services are furnished through another program, including when they are considered "intrinsic elements" of that program. More

United Way
609 Gary Street, Durham, NC
Mailing Address: P.O. Box 11706, Durham, NC 27703
Telephone: (919) 682-4124 Facsimile (919) 956-7703

Insert additional language into 441.45(a)(2) to describe when services may be furnished with the goal of retaining or maintaining functioning.

Definition of Restorative Services: 440.130(d)(1)(vi)-

This definition stipulates that restorative services are those that enable an individual to perform a function, and that the individual does not have to have actually performed the function in the past. Similar to the concerns raised regarding the Rehabilitation Services section are concerns that the definition of Restorative Services focuses on achieving a rehabilitation goal and not maintaining a functional level necessary to avoid the need for more intensive and expensive medically necessary and covered services. It is our understanding the CMS had both the authority and obligation to fund needed "rehabilitation and other services" for helping covered individuals "retain" improved functioning and that allows for independence from more intensive and expensive services.

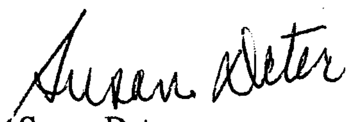
Recommendation:

There should be clear language in this section that allows for funding services that are determined thorough approved rehabilitation plans to be necessary to achieve and maintain the least intensive service level and most independence possible, to include as an acceptable goal of a rehabilitation plan the retaining of functional level for individuals who can be expected to otherwise deteriorate.

Conclusion

Unfortunately, Medicaid has become the single largest funding source for mental health services in this country today. Sweeping mental health reform may indeed be needed, but essentially taking away the only funding source for mental health services on the ground will greatly damage the progress that has been made to provide critical services for some of our nation's most vulnerable citizens. The proposed rules would: over time only increase Medicaid costs due to more expensive psychiatric hospitalizations; effectively disallow important aspects of psychosocial rehabilitation by removing any long-term solutions; and create such needless and burdensome paperwork that it will adversely impact service delivery to those that Medicaid is charged with protecting. Cutting corners now will only make things worse in the long run. I strongly urge you to carefully reconsider the proposed changes or to at least carefully consider the comments here and from others who provide services in the mental health area.

Sincerely,



Susan Deter
Executive Director, Threshold

609 Gary Street Durham, NC 27703

265

2007 OCT 24 PM 10: 17

October 2, 2007

Centers for Medicare & Medicaid Services
Attention: CMS-2261-P
Mail Stop C4-26-05
7500 Security Boulevard
Baltimore, MD 21244-1850

To Whom It May Concern:

Reference: File Code CMS-2261-P

As a provider of mental health supportive housing services, I am submitting the following comments on the Proposed Rule to amend the definition of Medicaid Rehabilitative Services as published in the Federal Register, August 13, 2007 (Volume 72, Number 155).

Re: Non-covered services 441.45(b)(1) where regulations refer to services intrinsic to other program.

The definition of "intrinsic" is unclear and this will probably lead to misuse of this rule to eliminate and deny medically necessary services that have been funded for a long time through Medicaid. (Including but not limited to rehabilitation services like employment, education and housing).

It is necessary to better define "intrinsic elements" and to insure that any services determined at the local level to be non-reimbursable due to this rule be readily available, effective, funded and accessible at another program before current funding is discontinued. Better would be to drop this section altogether.

Re: Rehabilitation Services 441.45(a)

The issue is the change in providing services to maintain current level of functioning only when it is necessary to help an individual achieve a rehabilitation goal. Continuation of rehabilitation services is at times essential to retain a person's functional level. Failure to provide such services could lead to further deterioration which might lead to reinstatement of intensive services including hospitalization.

It is very important that this section include language that determines when and how to determine if a rehabilitation service or services is necessary to maintain a desired functional level.

266-O

President
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Medical Director
Andrew Levin, MD
Chief Financial Officer
Debra Feldman, CPA

October 2, 2007

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

To Whom It May Concern:

Reference: File code CMS-2261-P

The Coalition of Behavioral Health Agencies, Inc. is submitting the following comments on the Proposed Rule for Coverage for Rehabilitative Services under the Medicaid program, as published in the Federal Register, August 13, 2007.

As a member of the Coalition of Behavioral Health Agencies, Inc. we are endorsing the enclosed comments and the commentary provided by its Executive Director, Phillip A. Saperia, Executive Director.

Sincerely,

Jeff Apotheker
Director

845 North Broadway, White Plains, NY 10603-2427 Tel: (914) 761-0600 Fax: (914) 761-5367
E-mail: hdq@wjcs.com Website: www.wjcs.com

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UJA Federation

Comments re: PROVISIONS OF THE PROPOSED REGULATIONS

<u>Section 440.130: Diagnostic, screening, preventive and rehabilitative services</u>

<u>440.130(d)(1)(i)</u>
The final rule should clarify the requirements of an acceptable "individualized recovery goal."

The proposed regulations do not include the criteria for a Medicaid reimbursable "individualized recovery goal". A client's goal may be to: (1) reduce frequency of hospitalization, (2) prevent hospitalization, and/or (3) remain in the community. Often times, once an individual stabilizes he or she may wish to maintain contact with the behavioral health care system because it is a resource and a support for them. It is unclear if these are acceptable recovery goals.

<u>Recommendation:</u>
We urge CMS to clarify the requirements of a Medicaid reimbursable "individualized recovery goal".

<u>440.130(d)(1)(v) Definition of Rehabilitation Plan</u>
The final rule should clarify the definition of an individual providing "input" and "active participation".

This section provides a general definition of the rehabilitation plan, including the role of the individual in the planning process. We applaud CMS for including requirements that are designed to ensure the individual's participation in this process, but believe the wording could be improved. There is a significant difference between an individual providing "input" and an individual having "active participation." By including both terms in different places, the regulation confuses this issue.

<u>Recommendation:</u>
We urge CMS to clarify the role of the individual and the definition of "input" and "active participation". We also urge CMS to ensure that the active participation of "collaterals" meets all of the necessary HIPAA requirements for the privacy rule.

<u>440.130(d)(1)(vi) Definition of Restorative Services</u>
The final rule should clarify the meaning of restorative services.

The proposed definition stipulates that restorative services are those that enable an individual to perform a function, and that the individual does not have to have actually performed the function in the past. This language is critical, as loss of function may have occurred long before restorative services are provided. This would be particularly true for children, as some functions may not have been possible (or age-appropriate) at an earlier date. <u>The regulation needs modification to make the meaning of this section clearer.</u>

The proposed regulations state that "services that provide assistance in maintaining functioning may be considered rehabilitative only when necessary to help an individual achieve a

rehabilitation goal as defined in the rehabilitation plan." While rehabilitation services should not be custodial, for people with serious mental or emotional disabilities, continuation of rehabilitative services are at times essential to retain their functional level. We are concerned that states and providers will interpret the current proposed regulations as prohibiting the coverage of services necessary for retention of improved functioning as well as maintaining the highest possible functional level. Failure to provide a supportive level of rehabilitation would result in deterioration necessitating a reinstatement of intensive services.

CMS in the Medicare program explicitly acknowledges the importance of maintenance of current functioning as an acceptable goal:

> For many other psychiatric patients, particularly those with long-term, chronic conditions, control of symptoms and maintenance of a functional level to avoid further deterioration or hospitalization is an acceptable expectation of improvement. "Improvement" in this context is measured by comparing the effect of continuing treatment versus discontinuing it. Where there is a reasonable expectation that if treatment services were withdrawn the patient's condition would deteriorate, relapse further, or require hospitalization, this criterion is met."
>
> Medicare Hospital Manual, Chapter II, Section 230.5 Hospital Outpatient Psychiatric Services; Medicare Intermediary Manual, Part 3, Chapter II, Section 3112.7 Outpatient Hospital Psychiatric Services.

The preamble and section 441.45(b) of the proposed regulations exclude prevocational services as covered rehabilitation services. However, rehabilitative services should include prevocational services when they are provided to individuals who have experienced a functional loss and have a specific rehabilitation goal of regaining that functioning. Examples include communication and social skills building and cognitive interventions such as taking instructions and/or guidance, asking for help, working at an appropriate pace, staying on task, increased attention span, and increasing memory.

Recommendation:
We urge CMS to indicate in the final rule that a child does not have to demonstrate that he or she was once capable of performing a specific task in the past if it were not possible or age-appropriate for the child to have done so. Specifically, the language should state that restorative services include services to enable a child to achieve age-appropriate growth and development and that it is not necessary that the child actually have performed the activity in the past. (Note, this phrasing is taken from current CMS regulation of managed care plans at 42CFR 438.210(a)(4)(ii)(B)). An example of the above point may be a child who was developmentally on track to perform a function, but did not because it was not yet age-appropriate.

Secondly, we strongly urge CMS to allow the "retaining of functional level" to be an acceptable individualized recovery goal and to reimburse services that enable an individual to maintain their functional level.

Lastly, we urge CMS to cover pre-vocational services that are tied to an individual's recovery goal.

440.130(d)(1)(vii) Definition of medical services
The final rule should include diagnosis as a covered rehabilitation service.

The proposed regulations state" medical services specified in the rehabilitation plan that are required for the diagnosis, treatment, or care..." However, it is extremely difficult to create an effective and meaningful plan of services without an assessment of the person's functional capacity. Typically, clinical assessments focus on clinical signs and symptoms (such as hallucinations) and are insufficient for preparation of a rehabilitation plan and do not provide a good basis of measuring change.

The proposed definition also includes the word "care" after treatment, but that term is nowhere else defined. Does it mean clinical care? The word rehabilitation should be inserted here to make clear the term "medical services" includes rehabilitation. This is important because the term "medically necessary" is used in this regulation to indicate necessary rehabilitation services.

Recommendation:
We urge CMS to revise the final rule to cover functional assessments as a rehabilitation service. Specifically, we ask CMS to add to section (vii) the word "assessment" before the word "diagnosis" and replace the word "care" with the word "rehabilitation."

440.130(d)(1)(viii)(2)Scope of Services
The final rule should clarify the definition of scope of services.

The proposed definition of scope of services is limited to medical or remedial services. However, the term restorative services are also used in this regulation to describe covered rehabilitation services.

Recommendation:
We urge CMS to insert the word "restorative" after "medical" in the first sentence of the definition of scope of services. The same change is needed to (d)(3)(vi).

The preamble phrase "services are to be provided at the least intrusive level to sustain health and ensure the maximum reduction of physical or mental disability and restoration of the individual to the best possible functional level" should be added to the definition of the scope of services. We also urge CMS to indicate in the final rule that services be required to be provided in a coordinated manner and in the most integrated, appropriate setting.

440.130(viii)(3) Written Rehabilitation Plan
The final rule should clarify the requirements of the written rehabilitation plan.

The inclusion of this section is to be commended, and generally we agree with the intention as well as the specific language. However, some of the language in this provision is unclear and needs clarification. The proposed requirements will be burdensome, both administratively and

financially, for agencies serving individuals in need of rehabilitative services. They will also create another level of complexity for documentation compliance and audits.

For example, how does CMS expect providers to indicate progress towards the goals in the rehabilitation plan? Need there be a progress note for every encounter? (Since CMS is currently requiring providers to account for and bill services in 15-minute increments, <u>a progress note for every encounter will become a major burden</u>, especially when services are delivered to a group.) We would recommend that progress notes be required at least monthly, leaving it to states to require, or providers to make, more frequent notes in cases where that may be appropriate. The guiding factor should be that the service record include information that is necessary for clinical purposes and that this information is presented in a way that meaningfully demonstrates the nature and course of services being provided.

Is it allowable for a service planning team to create a single plan of services that address both treatment issues and rehabilitation issues? Frequently, in mental health service delivery, clinical issues (such as medication and therapy) are planned in conjunction with rehabilitation needs (skill building, etc.). <u>Requiring two separate planning processes and two separate planning documents is burdensome not only on providers but also on the individual consumer</u>. Clearly, multiple service plans do not facilitate coordination or accountability.

The requirement to "indicate the anticipated provider(s) of the service(s) and the extent to which the services may be available from alternative provider(s) of the same service" is very problematic. First, it is unlikely and time-consuming for a practitioner to list all potential providers of a service. This can also become a conflict of interest because it is typically the clinician who is providing the service who will develop the rehabilitation plan. Lastly, if an individual chooses to go to another provider, that provider typically does not want to be handed a rehabilitation plan developed by someone else.

The proposed regulations recommend the use of "person-centered planning", which requires the active participation of the individual, involvement of the consumer's family, or other responsible individuals. However, requiring the signature of the client or representative can be problematic. There may be instances in which a person, because of the symptoms of their illness, may not believe they are sick or comply with the treatment plan. There is also no guarantee that the individual will appoint a representative, or that the consumer when in crisis could identify this person.

<u>Recommendation</u>:
We urge CMS to include the following requirements regarding the written rehabilitation plan:

- that the plan be written plainly in multiple languages so that it is understandable to all individuals;

- that the plan indicate the individual's level of participation, as well as his or her concurrence with the plan;

- that the plan allow for a qualified provider to sign the treatment plan when the client or their representative is unable to do so or has no family or designated representative;

- that the plan of services be based on a strengths-based assessment of needs;

- that the plan include intermediate rehabilitation goals;

- that the plan include, if necessary, provisions for crisis intervention;

- that the plan include individualized anticipated review dates that correspond with the anticipated achievement of long-range and intermediate rehabilitation goals;

- provide certification that the individual has been informed about their rights regarding advance directives;

- that the plan allow providers to provide information on potential alternate providers of the same service instead of listing all of the alternative providers in the treatment plan.

We also urge CMS to indicate in the final rule the use of a single treatment and rehabilitation plan and a single planning team and service planning meetings. The content of the plan needs to be flexible in order for providers to feel comfortable providing flexible level of services without risking disallowances.

We urge CMS to revise the language under paragraph (v) to require that the plan be developed by a team, led by "a qualified provider working within the State scope of practice act". The plan should require the active participation of the individual (unless it is documented that he/she is unable to actively participate due to his or her medical condition), the individual's family (if a minor or if the adult's individual desires), individual's authorized decision maker (of the individual's choosing) in the development, review and modification of the goals and services provided. We also urge CMS to ensure that the active participation of "collaterals" meet all of the necessary HIPAA requirements for the privacy rule.

440.130(4) Impairments to be addressed

The final rule should state that all individuals are eligible for coverage of rehabilitation services.

The proposed regulations state that "services may address an individual's physical impairments, mental health impairments and/or substance-related disorder treatment needs." The preamble

states that "because rehabilitative services are an optional service for adults, states have the flexibility to determine whether they will be limited to certain services for specific populations."

Limiting services to only one group, based on diagnosis or disability violates Medicaid's requirement that services be furnished in sufficient amount, duration and scope to reasonably achieve their purpose. Not providing coverage of rehabilitative services to individuals with a mental illness would also violate Title II of the Americans with Disabilities Act, 42 U.S.C. § 12132.

Recommendation:
We urge CMS to delete the word "or" after the word "and" in Section 440.130(4).

440.130(5) Settings
The final rule should include a more extensive list of settings where rehabilitative services can be provided.

Recommendation:
We urge CMS to add to the list of appropriate settings for rehabilitation services described in the preamble and to include the list in all sections of the proposed regulations. Specifically, we urge CMS to include schools, therapeutic foster care homes, and mobile crisis vehicles to the list of appropriate settings where rehabilitation services can be provided.

Section 441.45: Rehabilitative Services

441.45(a)(2)
The final rule should clarify the definition of a rehabilitative service.

This section limits rehabilitative services to those furnished for the maximum reduction of physical or mental disability and restoration of the individual to their best possible functional level, as defined in the law.

Recommendation:
We urge CMS to insert additional language into 441.45(a)(2) to describe when services may be furnished with the goal of retaining or maintaining functioning (see previous comments). We also urge CMS to include the language in the preamble (page 45204) regarding how to determine whether a particular service is a rehabilitation service, based on its purpose.

441.45(b) Non-covered services
The final rule should not deny Medicaid coverage for services provided to Medicaid-covered individuals if such services are furnished through another program.

This section introduces a whole new concept into Medicaid, one that conflicts with current federal statutory requirements. It denies Medicaid coverage for services provided to Medicaid-

covered individuals if such services are furnished through another program, including when they are "intrinsic elements" of that program. There is little clarity on how to determine whether a service is an "intrinsic element" of another program or how it would be applied.

Without revision, this new rule would conflict with the federal statutory mandate to provide all medically necessary services covered by the state Medicaid plan, and for children, all medically necessary services covered by 42 U.S.C. § 1396d(a). See 42 U.S.C. §§ 1396a(a)(10), 1396d(r)). The result of this new rule will be that Medicaid-eligible individuals will be denied services, both by Medicaid and by the other programs due to lack of resources (i.e. therapeutic foster care, foster care or child care institutions for a foster child). What is the legal basis for denying federal financial participation (FFP) for the Medicaid-covered individual? Thus, the rule effectively denies individual's medically necessary Medicaid services, in direct contradiction of current federal statute.

Recommendation:
We strongly urge CMS to remove this entire section, because it conflicts with Medicaid statute. Alternatively, the section should be clarified and narrowed so as to specifically focus on situations where an entity (e.g. an insurer) has a specific legal obligation to pay for the services for the specific Medicaid-covered individual. Programs operated through capped or discretionary appropriations from states or localities should be specifically excluded from this provision.

We strongly urge CMS to include a list of settings (therapeutic foster care, foster care or child care institutions for a foster child) where children can receive medically-necessary rehabilitation services as long as they are provided by qualified Medicaid providers. Specifically, this language should be included in Section 441.45(b)(1).

We also urge CMS to include language in Section 441.45(b) that will indicate Medicaid rehabilitative services must be coordinated with services furnished by other programs (similar to language in the preamble)

441.45(b)(1)(i) Therapeutic foster care
The final rule should list therapeutic foster care as a covered rehabilitation service for children with serious mental disorders.

Therapeutic foster care is the least restrictive out-of-home placement for a child with a serious mental disorder. Therapeutic foster care is a widely covered evidence-based practice with more than half a dozen controlled clinical trials demonstrating improved outcomes (see the Report on Mental Health from the U.S. Surgeon General). This mental health intervention is designed for children both in and outside of the foster care system; it is not a service exclusively for children in the foster care system. The alternative for most children would be immediate placement in an institutional setting, such as a residential treatment program or psychiatric hospital, a significantly more costly setting.

The proposed regulations deny payment for therapeutic foster care as a single program, requiring instead that each component be billed separately. If states are not able to provide and bill for services as a package, the effectiveness of treatment will decrease while administrative costs rise.

Recommendation:
We strongly urge CMS to list therapeutic foster care as a covered rehabilitation service for children with serious mental disorders at imminent risk of placement in a residential treatment facility. Covered services should not, however, include room and board costs.

In discussing therapeutic foster care, the preamble states that states must define all of the services to be provided and the payment methodology for a covered service. Accordingly, states should be given the discretion to define therapeutic foster care as a single service and pay through a case rate, daily rate or other appropriate mechanism.

We also urge CMS to include language in Section 441.45(b)(1)(i) to clarify that mental health rehabilitation providers are eligible to provide and bill for rehabilitation services for children in therapeutic foster care.

441.45(b)(2)
The final rule should clarify the difference between "exclusion for habilitation services as opposed to the exclusion from Federal Financial Participation (FFP) for rehabilitative services."

The Omnibus Reconciliation Act of 1989 (OBRA 89) prohibited CMS (the HCFA) from disallowing claims for day habilitation services until CMS issued a new regulation that specified the types of habilitation services that would only be covered. Therefore, the provision in the proposed regulations that would exclude coverage for habilitation services for persons with mental retardation and related conditions is unprecedented, inconsistent with Congressional intent, and not justified.

It should be noted that the exclusion of habilitation services does and should not equal exclusion from FFP for any rehabilitative services provided to persons with mental retardation or related conditions (i.e. cerebral palsy and epilepsy) that would gain functionality from rehabilitative services. Individuals with serious mental illness may experience periods of cognitive impairment as a result of their illness. If they do experience cognitive impairment, will the rehabilitation services they receive be covered?

If CMS approves this change, it is going to require a considerable amount of time and planning to transfer coverage of habilitation services from the rehabilitation option into another appropriate Medicaid authority. The proposed rule does not specify how CMS will provide technical assistance during the transition period.

Recommendation:

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October 3, 2007

Centers for Medicare & Medicaid Services
Attention: CMS-2261-P
P.O. Box 8018
Baltimore, MD 21244-8018

To Whom It May Concern:

Reference: File code CMS-2261-P

Adventure House is submitting the following comments on the Proposed Rule to amend the definition of Medicaid Rehabilitative Services as published in the Federal Register, August 13, 2007 (Volume 72, Number 155). Adventure House is a Day Rehabilitation Program based on the Clubhouse Model, located in a rural community of North Carolina. We serve adults with severe and persistent Mental Illness, with 80% of our Members (clients) having a diagnosis of Schizophrenia. We have been in business as a Non-Profit Organization for over 20 years, relying on Medicaid and state funding to provide needed services in our community. We currently have 115 active Members, with an average daily attendance of 65.

It is clear from the published "Summary" of this proposed Rule, that the intent of CMS is to severely restrict rehabilitative services to Medicaid eligible individuals with long term Mental Illness, through increased documentation requirements for already overburdened Providers and through extremely restrictive service definitions. CMS appears to want to cut funding for medically necessary services to the most vulnerable segment of this country's citizens- those with long term Mental Illness. We know these cuts will far exceed the projected reduction in Medicaid spending of $2.2 billion over five years, through putting small Providers out of business and through "Paybacks" as a result of audits of larger providers. It is shameful for CMS to refer to "important beneficiary protections," as having anything to do with the maintenance of case records. Our Members rely on Medicaid as their only health insurance and are alarmed by the degree to which their coverage could be reduced by the proposed Rule change.

Like it or not, Medicaid has become the single largest funding source for Mental Health services in this country. If CMS truly wants to cut Medicaid funding, the agency needs to stop blaming the states for viewing rehabilitation benefits as a "catch-all category" and accept responsibility for their approval of all state plans. CMS should then begin

CLEVELAND PSYCHOSOCIAL SERVICES, INC.
924 N. Lafayette Street, Shelby, North Carolina 28150 Telephone 704-482-3370
"a clubhouse model rehabilitation program"

working with other federal, state and local agencies to develop alternative funding sources and develop a transition plan that will prevent the disruption of vital services to adults with severe Mental Illness. For CMS to proceed with their current strategy of a "Rule change," will result in precious funding being wasted on challenging the creative writing skills of Mental Health Professionals to document needed services in a manner that Medicaid will pay for. Or, worse yet, the funds will be misused to provide specific, time limited, and ineffective interventions to adults with Mental Illness in a misguided effort to at least offer them something, rather than abandoning them to isolation in the community, only to decompensate. Much more intensive and expensive services will then be needed to stabilize the individual only to again be abandoned. In my 30 years of community mental health work, the most effective program to stop this revolving door, the Clubhouse Model, is being directly threatened by the proposed Rule changes. We can not be effective under these proposed Rules as specified below.

PROVISIONS OF THE PROPOSED REGULATIONS

Section 440.130(d) (3)

The requirements outlined in this section focus on documentation. Taken individually, they all make sense from an accountability stand point. But CMS knows that such requirements are utilized not to improve services, but to extract large "Paybacks" from Providers. The more requirements there are, particularly vague requirements (such as "recovery goals" and "reasonable plans") that can be open to interpretation, the more Paybacks that can be imposed.

With private insurance, a claim is filed by the provider and the insurance carrier pays or rejects the claim. If rejected, the Provider corrects errors and provides additional documentation needed for reimbursement. If the claim is still denied, the patient is then billed for the "uncovered services."

Under Medicaid, the claim is paid. The Provider is then vulnerable to federal, state, and local auditors who require a 100% payback if they believe the documentation is inadequate. The proposed Rule arms these auditors with many more avenues to extract a payback. A simple oversight or clerical error results in a 100% payback. If the written rehabilitation plan contains an error, then all services provided under that plan are subject to payback. Put simply, Medicaid plays the "gotcha game," with no lesser penalty in their arsenal than a 100% payback. The Provider cannot then turn to the indigent patient and expect payment, nor can they payback the funds they expended providing the service. The result is that the Provider's focus is shifted from the client to the record as the most important element of their job. Clients become a bothersome interruption to the mandated and critical documentation work of the professional staff. This is already happening and can be seen in the dramatic increase in workshop offerings to Mental Health staff on record keeping and "Audit Proofing Your Records." "Quality Improvement" refers to records, not services, and the client suffers.

Recommendation: Develop a Rule change that would stop the "gotcha" game and truly benefit the clients served. Develop "fines" short of full paybacks and work to reduce the paper work demands on Providers so that they can focus on service delivery to their clients. Surely there is a way to pursue unscrupulous Providers without overwhelming good Providers with paper work.

Section 440.130(d)(l)(vi)

This section, and others, has to do with the expectation that there will be a "measurable reduction of disability and restoration" and the exclusion of services to "maintain a level of functioning." Severe and Persistent Mental Illness, such as schizophrenia, has a devastating effect on a person's whole life. One can not chop that life up into specific measurable goals, prescribe a specific intervention, in a predetermined amount and expect to impact that life. The proposed Rule goes even further in the wrong direction by disallowing most of the elements of that life as billable under Medicaid. In fact, I'm hard pressed to even think of an intervention that could not be interpreted as being vocational, prevocational, educational, social or recreational. Even "Housing" is listed, which may be interpreted as any intervention to support a person in living more independently. Then there are "services that are intrinsic elements of programs other than Medicaid" which are also disallowed. How can this be considered "Person Centered?"

I understand that CMS provides an example of what might appear to be a "social activity" which may in fact be addressing the rehabilitation goal of social skills development as identified in the rehabilitation plan. They go on to state that such an activity would need to be specifically related to an identified rehabilitative goal as documented in the rehabilitation plan with specific time-limited treatment goals and outcomes. Furthermore, the social activity would need to be provided by a qualified provider, be documented in the case record and meet all requirements of this proposed regulation. Can CMS not see the absurdity in this? How did CMS staff develop their social skills without all of the above? Do they really think that a person with mental illness is so different from them as to require all of the above? Why would a Provider even attempt such billing, knowing that the goal must be time limited and the individual would often have no place to use the social skills developed upon goal attainment?

I am not trying to make the case that Medicaid should pay for playing Bingo. In fact, Adventure House backs social activities out of the program time billed to Medicaid. But, under the proposed Rule, Providers could bill Medicaid for Bingo, TV watching, horseback riding and practically anything else, as long as they met all the above requirements. CMS can not stop such abuse by increasing documentation requirements. Instead, CMS will further shift the focus on the requirements and the documentation and not on the clients, who would most likely exhibit good social skills if given the opportunity, or develop those skills (as most people have) by being provided with the opportunity to participate in a social setting.

Rehabilitation as it applies to adults with severe Mental Illness can not be seen as picking out a narrowly defined and measurable segment of a person's disability and then providing an intervention, in some kind of prescribed formula, which should be administered in calibrated dosages by qualified professionals to their ill patents. The rehabilitation services must be in some context that provides meaning and purpose. What good are measurable goals and allowable interventions to impact budgeting skills, when there is nothing in this world that the client can envision as worth budgeting for. Don't we understand that there is no reason to save to buy new clothes, when there is no place to go in them, or for a vacation, when there is no one with whom to go and nothing from which to take a vacation? Providing that context, that purpose, is the best way I have found to reduce the disabling effects of a major Mental Illness.

The proposed Regulations threaten our ability to provide a context within which real Rehabilitation happens. If CMS applied these regulations to persons who are not diagnosed with a Mental Illness, I truly believe they would become disabled. Their lives would be fragmented into measurable pieces. Large areas of their lives would be ignored because we are not able to identify measurable goals nor can we specify an anticipated outcome that would reasonably impact those areas. We can impact those areas! We do it every day with our friends, family and co-workers. We just can't document what we do to accomplish this under the requirements set forth in this proposed Rule change and to try would risk audit repercussions.

This objection to the proposed rule is IMPORTANT. In the Federal Register, CMS describes ball throwing as a billable service for a stroke victim needing to improve balance and coordination. There is an assumption here that the client has a life in which balance and coordination are needed and that this life includes activities that will sustain balance and coordination long after the professional intervention.

The same assumptions can not be made for an adult with a long term Mental Illness. Members have reported being in time limited programs where they hid improvement for fear of being discharged from the very service that helped them improve. They report having no where to go upon discharge, nothing meaningful to do and no one with whom to share any goal attainment they may have made. They also fear the return of depressive and psychotic symptoms that they know may reoccur despite compliance with medications. The words "Recovery goals" appear to have been inserted into the proposed regulation, with no understanding of what that means. It appears to be just another documentation requirement to CMS. People rarely recover from severe Mental Illness. It is a biological illness with no known cure. The word "Recovery" as it applies to Mental Illness refers to the often life long struggle of an individual to recover their lives to the greatest extent possible despite the illness. To set recovery goals means to provide supports and services specifically listed as not covered under the proposed Medicaid rule. The exclusion of services that are "prevocational" is particularly troublesome, as many interventions and supports necessary for "recovery" fall within this realm.

CMS can not simply make a Rule and abandon the Medicaid eligible people with Mental Illness. We have discharged these people from institutions with promises of providing

community based services that were nonexistent or grossly under funded. Now, the single largest funding source used to develop those services in the community is threatening to make a Rule change. It is inhumane and unethical to hide what CMS is doing behind the stated purpose of "rectifying the improper reliance on the Medicaid rehabilitation benefit" without identifying/developing an adequate and alternative funding source.

CMS has allowed or has looked the other way while states have utilized Medicaid funding to sustain and maintain the highest possible functional level for adults with severe Mental Illness. This MUST remain as an acceptable goal for delivering services under Medicaid.

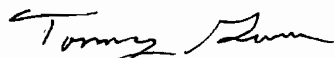
Section 440.130(vii)(3)

In North Carolina, we know how CMS expects Providers to document progress towards goals in the rehabilitation plan. They expect a progress note for every encounter. CMS imposed a daily note requirement on Psychosocial Rehabilitation (PSR) programs last year, claiming that this was not new, but a long standing requirement that most states have failed to meet. They stated that they are now "cracking down on states to comply" and will expand this "crackdown" to other states as their State Plans are reviewed. CMS officials failed to explain how the state was at fault, when CMS has allowed monthly documentation for PSR services in North Carolina for over 17 years. Didn't CMS have to approve our State Plan?

I can not state this strongly enough. A progress note requirement for every encounter is an unnecessary and major burden, especially for services, like PSR, that are delivered to groups. This requirement has rendered our service record useless. The record can no longer be used to track the course of services being provided or for any clinical purpose due to the sheer volume of notes. Instead of producing 115 progress notes per month, Adventure House professional staff must now write over 2,000 notes per month, at a cost of $35,000 per year.

WE STRONGLY RECOMMEND that progress notes be required on a monthly basis, leaving it to the Provider to make more frequent notes in cases where that may be appropriate!!

Sincerely,



Tommy Gunn, M.S.
Executive Director

cc:
Mike Leavitt, U. S. Secretary of the Department of Human Services
Mike Easley, North Carolina Governor

U.S. Senator Richard Burr
U.S. Senator Elizabeth Dole
U.S. Representative Sue Myrick
U.S. Representative Patrick McHenry
Senator Nesbitt, Co-Chair of the N. C. Legislative Oversight Committee
Rep. Verla Insko, Co-Chair of the N. C. Legislative Oversight Committee
NC Rep. Debbie Clary
NC Rep. Tim Moore
Dempsey Benton, N.C, Secretary of the Department of Human Services
Mike Mosley, Director of the N.C. Division of Mental Health
Leza Wainwright, Deputy Director of the N.C. Division of Mental Health
William Lawrence, Jr., Director of the N.C. Division of Medical Assistance
Tara Larson, N.C. Division of Medical Assistance
Jo Perkins, N.C. Division of Vocational Rehabilitation
Carl Britton-Watkins, Chair of the N.C. Consumer Family Advisory Committee
Debra Dihoff, Director, NC-Alliance for the Mentally Ill
John Tote, Director, Mental Health Association of NC
Yvonne Copeland, NC Council of Community Programs
Tisha Gamboa, Director, N.C. Mental Health Consumer Organization
Joel Corcoran, Director, International Center for Clubhouse Development
Renee Gray, Director, Cleveland County Mental Health Association
Rhett Melton, Director of Pathways (LME)
Regina Moody, Chair Local Provider Association
Adventure House Board of Directors

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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

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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).

<u>Elimination of FFP for habilitation services provided under the rehab and clinic options</u>: 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.

<u>Discriminatory and arbitrary exclusion from receiving many rehabilitative services for people with mental retardation and related conditions:</u> 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

269-D 10/10/07

To Whom it may concern:
I am writing about the notice of proposed rulemaking (NPRM) with respect to Medicaid coverage of rehabilitative services, published in the Federal Register on August 13, 2007. I am writing to urge you to oppose the provisions related to excluded federal financial participation (EFP) for habilitation services and urge you to withdraw this proposed law.
I have been working at Riverside Industries, Inc. in Easthampton, MA for 1 1/2 year and came to discover how important this place can be for many individuals w/ mental retardation or other conditions. Rehabilitation services is so important

for the individuals. It's not only receiving direct therapies from the services, but it also becomes a workplace, learning place, and many more. Habilitations services has become a daily routine and a major part of their lives. Eliminating these wonderful services and places for certain individuals you will be ruining many lives.

Once again, I strongly oppose the proposed rules.

Thanks for listening and understanding

Angelina Roman

210-0

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. Proposed Regulations on Coverage for Rehabilitative Services.

Dear Sir or Madam:

The National Alliance on Mental Illness (NAMI) is grateful for the opportunity to comment on the proposed rules regarding coverage for rehabilitative services under the Medicaid program. With 1100 affiliates, NAMI is the nation's largest grassroots organization representing individuals living with serious mental illnesses and their families. Many of our members have personally experienced the effectiveness of rehabilitation services and have been able to live, work and participate in their communities as a direct result of these services.

Research confirms that individuals with serious mental illnesses who receive rehabilitation services achieve better outcomes, such as stable housing and employment. They also experience fewer hospitalizations and less involvement with the criminal justice system. Yet, despite these well documented findings, these services remain out of reach for the vast majority of individuals with mental illnesses and their families.

NAMI conducted a survey of the 50 state mental health agencies and found that evidence-based practices funded by Medicaid under the rehabilitation services option were woefully inadequate in the states. In our 2006 *Grading the States* report, the average state grade was a D. For every poor grade NAMI gave, we know that there are hundreds of thousands of individuals who are being jailed, living on the streets or dropping out of school because they were unable to access the services that we know work. For this reason, we are particularly concerned that any new regulations governing rehabilitation services facilitate the provision of these services and in no way discourage systems and providers from increasing the availability of these critical services. Many of our members are very troubled by the estimate in the proposed regulation that these rules would remove 2.2 billion dollars from an already under-resourced service system.

NAMI is very appreciative of the effort in the proposed rules to encourage states to use rehabilitative services to meet the goals of the New Freedom Commission. We particularly agree with the quote from the Commission referenced in the preamble to the rules, "[m]ore individuals would recover from even the most serious mental illnesses and emotional disturbances if they had earlier access in their communities to treatment and supports that are evidence-based and tailored to their needs."

We believe that the emphasis on recovery and person-centered planning and the inclusion of the individual, their families and other individuals in treatment planning is a very positive development that will further improve access to treatment. However, other sections of the proposed regulations have the potential to frustrate the ability to engage individuals in the process of recovery and provide evidence based and tailored services. We are particularly concerned about the prohibition on billing for services that may maintain a person's functioning and the broad exclusion of services that are "intrinsic" to other programs. We will describe these concerns in greater detail below.

Overall, NAMI believes that a system of rehabilitative services must follow these principles:

- Services should attain a high degree of accessibility and effectiveness in engaging and retaining persons in care.
- The effects of these services shall be sustained rather than solely crisis-oriented or short-lived.
- Services must be age and gender appropriate, culturally competent, and attend to trauma and other factors known to impact on one's recovery.
- Whenever possible, services should be provided within the person's home and/or community, using the person's natural supports.

Specific comments on sections of the preamble and regulations follow:

Section 440.130 Diagnostic, screening, preventative, and rehabilitative services.

Section 440.130(d)(1)(iii) – Definition of qualified providers of rehabilitative services

This section provides general requirements for providers of rehabilitative services. While NAMI fully supports choice for consumers of services, we request clarification that schools and other systems could be reimbursed under Medicaid for services provided by employees of that system who meet Medicaid provider requirements. For example, it is often most efficient for schools to hire a therapist or behavioral aide rather than contract with an outside provider. This also allows for proper training and accountability.

Our members report great barriers to coordinating their services and supports so we would like to ensure that the burden is not shifted to consumers and their families to find service providers who will accept Medicaid because other systems such as education are no longer providing someone to give the service. Nothing in the current regulations prohibits schools and other systems from using their own employees, but CMS should clarify in the preamble that such practices are permissible as long as individuals are informed of their choice to seek another Medicaid provider if they wish to do so.

Section 440.130(d)(1)(v) Definition of Rehabilitation Plan

NAMI commends CMS for the emphasis on a person-centered planning process including the individual, the individual's family and others of the individual's choosing. The active participation of the individual is an essential part of the recovery process. In addition, research indicates that recovery is greatly facilitated by support from an individual's family.

NAMI also applauds the requirement that the plan include goals for the rehabilitation services, the services to be provided, and a timeline for assessment of the effectiveness of the provided services. It is important that individuals and their families have clear information about the services that are being made available so they can ensure that the services are actually received. It is also necessary for a treatment plan to have clear goals and for providers and the individual to periodically review whether goals and services need to be altered.

Several of our members have raised concerns, however, about the relationship between a rehabilitation plan and other service plans. CMS should clarify that plans produced by other entities, such as an individualized education plan or provider treatment plan, can be the rehabilitation plan as long as they meet the requirements of Section 440.130(d)(3).

Recommendation:

Add: **The requirement for a rehabilitation plan may be met by a treatment plan, individualized educational plan or other plan if the written document meets the requirements in Section 440(d)(3).**

Section 440.130(d)(vi) Definition of Restorative Services:

The proposed regulation and the preamble indicate that services that provide assistance in maintaining functioning may only be reimbursed as a rehabilitative service when necessary to help an individual achieve a rehabilitative goal. They further clarify that rehabilitative goals must be designed to assist with the regaining or restoration of functional loss. We have received overwhelming feedback from our members regarding their concern with the exclusive emphasis on restoring functioning rather than maintaining functioning. Many of our members describe their personal recovery process as varied, with periods of maintenance as well as periods of restoration. As one NAMI member stated, "recovery is not a linear process trending upward." Instead, consumers and family members describe their illnesses as up, down and stable depending on the period of time. In addition, many times these fluctuations did not depend on the rehabilitation services, but rather on outside events, changes in the course of the illness, or changes in medication effectiveness.

Moreover, our members noted that a person's history and severity of illness could be such that a period where the person is not regressing is meeting a rehabilitative goal. For example, an individual with schizophrenia who has experienced multiple hospitalizations and contacts with law enforcement and who has gained sufficient living skills to maintain

stable housing may need services to continue those skills. Withdrawing services as soon as the person's living skills were sufficiently restored to allow him or her to live in home for a brief period is inadvisable because the person's history and severity of illness indicate that he or she is likely to regress without further support.

Requiring that a person deteriorate before services can be provided is not cost effective For individuals with serious mental illnesses, a break in services and support can lead to a downward spiral and long period of acute illness. Thus, NAMI recommends that the proposed rule be amended to allow provision of rehabilitative services if the rehabilitation plan documents that based on the individual's history and severity of illness, such services are needed to prevent regression. The provider would be required to periodically review whether the history and severity of illness continue to merit rehabilitative services to prevent regression as part of the review of the rehabilitation plan.

Moreover, NAMI recognizes the value of consumer run services such as clubhouses and peer support services. Many of our members find these services to be instrumental in their recovery. These programs also recognize that progress is not always linear and prohibiting services to prevent regression can be a barrier to their ability to serve people in need of services.

CMS has full authority to allow rehabilitation services which will prevent regression or deterioration. Section 1901 of the Medicaid Act clearly authorizes expenditures for rehabilitation and other services to help families and individuals "attain and **retain** capability for independence and self-care."(emphasis added).

In addition, NAMI commends CMS for specifying that rehabilitative services enable an individual to perform a function, but the individual is not required to demonstrate that they actually performed the function in the past. This is particularly true for children, who will not necessarily have had the ability to perform a function in the past due to their level of development and acquisition of age appropriate skills. It would be helpful for CMS to further clarify that rehabilitation services may be provided to children to achieve age appropriate skills and development.

Medicaid is a critical funding source for evidence based practices for children with serious mental illnesses. For example, multi-systemic therapy has been funded under Medicaid and has been proven in multiple clinical trials to produce good outcomes for children, including reduced psychiatric symptoms, decreased substance use and abuse, decreased hospitalizations and out of home placements, less contact with law enforcement, and increased school attendance. However, NAMI hears from many of our members regarding their inability to access MST and other services. The proposed regulations should encourage the further dissemination of evidence based services for children by clarifying that rehabilitative services are available to allow children to gain age appropriate skills and development.

Recommendation:

Amend the language of restorative services to add: In these instances, services that provide assistance in maintaining functioning may be considered rehabilitative only when necessary **to prevent regression based on a documented history and severity of illness** or to help an individual achieve a rehabilitation goal defined in the rehabilitation plan.

Secondly, amend the language to add bolded language: Restorative services means services that are provided to an individual who has had a functional loss and has a specific rehabilitative goal toward regaining that function. **For children, this can include services to achieve age appropriate skills and development.**

Section 440(d)(1)(vii) Definition of Medical Services

The proposed regulations provide that medical services are those required for the diagnosis, treatment or care of a physical or mental disorder. It would be helpful to clarify that rehabilitation services include a functional assessment of the individual. It is critical for a provider to attain the correct diagnosis, but our members experiences indicate that individuals with the same diagnosis may have very different rehabilitative goals and services based on their current functional level and their stage of recovery from the illness. Accordingly, we recommend that CMS amend this section to specifically include functional assessment or to indicate in the preamble that such an assessment is part of the meaning of diagnosis. This would provide consistency with later requirements in the proposed regulation for a rehabilitation plan which must be "based on a comprehensive assessment… including diagnosis and presence of a functional impairment in daily living."

Recommendation:

Add bolded language: services that are required for the "diagnosis, **assessment**, treatment or care of a physical or mental disorder…"

Section 440.140(d)(3) Definition of Written Rehabilitation Plan

NAMI commends CMS for requiring a written rehabilitation plan to guide treatment. We support the inclusion of the individual and the individual's family in the development of the rehabilitation plan.

However, NAMI strongly urges additional language to provide needed flexibility to address the nature of mental illness and the current practices in mental health service delivery.

For example, as indicated in our prior comments on restorative services, NAMI encourages language which allows the reevaluation process to determine whether services were effective in preventing regression or deterioration as well as achieving reduction of disability and restoration of functional ability.

We further note that while individuals should always be encouraged to actively participate in treatment planning, rehabilitative services are often required to assist an individual in acquiring the skills necessary to understand the benefits of treatment and begin a recovery process. Assertive community treatment teams (ACT) for example, is an evidence based practice based on an outreach model and a team approach to providing services to individuals with serious mental illness who also have a history of multiple hospitalizations and/or involvement with law enforcement. ACT teams report that they often will need to provide services for a period of time before an individual is ready to sign a treatment plan. However, they can develop the plan and provide services with the goal of developing social and living skills such that the individual is able to more actively participate and sign a treatment plan.

Moreover, the mental health service delivery system is not always coordinated and individuals with serious mental illnesses can move into new communities. It is not uncommon for an individual with serious mental illness to lack sufficient linkages to the community provider system. An individual with a serious mental illness who has been released from jail or the hospital without continuity of care or someone who has recently moved to a new community may experience a crisis and require rehabilitation services such as mobile crisis services. At the point of service, the provider of mobile crisis may not have a treatment plan signed by the individual on file, particularly if that individual was not a previous resident of that community. In addition, an individual in a psychiatric crisis may not be able to actively participate in a treatment plan at that time. If the individual has Medicaid coverage, they should be able to get coverage for this intervention regardless of the fact that these requirements for a written treatment plan could not be met. The proposed regulations should have sufficient flexibility to allow Medicaid financing for crisis stabilization services.

Of course, it is preferable to have a planning process and a crisis plan included in the rehabilitation plan. However, the regulations should have sufficient flexibility to recognize that this will not always be possible.

In addition, a mental health provider does not always have knowledge of alternate providers of the same service and it may be confusing to the individual being served if the provider attempts to give this information. However, the rehabilitation plan should indicate that the person has been given information about any available resource listing alternative providers. We suggest adding language that clarifies this obligation and recognizes that in some circumstances, such as an emergency intervention, it may not be feasible to do so.

Recommendation:

Amend the proposed rule to add bolded language:

(xi) indicate the anticipated provider(s) of the service and **when feasible document that the individual was informed of any available resource for identifying alternate providers of the same service.**

(xiv) … if it is determined that there has been no measurable reduction of disability, **prevention of regression**, or restoration of functional level, any new plan…

(xv) document that the individual or representative participated in the development of the plan, signed the plan, and received a copy of the rehabilitation plan **or document the exigent circumstances which prevented such participation in the development of the plan, signing of the plan and/or receipt of a copy of the plan. Such circumstances may include, but are not limited to, the need to provide services to allow an individual to begin the planning process or to receive services in the event of an emergency or crisis.**

<u>Section 440.130(d)(4) Impairments to be Addressed</u>

The regulation states that services "may address the individual's physical impairments, mental health impairments, and/or substance-related disorder treatment needs." NAMI appreciates the express inclusion of mental health and substance-related treatment needs. However, NAMI is concerned about the explicit omission of developmental disabilities from the list of impairments to be addressed in this section and in other parts of the rule and preamble. NAMI believes that a categorical exclusion of a particular disability is disability-based discrimination and should not be included in the proposed regulations. We urge CMS to allow all individuals regardless of disability to be eligible to receive rehabilitative services if the requirements for provision of the service are met.

Recommendation:

Amend to add bolded language: may address the individual's physical **or mental** impairments, mental health impairments, and/or substance-related disorder treatment needs."

<u>Section 440.130(d)(5) Settings</u>

This section of the regulation can be very helpful in reinforcing that rehabilitative services may be provided in natural settings and build upon natural supports. However, NAMI urges CMS to revise the preamble language which gives states the authority to determine the setting for the service. Rehabilitation services should be available in whatever setting will yield the best results and the appropriate setting should be determined as part of the rehabilitation planning process with input from the individual with mental illness and his or her family.

We also recommend adding to the settings listed in the proposed regulations to clarify that rehabilitative services can be provided in setting such as schools, workplaces and in the community. Assertive community treatment and mobile crisis, for example, often take place in the community and outside of a home or facility. The preamble includes some of these settings, but it would be helpful to also have them in the regulation itself.

Recommendation:
Delete section of the preamble granting states the authority to determine the setting.

Add to the list of settings: ... **school, workplace, foster home, group home, mobile crisis vehicle, community mental health center, substance abuse treatment setting, community setting** and other settings.

Section 441.45 Rehabilitative Services

Section 441.45(a)(1) – Assurance of compliance with other federal regulations

NAMI appreciates the specific inclusion of these regulatory requirements. However, it would be helpful to also include the regulatory and statutory requirements of Early and Periodic Screening, Diagnosis and Treatment Services (EPSDT), which mandate that Medicaid beneficiaries under the age of 21 must receive all medically necessary services to ameliorate or correct a physical or mental condition regardless of whether the services are included in a state's Medicaid plan. 42 U.S.C. Section 1396d(r)(5) and 42 C.F.R. Section 440.40(b).

EPSDT is a critical requirement for children with mental illness who require rehabilitative services to facilitate their recovery and full participation in their schools and communities. States should be required to ensure that nothing in their implementation of these regulations will compromise the mandate in the EPSDT provisions.

Recommendation:

Add bolded language: **and 440.40(b)** of this chapter and **42 U.S.C. Sections 1396d(r)(5) and 1396a(a)(43).**

Section 441.45(a)(5)(iii) Specifies the methodology under which rehabilitation providers are paid.

As states submit state plan amendments on rehabilitation services, NAMI strongly urges CMS to allow maximum flexibility in payment methodology to support evidence based practices. As the preamble notes, the President's New Freedom Commission determined that more adults and children with serious mental illnesses would recover if they had access to evidence based treatment. NAMI's research indicates that there are critical shortages of these services in all states. CMS should ensure that its policies facilitate providing more access to effective services such as Assertive Community Treatment, Multi- Systemic Therapy and Therapeutic Foster Care.

Many states find it administratively efficient to combine services provided in these evidence based treatment programs, a practice commonly known as "bundling." Services can be bundled into a case rate, daily rate or similar arrangement. This allows a provider to predict revenue and facilitates its ability to hire the extensive teams of individuals

required to provide these services with fidelity to the model. ACT services, for example, will often be provided by a 10 member team, including nurses, a psychiatrist, a peer specialist, a substance abuse specialist and others. Numerous research studies have confirmed that good outcomes are dependent on fidelity to the model, including the active participation of a full team. States should be given the flexibility to choose the method that they believe will best allow them to ensure fidelity to the evidence based practice and replication throughout the state.

While CMS's goal of ensuring that Medicaid is not paying for non-rehabilitative services is laudable, this objective can be achieved by examining the services that are combined in the bundled rates. States should be required to explain their rate setting methodology, but they should not be arbitrarily prohibited from using bundling methodologies that are efficient and essential to significant expansion of the availability of the evidence based services. CMS allows managed care arrangements that use similar methodologies and should be consistent in its review of state rehabilitation plan amendments.

Recommendation:

In reviewing state plan amendments, CMS should allow states flexibility in rate setting methodologies. If there are concerns about the services that are provided within a bundled rate methodology, CMS should review the state's documentation of the specific services they intend to provide within the combined rate.

<u>Section 441.45(b)(1) Services that are excluded from rehabilitation, including those that are intrinsic elements of other programs</u>

NAMI strongly urges CMS to strike this section of the regulation because these provisions create an ambiguous standard that states and beneficiaries will be unable to apply. The preamble and the regulation give no guidance on how to determine if a service is an intrinsic element of programs other than Medicaid. Individuals with mental illnesses, their families, and state policymakers will not be able to determine what is intrinsic to other programs and this lack of clarity undermines the integrity of the Medicaid program.

Moreover, the ambiguity of the proposed regulations places states in an untenable position. They can either forego federal funds that they may be entitled to or they can bill Medicaid and risk an audit and the eventual loss of state dollars. For Medicaid to operate successfully as a state-federal program, the terms and conditions of the relationship and what can be provided must be clear and readily applied by states.

Furthermore, the current language in the proposed rule can be read to disallow rehabilitative services that are furnished through a non-medical program as either a benefit or an administrative activity, including those that are intrinsic elements of other programs. However, under the Medicaid statute, a Medicaid eligible individual who resides in a state that has chosen the rehabilitation option is entitled to rehabilitative services paid for by Medicaid regardless of their participation in another program. The

proposed language in Section (b) (1)(i) regarding therapeutic foster care acknowledges this distinction and provides an exception for "medically necessary rehabilitation services for an eligible child." This language should be included in Section (b)(1) to clarify the agency's intent.

Clarifying language is particularly important for children, who are entitled to Early and Periodic Screening, Diagnostic and Treatment Services (EPSDT). As previously noted, this mandate requires that children receive all necessary services to correct or ameliorate a physical or mental condition, regardless of whether the service is covered under the state Medicaid plan. *See* 42 U.S.C. Section 1396d(r)(5). Thus, Medicaid eligible children are entitled to all rehabilitative services necessary to ameliorate a physical or mental condition such as mental illness. This clear mandate also applies regardless of whether the rehabilitative service is intrinsic to another program or is furnished as a benefit or administrative activity of another program.

Finally, third party liability rules under Medicaid have recognized that states have an obligation to determine if another entity is legally liable for payment of the services. If CMS is unwilling to strike the language, the proposed regulations should be clarified such that services are only excluded if the other program has a specific legal obligation to pay for services to a specific Medicaid recipient. Programs that are financed by capped or discretionary appropriations from state or local entities should be specifically excluded from these provisions.

NAMI believes that if this language is unchanged, it will have a devastating effect on the ability and willingness of other programs to provide quality treatment to adults and children with serious mental illnesses. These other programs are often operating with little resources and growing need. If they are denied Medicaid resources to pay for the treatment for individuals with mental illnesses, some are likely to fail to provide needed services and others may refuse to serve individuals with mental illnesses.

Moreover, the ambiguity inherent in the language of the proposed rule will discourage the dissemination of evidence based practices in these other programs. NAMI is just beginning to see child welfare, juvenile justice and corrections programs that serve large numbers of adults and children with serious mental illnesses recognize the value of these mental health interventions and coordinate with the mental health system to adopt such practices. Research clearly shows that this coordination leads to better outcomes. The proposed rule should facilitate and not impede such progress.

Finally, the President's New Freedom Commission report decried a fragmented service system that denied hope and opportunity to adults and children with serious mental illnesses. They wrote:

> The promise of the New Freedom Initiative-a life in the community for everyone-can be realized. Yet, for too many Americans with mental illnesses, the mental health services and supports they need remain fragmented, disconnected and often inadequate, frustrating the opportunity

for recovery. Today's mental health care system is a patchwork relic-the result of disjointed reforms and policies. Instead of ready access to quality care, the system presents barriers that all too often add to the burden of mental illnesses for individuals, their families, and our communities.

NAMI strongly urges CMS to reconsider the current language in this section of the proposed rule which furthers fragmentation by discouraging other systems from offering treatment to individuals with serious mental illnesses. NAMI is deeply concerned that this provision will move us in the wrong direction at a time when states are showing progress in moving toward systems' coordination.

Recommendation:
Strike Section 441.45(b)(1).

If CMS is unwilling to strike this section, add:

"including services that are intrinsic elements of programs other than Medicaid [list of programs], **except for services which are medically necessary rehabilitation services for an eligible individual.**

And add: **This exclusion will only apply if the programs other than Medicaid are legally liable to provide the services to a specific Medicaid eligible individual. Discretionary appropriations do not constitute legal liability to a specific individual.**

<u>Sections 445(b)(i) and (ii) Exclusion of Therapeutic Foster Care Services</u>

Therapeutic foster care, also known as treatment foster care (TFC), has a strong evidence base supporting its effectiveness for children with serious mental illness. Trained parent/providers work with youth in the treatment home to provide a structured and therapeutic environment while enabling the youth to live in a family setting. These services are effectively used to avoid out of home placement and more trauma to the child and family. Moreover, this intervention has been proven in multiple clinical trials to improve functional behavior, reduce contact with law enforcement, and decrease hospitalization and out of home placements.

As part of the President's Executive Order on Community Based Alternatives for People with Disabilities, the President ordered federal agencies to review their policies and regulations "to improve the availability of community-based services for qualified individuals with disabilities" and promote the integration of adults and children with disabilities in their local communities. The proposed language in these sections should be altered to facilitate the provision of treatment foster care so children with mental illnesses can continue to live in the community, rather than in more costly residential and hospital settings.

The preamble to the regulation indicates that CMS is promulgating this regulation because some states have packaged services within therapeutic foster care which are not

medically necessary rehabilitative services. CMS should clarify in the regulation that states may only provide medically necessary rehabilitative services as part of any bundling of services, but should allow states to use a case rate, daily rate or other arrangement as long as the services included in that rate are medically necessary rehabilitation services.

Recommendation:

Revise these sections to read:

(i) **Services that are packaged as part of therapeutic foster care services which are not medically necessary rehabilitation services for an eligible child. States are permitted to package medically necessary rehabilitation services to provide therapeutic foster care to an eligible individual child.**

Section 445(b)(1)(iv): Exclusion for Teacher Aides

NAMI urges CMS to clarify that the language regarding school services does not apply to behavioral health aides and other mental health providers who address a child's functional impairments which interfere with his or her ability to learn. Mental health providers in the schools play an essential role in allowing children to develop into productive, independent adults and the proposed regulations should encourage the provision of these services. The New Freedom Commission called for schools to play a far greater role in effectively addressing the mental health needs of students and NAMI recommends amending this provision to ensure consistency with that call to action.

Recommendation:

Add: Routine supervision and non-medical support services provided by teacher aides in school setting (sometimes referred to as "classroom aides" and "recess aides"), **however this exception shall not apply to behavior aides and other related service providers in the classroom that are designated to address a specific child's functional impairments and to provide rehabilitative services for that child.**

Section 445(b)(2): Exclusion of habilitation services

As previously noted, NAMI is concerned about policies that exclude a particular disability or group of disabilities from eligibility for a Medicaid service. Individuals with mental retardation and related conditions, such as cerebral palsy, appear to be categorically excluded in this proposed regulation from rehabilitation services.

In addition, in Section 6411(g) of the Omnibus Reconciliation Act of 1989 (OBRA 89), Congress required that a final regulation specify the type of habilitation services to be covered. This Congressional directive does not contemplate complete exclusion of the services from coverage under the rehabilitation option.

Recommendation:

Delete the categorical exclusion for habilitation services. Additionally, delete the categorical exclusion of people with mental retardation and related conditions from eligibility for rehabilitation services.

Section 445(b)(3): Exclusion for recreation or social activities that are not focused on rehabilitation.

NAMI applauds CMS's statements in the preamble that specifically note that "for an individual with a mental illness, what may appear to be a social activity may in fact be addressing the rehabilitative goal of social skills development as identified in the rehabilitation plan." We also appreciate earlier clarification that an activity that may appear to be recreational may be rehabilitative if it is addressing a particular impairment and functional loss. NAMI urges CMS to include this clarifying language in the regulation itself in addition to the discussion in the preamble.

We also urge CMS to clarify that personal care services that are performed to teach the individual some independent living skills are coverable services. For individuals with mental illness, modeling and cuing are often used to teach these skills and personal care services may be provided as part of the process in furtherance of the rehabilitation goal. The purpose of the service is to achieve a rehabilitative goal, rather than to provide personal care to the individual. The preamble recognizes this distinction by specifying that teaching an individual to cook a meal to re-establish the use of her or his hands or to restore living skills may be a coverable rehabilitation service. It would be helpful to provide that clarification in the regulation as well.

NAMI further urges CMS to clarify that supportive services furnished to address rehabilitative goals may be provided in community settings, including employment and academic settings or in the context of preparing to enter employment or academic settings as long as the primary purpose of the services is to achieve a rehabilitative goal rather than to assist the person with gaining employment or education. Employment and education settings or contexts can be therapeutic because the individual must interact or prepare to interact with others and manage symptoms in an increasingly challenging environment. As long as the service is directed at achieving the rehabilitative goal rather than retaining a job or furthering an education, the services should be reimbursable as rehabilitation services.

Recommendation:

Add: **Recreational and social activities that are addressing a particular impairment or functional need, such as social activities addressing a goal of social skills development, are reimbursable as rehabilitation services.**

Add: **Services, however, that are directed at achieving a rehabilitative goal may be provided in the context or setting for work or education if the purpose of the service**

is to address a functional impairment rather than to assist with employment or academic enhancement.

Add bolded language: Personal care services, **except for those which are furnished to teach a skill in furtherance of a rehabilitative goal.**

Section 441.45(b)(4): Exclusion of services provided by public institutions.

This section of the proposed rules restates current law with respect to public institutions. NAMI appreciates the language stating that "rehabilitative services could be reimbursed on behalf of Medicaid-eligible individuals paroled, on probation, on home release, in foster care, in a group home, or other community placement..."

The language, however, also states that such community services cannot be "part of the public institution system." NAMI strongly urges CMS to strike the word "system" to be clear that community services which are rehabilitative are reimbursable regardless of whether a child or adult remains part of the juvenile justice or correctional system. This is particularly important for rehabilitation services that are provided in the community while the youth or adult with mental illness is still under the auspices of the correctional system, such as mental health services in a group home for children who are under juvenile court jurisdiction or forensic assertive community treatment for adults who are still in the corrections system. This clarification is very important given the large numbers of youth and adults with mental illnesses who come under the jurisdiction of these systems. It is consistent with other sections of the preamble and regulation which recognize that involvement in other programs does not affect Medicaid eligibility for services.

NAMI also strongly urges deletion of language indicating that community services can only be reimbursable if they are not used in the administration of other non-medical programs. This language is ambiguous and the preamble gives no guidance to determine whether services are used in the administration of a non-medical program. NAMI believes that a Medicaid eligible individual should receive rehabilitative services if medically necessary to address a functional impairment regardless of any involvement in another program. This point is included in the preamble language noting "enrollment in these non-Medicaid programs does not affect eligibility for Title XIX services." NAMI seeks similar language in the final regulation.

Recommendation:
Strike the following language: ... that are not part of the public institution ~~system~~, when the services are identified due to a medical condition targeted under the State's Plan, ~~are not used in the administration of other non-medical programs.~~

Section 441.45(b)(8): Exclusion of services that are not provided to a specific individual.

NAMI applauds the discussion in the preamble recognizing that "effective rehabilitation of eligible individuals may require some contact with non-eligible individuals." The

preamble further explains that counseling sessions for the treatment of the child may include the parents or other non-eligible family members and concludes that "contacts with family members for the purpose of treating the Medicaid eligible individual may be covered under Medicaid."

NAMI appreciates this recognition of the importance of family relationships in supporting recovery. Recent research studies have confirmed that family support leads to better outcomes from treatment. NAMI urges CMS to amend the rule to add language from the preamble to be clear on this point.

Recommendation:

Add: **Contacts with and services to family members and other non-eligible individuals for the purpose of treating the Medicaid eligible individual may be covered as a rehabilitative service.**

Thank you for the opportunity to comment on the proposed regulations. We appreciate your consideration of our recommendations.

Sincerely,

HELENE AND SANFORD JONES