Submitter : **Mrs. Linda Quinet** **Date: 09/29/2007**

Organization : **NAMI**

Category : **Individual**

Issue Areas/Comments

Background

Background

I am very troubled by the estimate in the rule that would save the federal government 2.2 billion dollars. Creating barriers to services will not save money in the long run. Rather, it will increase the costs from hospitalization, incarceration and other bad outcomes that result from a failure to get needed treatment. I am the mother of a mentally ill son in prison, resulting largely from lack of services and a member of NAMI for many years. His having been in prison nearly half his life without meaningful treatment only exacerbates the problem. But the system all too often handles it this way.

Policy needs to make it clear that the federal government encourages any state system to do all they can to provide effective treatments to people with serious mental illnesses.

There are good points, such as family participation and encouragement of communication between providers, the individual and family members. However, these changes are recommended.

GENERAL

GENERAL

See attachment

CMS-2261-P-190-Attach-1.TXT

CMS-2261-P-190-Attach-2.RTF

#190

September 27, 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.

I am very troubled by the estimate in the rule that would save the federal government 2.2 billion dollars. Creating barriers to services will not save money in the long run. Rather, it will increase the costs from hospitalization, incarceration and other bad outcomes that result from a failure to get needed treatment. I am the mother of a mentally ill son in prison, resulting largely from lack of services and a member of NAMI for many years. His having been in prison nearly half his life without meaningful treatment only exacerbates the problem. But the system all too often handles it this way.

Policy needs to make it clear that the federal government encourages any state system to do all they can to provide effective treatments to people with serious mental illnesses.

There are good points, such as family participation and encouragement of communication between providers, the individual and family members. However, these changes are recommended.

Recommended changes:

Section 440.130(d)(1)(v) and 440.130(d)(3) Rehabilitation Plan:

The proposed regulations require that a written rehabilitation plan set out the services that will be provided. The plan is to be written with the involvement of the individual and the family. We very much applaud the agency for including the person and the family in the planning and for encouraging person centered planning.

We would like to see some flexibility in the rules to allow providers to conduct outreach to individuals who may not be ready to be part of a formal treatment planning process. Sometimes, it takes repeated visits before a person is ready and understands how treatment will be a benefit to him or her.

In addition, there are times when a person is in crisis and needs help. At that point, they might not be able to be part of a planning process. If they are new to a community or have recently been in the hospital or jail, they also may not have a treatment plan on record. The rules should allow treatment in these narrow circumstances.

Recommendation:

Clarify the provisions in the regulation to allow payment for outreach and emergency services.

Section 440.130(d)(1) Rehabilitation and Restorative Services:

Under the proposed regulations and the preamble, rehabilitative goals have to be targeted at progress. They can't be used to maintain stability unless that is linked to another goal where they are still working on improvement. But mental illness does not work in a straight line upward. For many of us and our loved ones, the path to recovery is not straight up or down. It is often a process with periods of progress and periods where symptoms may have to be closely managed to prevent deterioration. The changing course of serious mental illness must be factored into the proposed regulations governing rehabilitative services.

For some of us and our family members who have been hospitalized or in jail, staying stable and in housing is not easy and is an achievement. It also requires services so we do not deteriorate and get worse. We hope the agency will adjust its regulations to take into account the nature of our illnesses and those of our family members and allow services to prevent deterioration of the illnesses.

Recommendation:

Revise the proposed rule to allow payment for rehabilitative services to prevent deterioration as well as to restore functioning.

Section 441.45(b) Exclusion of services, including those that are an "intrinsic element" of other programs:

Many adults and children with mental illness and their families are also part of other service systems– including criminal justice, juvenile justice, education, housing, and child welfare. In my community, people with mental illness are overrepresented in these systems and we face major challenges to make sure that people with mental illness do not fall through the cracks.

The proposed regulations could make that challenge much more difficult. We are just starting to see some of these other systems provide the help that people with mental illness need. If these regulations are a barrier to getting federal dollars for some of the costs, then other systems will either stop providing the care or they will stop serving people with mental illness. Either way, people with mental illness and their family members are the ones who will get hurt.

We have reviewed this proposed regulation and the preamble and we do not know how to determine whether something is "intrinsic" to another system. We urge the agency to use terms and factors that are easily understandable by those who use these services and their families as well as state policymakers.

Finally, Medicaid is a program that people rely upon to pay for their care. If Medicaid is required to pay for healthcare services, then it should not matter whether the service is "intrinsic" to another system. It is important that Medicaid remain a reliable source of payment for people.

Recommendation:

Delete all references to other systems and pay for rehabilitative services for individuals with serious mental illnesses when they need them and where they need them.

Section 441.45(b) Exclusions for therapeutic foster care and classroom aides:

Many children with mental illnesses rely upon therapeutic foster care. This is a service that works well and creates good outcomes such as going to school more, staying out of trouble with law enforcement, and living in a stable place. The proposed regulations should give states the ability to get federal resources to support this effective service as long as the services are rehabilitative.

The proposed regulations say that the federal government will not provide resources for recess aides or classroom aides. We believe that the rule also needs to clearly inform schools that Medicaid will pay for behavior aides and other mental health providers who are giving services to a particular child. Children with mental illnesses and their families have been fighting a long battle to get mental heath services provided to children in schools and this regulation should support that effort by clearly encouraging school based mental health services.

Recommendation:

Amend the proposed rule to allow therapeutic foster care and let states combine the services in one rate if that works best for them. The federal government can meet its goals by making sure that the rate only includes rehabilitative services.

Amend the regulation to say that the exclusion does not include behavior aides or other related service providers who are providing services to a particular child.

Section 441.45(b)(2) Exclusion for Mental Retardation and other conditions and Habilitation Services:

The proposed regulations prohibit people with mental retardation or related conditions, like cerebral palsy, to get rehabilitation services. As advocates for one group – people with mental illness – we do not support the exclusion of any other group on the basis of their disability.

We also understand that Congress asked the federal agency to determine which habilitation services to cover. It did not give the agency the option to ban all habilitation services.

Recommendation:

The proposed rules should not exclude people with mental retardation and related conditions and habilitation services.

Linda Quinet
American living in France
Voting state: Connecticut
lquinet@earthlink.net
Mailing address:
41 Morena, Irvine, CA 92612

Submitter : Lisa Feyen **Date:** 09/29/2007

Organization : NAMI Member

Category : Individual

Issue Areas/Comments

Background

Background

Scope of Services - Room and Board
Written rehabilitation Plan - s440.130 (d) (3)
Family inclusion
States limiting the scope of coverage to physical impairment at thier own discretion.

Collections of Information Requirements

Collections of Information Requirements

I am a member of NAMI because I have (along with other things) Bipolar Illness. My min concern, however, is how this act would effect my brother (substance abuse/ bipolar) and his family.

I have more health insurance than a person has a right too, being a veteran of Desert Storm, wife of a soldier that died on active duty, and Medicar receipiant. This is not the case for my brother.

In Feb. of 2006, he was admitted to the hospital for drug overdose. You must understand, our father thought it was "cool" to do cocaine and alcohol with his elementary school age children, and my brother Kevin never recovered from those addictions. He was in a coma for a week, not expected to live. He did recover, and was sent to a rehabilitation facility in a part of the country I no longer live in. I praise the Lord that he lived thier and not in NC where he would not have received that kind of care under our programs. He stayed inpatient for many months, with no money, leaving behind a family to fend for themselves. If, as under this provision, his room and board would not have been covered, just how many individuals would have to go untreated due to lack of funds?

What about his treatment plan, that grew and grew as they discovered all of the mental illness that he was using the drugs to mask? Due to the fact that Kevin and I were introduced to drugs and alcohol in elementary scool and addicts by 12 years of age, Kevin's mental development arrested at age 12. He has seen a child Psychologist since leaving the hospital and will need to for some time to come or will risk a relapse. This, in his case at least, would be life threatening. This is why the one year time limit concerns me so greatly.

It troubles me deeply that under CMS-2261-P States can (and in my opinion will) limit rehabilitaion services to physical impairment only. Research confirms that individuals with serious mental and substance abuse issues who receive rehabilitaion services achieve better outcomes, such as stable housing, employment, and such. They also experiance fewrer hospitilizations 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 illness and thier families.

I would be remiss not to give kudos for a few things that I think I highlights of this Act. Including the whole family and support system is a huge step forward and will help tremendously.

Provisions of the Proposed Rule

Provisions of the Proposed Rule

S440.130(d)(3)- make time limit more flexible, allowing for circumstances.

S1905(a)- include room and board.

Require states to include mental illness and substance abuse in rehabilitation programs- DO NOT ALLOW DISCRIMINATION!

Submitter : **Mr. lawrence gauthier** **Date: 09/29/2007**

Organization : **Mr. lawrence gauthier**

Category : **Individual**

Issue Areas/Comments

GENERAL

GENERAL

My son has been struggling with schizophrenia. Last year, he was hospitalized three times just in December. Only in emergencies does there seem to be adequate care, but it comes at such a high price. Please help us to get him and others like him the treatment, medications, and the rehabilitative services necessary to function productively in society. Thank you.

Submitter : **Mrs. Judith Shujman** **Date: 09/29/2007**

Organization : **NAMI**

Category : **Individual**

Issue Areas/Comments

GENERAL

GENERAL

See attachment

CMS-2261-P-193-Attach-1.DOC

CMS-2261-P-193-Attach-2.DOC

#193

September 27, 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.**

Section 440.130(d)(4) Impairments to be Addressed

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."

Section 440.130(d)(5) Settings

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 1396(d)(r)(5) and 1396a(a)(43).**

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

Each state will be required to submit a state plan amendment on rehabilitation services. NAMI strongly urges CMS to allow states 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.

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

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.**

Sections 445(b)(i) and (ii) Exclusion of Therapeutic Foster Care Services

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,

Judith H. Shujman
P.O. Box 947816
Maitland, FL 32794

Submitter : Ms. Patricia White **Date:** 09/29/2007

Organization : University of Pennsylvania

Category : Nurse

Issue Areas/Comments

Background

Background

see attached

Collections of Information Requirements

Collections of Information Requirements

see attached

GENERAL

GENERAL

"See Attachment"

Provisions of the Proposed Rule

Provisions of the Proposed Rule

see attached

Provisions of the Proposed Rule

Provisions of the Proposed Rule

see attached

Regulatory Impact Analysis

Regulatory Impact Analysis

see attached

Response to Comments

Response to Comments

see attached

CMS-2261-P-194-Attach-1.TXT

#194

September 27, 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.**

Section 440.130(d)(4) Impairments to be Addressed

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."

Section 440.130(d)(5) Settings

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 1396(d)(r)(5) and 1396a(a)(43).**

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

Each state will be required to submit a state plan amendment on rehabilitation services. NAMI strongly urges CMS to allow states 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.

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

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.**

Sections 445(b)(i) and (ii) Exclusion of Therapeutic Foster Care Services

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,

Submitter : Mrs. Elizabeth Berg **Date:** 09/29/2007

Organization : Mrs. Elizabeth Berg

Category : Individual

Issue Areas/Comments

Background

Background

As members of The National Alliance on Mental Illness (NAMI), the nation s largest grassroots organization representing individuals living with serious mental illnesses and their families, we have lived with the experience of mental illness and bring that unique perspective to our comments on these rules.

Access to rehabilitative services makes all the difference -- services to help them recover from their illness. We have also seen the results from untreated mental illness. Often the person will have multiple stays in hospitals and jails. WE ARE VERY TROUBLED BY the estimate in the proposed regulation that these rules would save the federal government 2.2 billion dollars. Our experiences tell us that creating barriers to vital services will not save money in the long run--it will increase the costs from hospitalization, incarceration and other bad outcomes that result from a failure to get needed treatment.

We have a few AREAS OF DEEP CONCERN WHERE WE ASK THE AGENCY WILL RECONSIDER ITS RULES. We would like to see services provided to help prevent deterioration of an individual. We also would like to see other systems encouraged, not discouraged, from providing help to adults and children with serious mental illnesses.

Section 440.130(d)(1)(v) and 440.130(d)(3) Rehabilitation Plan:
Recommendation:
Clarify the provisions in the regulation to allow payment for outreach and emergency services.

Section 440.130(d) (1) Rehabilitation and Restorative Services:
Recommendation:
Revise the proposed rule to allow payment for rehabilitative services to prevent deterioration as well as to restore functioning.

Section 441.45(b) Exclusion of services, including those that are an intrinsic element of other programs:
Recommendation:
Delete all references to other systems and pay for rehabilitative services for individuals with serious mental illnesses when they need them and where they need them.

Section 441.45(b) Exclusions for therapeutic foster care and classroom aides:
Recommendation:
Amend the proposed rule to allow therapeutic foster care and let states combine the services in one rate if that works best for them. The federal government can meet its goals by making sure that the rate only ineludes rehabilitative services. Amend the regulation to say that the exclusion does not include behavior aides or other related service providers who are providing services to a particular child.

Section 441.45(b) (2) Exclusion for Mental Retardation and other conditions and Habilitation Services:
Recommendation:
The proposed rules should not exclude people with mental retardation and related conditions and habilitation services.

Conclusion:
Rehabilitation services can change the course of a person s life. The research data confirms what we already know services are very effective at keeping people out of hospitals and living better lives in the community. We know what works, but too many people can t access these treatments. The federal government should be doing everything possible to encourage states to provide better and more effective services for people living with mental illnesses. We do not want to see billions of dollars taken out of the Medicaid funded system of care for people with mental illnesses. We ask you to revise these regulations to make it clear that the federal government encourages any state system to do all they can to provide effective treatments to people with serious mental illnesses.

Submitter : Shelley Dawn Pawlowski **Date:** 09/29/2007

Organization : National Alliance on Mental Illness [NAMI]

Category : Individual

Issue Areas/Comments

GENERAL

GENERAL

See Attachment

CMS-2261-P-196-Attach-1.TXT

#196

September 27, 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.

Section 440.130(d)(4) Impairments to be Addressed

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."

Section 440.130(d)(5) Settings

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 1396(d)(r)(5) and 1396a(a)(43).

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

Each state will be required to submit a state plan amendment on rehabilitation services. NAMI strongly urges CMS to allow states 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.

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

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.

Sections 445(b)(i) and (ii) Exclusion of Therapeutic Foster Care Services

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,

Shelley Dawn Pawlowski

Submitter : **Mr. Charles Townsend** **Date: 09/29/2007**

Organization : **Mascoma Valley Health Initiative**

Category : **Other Health Care Provider**

Issue Areas/Comments

Background

Background

Proposed Regulations on Coverage for Rehabilitative Services.

Collections of Information Requirements

Collections of Information Requirements

I am writing as Chair of the Board at the Mascoma Valley Health Initiative (MVHI). We work as a non-profit agency to bring programs which assure the health of the publie into our area of New Hampshire. At MVHI we have worked to improve the lives of people living with mental illness. I write also as a person affected by mental illness in a member of my family.

We know from personal experience that access to rehabilitative services can make all the difference in a person s life. We have seen people get services to help them recover from their illness. With services and support, individuals with serious mental illness can and do live very well in the community and have strong relationships with family and friends. We have also seen those who can t get help and have seen the pain and trauma from untreated mental illness for the individual and his or her family. Often the person will have multiple stays in hospitals and jails.

Rehabilitation services can change the course of a person s life. Our experiences tell us what a difference they can make. The research data confirms what we already know services are very effective at reducing symptoms, keeping people out of hospitals, and allowing people to live better lives in the community.

We know what works. But we also know that too many people can t access these treatments. And the terrible consequences are seen in every jail and prison in America.
The federal government should be doing everything possible to encourage states to provide better and more effective services for people living with mental illnesses.
We do not want to see billions of dollars taken out of the Medicaid funded system of care for people with mental illnesses. We do not want to see adults and children ignored and left behind in school, work, and life.

We ask that you revise these regulations to make it clear that the federal government encourages any state system to do all they can to provide effective treatments to people with serious mental illnesses.

Thank you,
Charles Townsend

GENERAL

GENERAL

I am writing as Chair of the Board at the Mascoma Valley Health Initiative (MVHI). We work as a non-profit agency to bring programs which assure the health of the public into our area of New Hampshire. At MVHI we have worked to improve the lives of people living with mental illness. I write also as a person affected by mental illness in a member of my family.

We know from personal experience that access to rehabilitative services can make all the difference in a person s life. We have seen people get services to help them recover from their illness. With services and support, individuals with serious mental illness can and do live very well in the community and have strong relationships with family and friends. We have also seen those who can t get help and have seen the pain and trauma from untreated mental illness for the individual and his or her family. Often the person will have multiple stays in hospitals and jails.

Rehabilitation services can change the course of a person s life. Our experiences tell us what a difference they can make. The research data confirms what we already know services are very effective at reducing symptoms, keeping people out of hospitals, and allowing people to live better lives in the community.

I know what works. But I also know that too many people can t access these treatments. And the terrible consequences are seen in every jail and prison in America.
The federal government should be doing everything possible to encourage states to provide better and more effective services for people living with mental illnesses.
I do not want to see billions of dollars taken out of the Medicaid funded system of care for people with mental illnesses. I do not want to see adults and children ignored and left behind in school, work, and life.

I ask that you revise these regulations to make it clear that the federal government encourages any state system to do all they can to provide effective treatments to people with serious mental illnesses.

Thank you,
Charles Townsend

Response to Comments

Response to Comments

Submitter : Dr. Barbara Meyers **Date:** 09/29/2007

Organization : Mission Peak Unitarian Universalist Congregation

Category : Individual

Issue Areas/Comments

GENERAL

GENERAL

Section 440.130(d)(1)(v) and 440.130(d)(3) Rehabilitation Plan:

The proposed regulations require that a written rehabilitation plan set out the services that will be provided. The plan is to be written with the involvement of the individual and the family. We very much applaud the agency for including the person and the family in the planning and for encouraging person centered planning.

We would like to see some flexibility in the rules to allow providers to conduct outreach to individuals who may not be ready to be part of a formal treatment planning process. Sometimes, it takes repeated visits before a person is ready and understands how treatment will be a benefit to him or her.

In addition, there are times when a person is in crisis and needs help. At that point, they might not be able to be part of a planning process. If they are new to a community or have recently been in the hospital or jail, they also may not have a treatment plan on record. The rules should allow treatment in these narrow circumstances.

Recommendation:

Clarify the provisions in the regulation to allow payment for outreach and emergency services.

Section 440.130(d)(1) Rehabilitation and Restorative Services:

Under the proposed regulations and the preamble, rehabilitative goals have to be targeted at progress. They can t be used to maintain stability unless that is linked to another goal where they are still working on improvement. But mental illness does not work in a straight line upward. For many of us and our loved ones, the path to recovery is not straight up or down. It is often a process with periods of progress and periods where symptoms may have to be closely managed to prevent deterioration. The changing course of serious mental illness must be factored into the proposed regulations governing rehabilitative services.

Recommendation:

Revise the proposed rule to allow payment for rehabilitative services to prevent deterioration as well as to restore functioning.

Section 441.45(b) Exclusion of services, including those that are an intrinsic element of other programs:

Many adults and children with mental illness and their families are also part of other service systems including criminal justice, juvenile justice, education, housing, and child welfare. In my community, people with mental illness are overrepresented in these systems and we face major challenges to make sure that people with mental illness do not fall through the cracks.

The proposed regulations could make that challenge much more difficult. We are just starting to see some of these other systems provide the help that people with mental illness need. If these regulations are a barrier to getting federal dollars for some of the costs, then other systems will either stop providing the care or they will stop serving people with mental illness. Either way, people with mental illness and their family members are the ones who will get hurt.

Finally, Medicaid is a program that people rely upon to pay for their care. If Medicaid is required to pay for healthcare services, then it should not matter whether the service is intrinsic to another system. It is important that Medicaid remain a reliable source of payment for people.

Recommendation:

Delete all references to other systems and pay for rehabilitative services for individuals with serious mental illnesses when they need them and where they need them.

Recommendation:

Delete all references to other systems and pay for rehabilitative services for individuals with serious mental illnesses when they need them and where they need them.

Recommendation:

The proposed rules should not exclude people with mental retardation and related conditions and habilitation services.

Response to Comments

Response to Comments

The National Alliance on Mental Illness (NAMI) conducted a survey of the 50 state mental health agencies for our Grading the States report and found what individuals with mental illness and their family members already know in all the states, there are gaps in services and many people with serious mental illnesses are not getting the help that they need. The average state grade was a D. So we know that there is much work to be done to ensure that people can get the treatment they need when they need it. NAMI members know that treatment works, if you can get it.

As a result, we are very troubled by the estimate in the proposed regulation that these rules would save the federal government 2.2 billion dollars. Our experiences tell us that creating barriers to vital services will not save money in the long run. Rather, it will increase the costs from hospitalization, incarceration and other bad outcomes that result from a failure to get needed treatment.

Submitter : Michael White **Date:** 09/29/2007

Organization : Michael White

Category : Individual

Issue Areas/Comments

Collections of Information Requirements

Collections of Information Requirements

I am an individual who before becoming ill, created hundreds of jobs, earned millions of dollars, and asa result paid "double" social security on myself, and $hundreds of thousands. Despite that, I have ben subjected to humiliating and more importantly limited availability of treatment.

That has precluded me from reentry to the workplace, placing unproductive economic benefit to the economy, and extreme stress to me.

GENERAL

GENERAL

It is such an ignorant and negatively impactfull impact on the economy to deny this group of millions of Americans full access to those things that will promote our reentry into society, that the misinformation propagated to that end is sad.

Regulatory Impact Analysis

Regulatory Impact Analysis

I strongly endorse those components of the legislation which innure to my ability to move my life forward,and those of others

Submitter : Dr. Marion Short **Date:** 09/29/2007

Organization : University of Chicago

Category : Physician

Issue Areas/Comments

Background

Background

Continued availability of care for mental illness can not and should not follow the idea that one gets sick and then one gets better, end of story. Mental illness like other chronic diseases will have periods of instability, plateau periods; care needs to provided that recognizes the nature of mental illness. It is not like a fractured hip!
Having worked in a state correctional unit, the amount of undiagnosed and untreated mental illness is astounding. Accessibility for care needs to reflect an understanding of the illness. Mental illness is not a character flaw, that if you just try real hard not to misbehave....you won't have any problems