

Submitter : Mr. Jorge Arenas
Organization : Mr. Jorge Arenas
Category : Individual

Date: 09/29/2007

Issue Areas/Comments

Background

Background

General Comments, Impact of rulings on service delivery

**Collections of Information
Requirements**

Collections of Information Requirements

People with illnesses deserve appropriate treatment

GENERAL

GENERAL

Local, State, and Federal entities can choose to address peoples' needs as soon as possible. In the case for individuals with mental illnesses governmental entities can choose to fund preventive and maintenance costs or fund jails to warehouse these same individuals. I stongly believe that funding paliative care is a LOT cheaper than funding the building of additional jails and adding burdens on the judiciary/criminal system.

Response to Comments

Response to Comments

Failure to address the populantion's needs only exacerbates the individual's condition thereby increasing the cost to the states and loss of employability thus changing tax payers to supportive services requirements.

Submitter : Mrs. K Baer Burke
Organization : Mrs. K Baer Burke
Category : Congressional

Date: 09/30/2007

Issue Areas/Comments

GENERAL

GENERAL

As the parent of a mentally ill child, I can speak firsthand to the inequity of care available for my son's chronic illness, vs. the care available to one afflicted by 'physical' illness. My son deserves fair and equal care for his disabilities, and his needs will be lifelong. Any attempt to limit his benefits would be immoral. As a civilized and progressive and wealthy society, we owe it to ALL of our citizens to provide the care that they deserve. Anything less is unconscionable.

Submitter : Mrs. Becky Scheidt

Date: 09/30/2007

Organization : DBSA Middletown

Category : Individual

Issue Areas/Comments

GENERAL

GENERAL

see attachment

#203

FILE:///ELECTRONIC%20COMMENTS/ELECTRONIC%20COMMENTS/E-Comments/Active%20Files/Missing%20file1.txt

DEPARTMENT OF HEALTH AND HUMAN SERVICES
CENTERS FOR MEDICARE AND MEDICAID SERVICES
OFFICE OF STRATEGIC OPERATIONS & REGULATORY AFFAIRS

Please note: We did not receive the attachment that was cited in this comment. We are not able to receive attachments that have been prepared in excel or zip files. Also, the commenter must click the yellow "Attach File" button to forward the attachment.

Please direct your questions or comments to 1 800 743-3951..

Submitter : Mr. Robert New
Organization : Mr. Robert New
Category : Academic

Date: 09/30/2007

Issue Areas/Comments

Background

Background

Please do not threaten services!

Collections of Information Requirements

Collections of Information Requirements

Please do not threaten services!

GENERAL

GENERAL

Please do not threaten services!

Provisions of the Proposed Rule

Provisions of the Proposed Rule

Please do not threaten services!

Provisions of the Proposed Rule

Provisions of the Proposed Rule

Please do not threaten services!

Regulatory Impact Analysis

Regulatory Impact Analysis

Please do not threaten services!

Response to Comments

Response to Comments

Please do not threaten services!

Submitter : Ms. Geraldine January

Date: 09/30/2007

Organization : None

Category : Nurse

Issue Areas/Comments

Background

Background

I would like to voice my professional and personal opinion concerning the proposed deletion of 2/2 billion dollars from the rehabilitation option. I worked as a Clinical Nurse Specialist in adult psychiatric mental health for over 30 years. I worked inpatient and outpatient. Improvements in psychiatric outpatient care has come a considerable distance during those years and not without real struggle on the part of patients, staff, families and others. We took people out of hospitals where they'd lived for years. Most did fine without them because intensive psychiatric mental health services were made available to help clients reintegrate into the community.

Assertive community treatment teams (ACT) make a significant difference for most of their clients. They're not homeless as often as ACT can manage their money and teach them how to clean and cook. They have some money to buy clothes and other necessities and can be assisted in purchasing these and other items by ACT. A good ACT teams' clients will have a much lower rate of hospitalization because ACT teams spend an average of 60% of their time with clients and this includes personally monitoring clients taking their medications. ACT teams are very expensive and the ideal ratio of staff to client is 1:5. If you review most states reports on this figure you will not likely see that 1:5 ratio. Instead, it will be an average of 1:10. Twice the number recommended by Stein and Test, the professionals who developed the program and showed such great results with their research. This is why states and the federal government appropriated money to fund ACT teams. ACT teams can help improve a persons' quality of life. They don't have to live in squalor or on the streets. Clients come to develop new friends, some find love and marriage. Most eat better, get better medical care and don't freeze in winter.

States can not afford to take on more of the financial burden than they take right now. Mental illness disables Americans from all races, religious beliefs and social class. It's a national problem for a nation to address. Please do not propose any rules that will cut funding further.

GENERAL

GENERAL

My comments can be found in the Background section.

Submitter : Mrs. Sally Kingsley
Organization : NAMI
Category : Individual

Date: 09/30/2007

Issue Areas/Comments

GENERAL

GENERAL

The seriously mentally ill need the funding for Medicaid. Assertive Community Treatment programs help them to gain skills to work part-time and give them something to hope for in life. Please continue to fund this program and also the community intergrated living arrangements.

I have observed both programs and know first hand how badly they are needed. Our daughter suffers from a serious mental illnes, and because of these programs, she is able to work part-time.

Thank you

Sally Y. Kingsley

Submitter : Mrs. Jane Ward

Date: 09/30/2007

Organization : Mrs. Jane Ward

Category : Individual

Issue Areas/Comments

Response to Comments

Response to Comments

My niece was released because of these rules with 15 different drugs which she used to commit suicide. LONGER rather than shorter times for mental health assessment is needed.

Submitter : Mr. Howard Simms

Date: 10/01/2007

Organization : Meridian Behavioral Health Services

Category : Comprehensive Outpatient Rehabilitation Facility

Issue Areas/Comments

Background

Background

I am concerned for consumers under the definition of Rehabilitation Services. My concern is for consumers who receive services for mental illness such as assertive community treatment (ACT), multi-systemic therapy for children and adolescents (MST) and other important evidence-based services. These consumers when given assistance for mental illness issues who are recovery focused like Meridian Behavioral Health Services is, these same medicaid consumers receive the help to return them to work, live a balanced social life and are less likely to turn to alternative self treatments which would put them at risk in breaking the law. Please carefully review your definitions and do not put at risk the consumers that are receiving mental health recovery services.

Thank you for your attention to this concern!

GENERAL

GENERAL

I have asked those who are considering Medicaid Program; Coverage for Rehabilitative Services definitions to carefully consider any restrictions in the definition for payment by states to Mental Health Providers on behalf of consumers. I am most concerned that these rules may restrict funding for people with mental wellness issues (formerly referred to as mental illness issues.) My concern is that the rules may limit payment for services such as assertive community treatment (ACT), multi-systemic therapy for children and adolescents (MST), and other important evidence-based services. I am concerned that these rules may have a negative impact on the ability of states to pay for these services.

Thank you for your careful consideration!

Before coming to work at Meridian Behavioral Health Services, I was a consumer with Mental Illness Symptoms. Because of the services I have received, I currently have full time employment. I no longer need any financial assistance from any source, other than my job with Meridian. Mental Health consumers need the opportunity for wellness and when given recovery oriented treatment are more likely to not need medicaid assistance in the future.

Bo Simms
Meridian Behavioral Health
154 Medical Park Loop
Sylva, SC 28779
Phone: 828-631-3973 ext. 1469

Submitter : Mrs. Lois Porter

Date: 10/01/2007

Organization : Mrs. Lois Porter

Category : Individual

Issue Areas/Comments

Background

Background

CMS-2261-P - Rehabilitation Services: State Plan Option

GENERAL

GENERAL

i.e. "See Attachment

CMS-2261-P-209-Attach-1.DOC

October 1, 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:

Our family would like to thank you for providing opportunities for individuals with mental illness and their family members to comment on the proposed rule regarding coverage for rehabilitative services under the Medicaid program. As members of The National Alliance on Mental Illness (NAMI) we try to keep abreast of issues, items and proposals regarding individuals living with serious mental illness.

As it is our loved one has had many gaps in services and supports that have led to extreme depreciation of a quality life. In and out of treatment, programs and then movement into the system of criminal justice at times has brought about suffering, near death, pain and a question as to recovery from all the set backs.

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. Our family member falls into this category. However, many, many times that could have easily been avoided if the services and supports were in place based on the recommendations of the experts, not the issues such as moving from adolescent to adult services or from treatment center, jail and even prison. When we experienced periods of time where services were seamless and provided the success of living within the community was truly evident. But, the stops and gaps sabotaged progress and maintenance of a quality life for our son.

Our extended family participate in the process and also provide as much funding and services as possible, based on our skills and financial resources. It is evident that with mental illness, which is a life long illness that is documented, the obvious thought of "pay now or pay later" comes to focus. It is hard to understand the systemic approach that appears to be in place at the current time. That approach is "a little here and a little there" which results in major expense at times that is massive. Hospitalizations, diagnosing the illness over and over again, jail and prison time, courtroom expenses, support services during all of that and the fact that they are not contributing to the community because the

gaps leave them unstable seems unwise and unproductive for our great country. We have the knowledge, we have the funds, but we don't have the commitment and the plans turning into true seamless delivery of services at the local level, where it happens.

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. Once again, 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.

For example, our son who was a very young adult was sentenced to time in prison. He was placed with men who had very long and life sentences, a history of violent behavior and the end result was a multiple stabbing that nearly took his life and has added post traumatic stress syndrome to his menu of diagnosis. Please stop this madness. Mental illness is just that, an illness. Treatment and rehabilitative services is a priority for all other illnesses.

We appreciate the emphasis on recovery in the rules. All individuals with mental illness and their families want the system to make it easier to recover. We also like the provisions about the participation of the individual and their family in the rehabilitative plan and receiving copies of the plan so we can hold the system accountable. We would like to see some flexibility to make sure that providers can still do outreach and provide crisis care, but we very much appreciate the agency's intent to encourage communication between providers, the individual and family members.

However, we have a few areas of deep concern where we hope 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:

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. In fact, the planning process for pre release from programs, jails and prisons should be carefully designed in order to enhance success.

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 health 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.

Conclusion:

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,

Lois and Tom Porter

Submitter : Ms. Traci Olivas
Organization : NAMI Member
Category : Individual

Date: 10/01/2007

Issue Areas/Comments

Background

Background

See my Attachment

Collections of Information Requirements

Collections of Information Requirements

See Attachment

GENERAL

GENERAL

See Attachment

Provisions of the Proposed Rule

Provisions of the Proposed Rule

See Attachment

Provisions of the Proposed Rule

Provisions of the Proposed Rule

See attachment

Regulatory Impact Analysis

Regulatory Impact Analysis

See Attachment

Response to Comments

Response to Comments

See Attachment

CMS-2261-P-210-Attach-1.DOC

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:

Thank you for providing opportunities for individuals living with mental illness and their family members to provide comments on the proposed rule regarding coverage for rehabilitative services under the Medicaid program. I am writing as a member of The National Alliance on Mental Illness (NAMI), the nation's largest grassroots organization representing individuals living with serious mental illnesses and their families. As members of NAMI, we have lived experience with mental illness and bring that unique perspective to our comments on these rules.

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.

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.

We appreciate the emphasis on recovery in the rules. All individuals with mental illness and their families want the system to make it easier to recover. We also like the provisions about the participation of the individual and their family in the rehabilitative

plan and receiving copies of the plan so we can hold the system accountable. We would like to see some flexibility to make sure that providers can still do outreach and provide crisis care, but we very much appreciate the agency's intent to encourage communication between providers, the individual and family members.

However, we have a few areas of deep concern where we hope 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:

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 health 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.

Conclusion:

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,

Submitter :**Date: 10/01/2007****Organization :****Category : Other Health Care Provider****Issue Areas/Comments****GENERAL****GENERAL**

I am writing to comment on the notice of proposed rulemaking (NPRM) with respect to Medicaid coverage of rehabilitative services that was published in the Federal Register on 8-13-07.

I strongly oppose the provisions related to excluded federal financial participation for habilitation services. I urge you to withdraw this proposed rule. As a human service professional who has worked with developmental disabled and Mentally retarded individuals for over thirty years, I know that this proposed rule would severely harm people with intellectual and other developmental disabilities in two major ways: it eliminates longstanding programs for providing day habilitation services to people with developmental disabilities and it imposes a discriminatory and arbitrary exclusion from receiving many rehabilitation services for people with mental retardation and related conditions.

Elimination of FFP for habilitation services provided under the rehab and clinic options: We believe that this proposed restriction contradicts the intent of Congress to protect access to day habilitation services to people with developmental disabilities when it enacted the Section 6411 (g) of the Omnibus Budget Reconciliation Act of 1989, P.L. 101-239. In enacting the provision of law, Congress clearly was intending to protect access to day habilitation programs for people with mental retardation and related conditions.

Furthermore, the preamble to the proposed rule states that the Secretary intends "to work with those states that have habilitation programs under the clinic services or rehabilitative services benefits under their state plans to transition to appropriate Medicaid coverage authorities, such as section 1915(c) waivers or Home and Community-Based Services State plan option under section 1915(i)." I take issue with the assertion that these are more appropriate coverage authorities. In particular, waiver programs operate as discretionary alternatives to their core Medicaid programs, which operate under their state plan. I believe that states should have the flexibility to continue to operate habilitation programs under the longstanding state plan. In section 1915(c), waiver programs require individuals to meet a nursing facility level of care requirement, something which is not required for rehab or clinic services. Further, the 1915(c) and 1915(i) coverage authorities have different financial eligibility standards. Most significantly, these coverage authorities do not extend an enforceable entitlement to services. Enrollment caps will be enacted under the waiver program. It should be noted that historically waiver programs have long and large waiting lists that can extend beyond two years in some cases. (Kaiser Commission on Medicaid and the Uninsured, 2006).

I strongly recommend that the propose exclusion of FFP for habilitation services under the clinic and rehab options not be implemented. This is discriminatory and arbitrary. Section 441.45(b)(2) states "including services provided to individuals with mental retardation and related conditions." This population exclusion violates a fundamental principle of Medicaid, that medical assistance provided to one Medicaid beneficiary shall not be less in amount, duration, and scope that the medical assistance made available to any other Medicaid beneficiary (see section 1902(a)(10)(B) of the Social Security Act). We urge the Secretary to rescind this constraint on rehab option services that so blatantly stigmatize and discriminate against people with intellectual and other developmental disabilities.

In short, I strongly oppose the proposed rulemaking by CMS that requires Massachusetts to move day habilitation services from the state plan to the Home and Community-Based waiver services. Such a move will have devastating effects on the thousands of people with intellectual and developmental disabilities.

Submitter : Mr. Charles Lynn

Date: 10/01/2007

Organization : Pathways Clubhouse, Adult and Child Center

Category : Individual

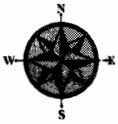
Issue Areas/Comments

GENERAL

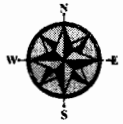
GENERAL

See attachment

CMS-2261-P-212-Attach-1.DOC



PATHWAYS CLUBHOUSE
A Part of: ADULT&child



December 4, 2007

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

To Whom It May Concern:

I am submitting the following opinion in response to the recent request for comments on the Proposed New CMS Rules on Medicaid Rehabilitation Services.

The recent changes in practice by CMS and the associated proposed rule changes published on August 13, 2007 are having a dramatically negative effect at the local level in many states and threaten to do the same throughout the country. The effect of the rule changes may be well intentioned but in practice they will create a situation where medically necessary services and supports will be eliminated for some of this country's most vulnerable citizens – those with severe and persistent mental illness.

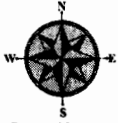
Although these rule changes may be appropriate for people with physical rehabilitative needs, according to a recent NAMI publication, 73% of people receiving Medicaid rehabilitative services have mental health needs. People with long term mental illness have a very distinct set of long term needs, for a wide array of supports; these are quite different from the needs of others requiring rehabilitative services, and must be funded differently. The dramatic shift of mental health funding to Medicaid has diminished the flexibility for states to provide the needed community services to people with mental illness.

Some of the proposed rule changes simply reduce this population's access to needed services - without any back up plan to fund services or programs. Many of these services have been working effectively with CMS approved Medicaid funding for more than ten years, However, with the recent changes in CMS practice, they now find that they are no longer able to provide the crucial support network that people with serious mental illness so desperately need. The net result is that vast numbers of people with persistent mental illness are being deprived of a chance to build a meaningful future for them.

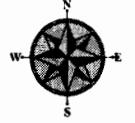
To create, or suddenly start enforcing, bureaucratic clinical and administrative processes without additional or alternative funding from states is the equivalent of a substantial cut in services for people who already have more than their fair share of burdens. A reduction or elimination of services puts individuals with severe and persistent mental illness at risk of unnecessary institutionalization in our hospitals or even worse in our prison system.

One example of the inappropriateness of these changes in funding programs for people with mental illness is the emphasis on returning a person to 'previous levels of functioning.' Because recovery from mental illness is often a long term process, this definition will likely reduce or eliminate many necessary psychosocial rehabilitation type services and supports.

Although I wholeheartedly support the idea of "person centered" services and rehabilitation plans, it would be ineffective and eventually very expensive to have this kind of plan without a consistent



PATHWAYS CLUBHOUSE
A Part of: ADULT&child



funding stream for the other necessary recovery focused services such as education, employment, housing and pre-vocational services. Clubhouses affiliated with the International Center for Clubhouse Development (ICCD) have a long and rich history of providing a cost effective array of services such as these in a community based environment. ICCD Clubhouses and other clubhouses using this model more than any other program have strong partnerships with the local business, educational institutions and other social service providers.

Therefore it is my opinion that none of the proposed rule changes should be implemented until each state (or the federal government) has a plan actively in place to provide the necessary recovery focused services that would no longer be "covered" by Medicaid. The plan must not exclude people with mental illness from psychosocial services needed to maintain their recovery progress, such as ICCD Certified Clubhouses and other clubhouses using this model.

It is a mistake to re-organize funding for long approved services in an effort to reduce short term spending. A poorly developed strategy will result in unnecessary - and more costly emergency spending and over-reliance on emergency services.

Most importantly, these changes will have a tragic impact on the lives and futures of millions of people struggling to recover from the long term effects of serious mental illness. In the interest of short term spending cuts, these changes will quickly erode the essential support networks that have allowed Americans with serious mental illness to begin the long and difficult process of rebuilding their lives. In my opinion, that would be an unconscionable mistake.

Sincerely,

Chuck Lynn
3841 S. Emerson Ave. #C
Indianapolis, IN 46203

p.s. Three years ago I became depressed and the hospital didn't do me any good and the groups I was in didn't help me either. I found a clubhouse program that helped me and it took me awhile to learn what I could do to help myself recover. I hope you don't cut programs like the clubhouse because we have lots of people who need programs like the clubhouse to support them in their recovery. All of us are not handicapped some of us really need the help to recover. If you cut the program, you may hurt a lot of people that are currently using the program. They wouldn't know where to go to get help. They may stay home and do nothing and might even die. You need to help us get this funding for clubhouses so that people don't get sicker. Please don't cut our medicaid for these programs.

Submitter : Miss. Patricia Williams
Organization : pathways clubhouse, adult and child center
Category : Individual

Date: 10/01/2007

Issue Areas/Comments

GENERAL

GENERAL

see attachment

CMS-2261-P-213-Attach-1.DOC

Submitter : Miss. George Dremonas
Organization : pathways clubhouse, adult and child center
Category : Individual

Date: 10/01/2007

Issue Areas/Comments

GENERAL

GENERAL

see attachment

CMS-2261-P-215-Attach-1.DOC

Submitter : Jenifer Pepling
Organization : Jenifer Pepling
Category : Individual

Date: 10/01/2007

Issue Areas/Comments

Background

Background

We recommend that CMS withdraw the proposed regulations and republish them again for further comment only after they have clarified how the proposed regulations would impact wraparound services for children and adolescents with autism spectrum disorders and those with mental retardation.

GENERAL

GENERAL

My son has autism and needs Wrap around services. If he gets wrap around I am told that he will be a usefull member of society. Without these he will not. Please do not take away my sons future.
My insurance does not cover these needed services. I need Medical Assistance to cover my sons therapy. Please make sure that new proposal is written to include Autism spectum disorders for service.

Submitter : Mrs. Audrey Greenfield
Organization : Hinds Behavioral Health Services
Category : Other Health Care Provider

Date: 10/01/2007

Issue Areas/Comments

GENERAL

GENERAL

See Attachment

CMS-2261-P-221-Attach-1.DOC

Submitter : Judith Brodie

Date: 10/01/2007

Organization : Judith Brodie

Category : Individual

Issue Areas/Comments

GENERAL

GENERAL

Dear Sir or Madam:

Thank you for providing opportunities for individuals living with mental illness and their family members to provide comments on the proposed rule regarding coverage for rehabilitative services under the Medicaid program. I am writing as a member 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 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.

I am 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.

We appreciate the emphasis on recovery in the rules. All individuals with mental illness and their families want the system to make it easier to recover. We also like the provisions about the participation of the individual and their family in the rehabilitative plan and receiving copies of the plan so we can hold the system accountable. We would like to see some flexibility to make sure that providers can still do outreach and provide crisis care, but we very much appreciate the agency's intent to encourage communication between providers, the individual and family members.

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.

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.

MENTAL ILLNESS OF A FAMILY MEMBER CAN BE HEARTBREAKING AND HAVE MAJOR SOCIAL AND ECONOMIC IMPACTS FOR EVERYONE. PLEASE TAKE THE ABOVE INTO ACCOUNT!

Submitter : Kathleen Baas

Date: 10/01/2007

Organization : Kathleen Baas

Category : Nurse

Issue Areas/Comments

GENERAL

GENERAL

It is irresponsible for the federal agency (CMS) to adopt these proposed regulations as written as they fail to clarify the potential impact on the thousands of children with autism spectrum disorders and mental retardation who currently receive wraparound services in Pennsylvania. I request that CMS withdraw the proposed regulations. After clarification of precisely how the proposed regulations would impact wraparound services for children and adolescents with autism spectrum disorders as well as those with mental retardation, the new proposal should be published and subject to comment. The burden of autism is great on the family, and with one person diagnosed of every 150 children, the burden will grow. Now is not the time to remove supports. Interventions lead to improved function in many children with autism, and help those with mental retardation improve their level of function; it is imperative that we help these children reach their maximum potential, or the burden of caring for these people as adults will overwhelm our social structures.

Submitter : Mr. Stanley Anderson
Organization : Hinds Behavioral Health Services
Category : Health Care Provider/Association

Date: 10/01/2007

Issue Areas/Comments

GENERAL

GENERAL

See Attachment

CMS-2261-P-225-Attach-1.DOC

Development (ICCD) have a long and rich history of providing a cost effective array of services such as these in a community based environment. ICCD Clubhouses more than any other program have strong partnerships with the local business, educational institutions and other social service providers.

Therefore it is my opinion that none of the proposed rule changes should be implemented until each state (or the federal government) has a plan actively in place to provide the necessary recovery focused services that would no longer be "covered" by Medicaid. The plan must not exclude people with mental illness from psychosocial services needed to maintain their recovery progress, such as ICCD Certified Clubhouses.

It is a mistake to re-organize funding for long approved services in an effort to reduce short term spending. A poorly developed strategy will result in unnecessary - and more costly emergency spending and over-reliance on emergency services.

Most importantly, these changes will have a tragic impact on the lives and futures of millions of people struggling to recover from the long term effects of serious mental illness. In the interest of short term spending cuts, these changes will quickly erode the essential support networks that have allowed Americans with serious mental illness to begin the long and difficult process of rebuilding their lives. In my opinion, that would be an unconscionable mistake.

Sincerely,

Stanley Anderson
Day Treatment Specialist I
Hinds Behavioral Health Services
3450 Highway 80 West
Jackson, MS 39209
601-969-7505

Submitter : Ms. Temeka Johnson
Organization : Hinds Behavioral Health Services
Category : Other Health Care Professional
Issue Areas/Comments

Date: 10/01/2007

GENERAL

GENERAL

See Attached

CMS-2261-P-226-Attach-1.DOC

December 4, 2007

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

To Whom It May Concern:

In response to the recent request for comments on the Proposed New CMS Rules on Medicaid Rehabilitation Services I am submitting the following opinion.

The recent changes in practice by CMS and the associated proposed rule changes published on August 13, 2007 are having a dramatically negative effect at the local level in many states and threaten to do the same throughout the country. The effect of the rule changes may be well intentioned but in practice they will create a situation where medically necessary services and supports will be eliminated for some of this country's most vulnerable citizens – those with severe and persistent mental illness.

Although these rule changes may be appropriate for people with physical rehabilitative needs, according to a recent NAMI publication, 73% of people receiving Medicaid rehabilitative services have mental health needs. People with long term mental illness have a very distinct set of long term needs, for a wide array of supports; these are quite different from the needs of others requiring rehabilitative services, and must be funded differently. The dramatic shift of mental health funding to Medicaid has diminished the flexibility for states to provide the needed community services to people with mental illness.

Some of the proposed rule changes simply reduce this population's access to needed services - without any back up plan to fund services or programs. Many of these services have been working effectively with CMS approved Medicaid funding for more than ten years, However, with the recent changes in CMS practice, they now find that they are no longer able to provide the crucial support network that people with serious mental illness so desperately need. The net result is that vast numbers of people with persistent mental illness are being deprived of a chance to build a meaningful future for them.

To create, or suddenly start enforcing, bureaucratic clinical and administrative processes without additional or alternative funding from states is the equivalent of a substantial cut in services for people who already have more than their fair share of burdens. A reduction or elimination of services puts individuals with severe and persistent mental illness at risk of unnecessary institutionalization in our hospitals or even worse in our prison system.

One example of the inappropriateness of these changes in funding programs for people with mental illness is the emphasis on returning a person to 'previous levels of functioning.' Because recovery from mental illness is often a long term process, this definition will likely reduce or eliminate many necessary psychosocial rehabilitation type services and supports.

Although I wholeheartedly support the idea of "person centered" services and rehabilitation plans, it would be ineffective and eventually very expensive to have this kind of plan without a consistent funding stream for the other necessary recovery focused services such as education, employment, housing and pre-vocational services. Clubhouses affiliated with the International Center for Clubhouse

Development (ICCD) have a long and rich history of providing a cost effective array of services such as these in a community based environment. ICCD Clubhouses more than any other program have strong partnerships with the local business, educational institutions and other social service providers.

Therefore it is my opinion that none of the proposed rule changes should be implemented until each state (or the federal government) has a plan actively in place to provide the necessary recovery focused services that would no longer be “covered” by Medicaid. The plan must not exclude people with mental illness from psychosocial services needed to maintain their recovery progress, such as ICCD Certified Clubhouses.

It is a mistake to re-organize funding for long approved services in an effort to reduce short term spending. A poorly developed strategy will result in unnecessary - and more costly emergency spending and over-reliance on emergency services.

Most importantly, these changes will have a tragic impact on the lives and futures of millions of people struggling to recover from the long term effects of serious mental illness. In the interest of short term spending cuts, these changes will quickly erode the essential support networks that have allowed Americans with serious mental illness to begin the long and difficult process of rebuilding their lives. In my opinion, that would be an unconscionable mistake.

Sincerely,

Temeka Johnson
Day Treatment Specialist I
Hinds Behavioral Health Services
3450 Highway 80 West
Jackson, MS 39209
601-969-7505

Submitter : Mary Rehmann
Organization : Mental Health America in Monongalia county
Category : Consumer Group

Date: 10/01/2007

Issue Areas/Comments

GENERAL

GENERAL

See attachment

CMS-2261-P-227-Attach-1.TXT

The Mental Health America in Monongalia County
An Affiliate of Mental Health America
364 High Street #224
Morgantown, West Virginia 26505

Telephone (304)292-0525 FAX (304)292-2318 E-Mail mha_mon@yahoo.com
Web <http://hometown.aol.com/MHAIInMonCounty>



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Program Assistants



October 1, 2007

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

Reference: File Code CMS-2261-P

To Whom It May Concern:

As Chair of the Public Policy Committee of Mental Health America of Morgantown, WV, I am writing on behalf of our Board of Directors and members. We wholly endorse the comments submitted by our national organization in relation to the proposed regulatory changes to the rehabilitation option of Medicaid. It is hard to believe that changes are being proposed to community-based services that help individuals to function at their highest capability or to maintain the level that they have achieved when ongoing services to do so are required.

The President's New Freedom Commission on Mental Health found that fragmentation of services and lack of access were major barriers to persons with mental illness. We particularly object to the provision in the rules that would prohibit Medicaid to reimburse services that may be available through other non-medical entities as this is projected to deny needed services to many individuals. How many courts are going to have to distinguish the specific purposes of funding when funding proposals speak in more generic terms and there is flexibility in the actual services depending on the needs of those served?

We urge you to withdraw these rules and do more research on the effectiveness of this option across the nation. These rules will destroy the existing rehab option programs and deprive a very vulnerable population of opportunities to develop to their maximum.

Sincerely,

Sister Mary Rehmann, Chair
Public Policy Committee

Submitter : Ms. merri Patterson
Organization : IMHD
Category : Health Care Professional or Association

Date: 10/01/2007

Issue Areas/Comments

Background

Background

GENERAL

GENERAL

To Whom It May Concern:

The purpose of this letter is to express concerns related to the proposed rule changes (CMS-2261-P) by the Centers for Medicare and Medicaid Services (CMS) as it relates to therapeutic foster care.

The proposed changes by CMS are a threat to the well being of seriously emotionally and behaviorally disturbed children and adolescents who have benefited from the service of therapeutic foster care. Therapeutic foster care provides an intensive level of service that provides an environment which allows for individuals to learn new ways to manage their emotional and behavioral challenges in the context of a family environment. This environment also teaches the skills necessary to become productive members of society. The act of prohibiting the use of Medicaid funds to pay for therapeutic foster care will result in the institutionalization of children and adolescents who are currently successful in community based placements, and will create a significant barrier to the process of transitioning children from hospital or acute care facilities, via therapeutic foster care, to community based settings.

We urge you to reconsider the proposed rule changes (CMS-2261-P), as they are a significant threat to the well being of children and youth.

Respectively,
Merri Patterson
Therapeutic Foster Care Parent

Submitter : Ms. Kelly J. Davis

Date: 10/01/2007

Organization : Wraparound services for autistic individuals

Category : Other Health Care Provider

Issue Areas/Comments

GENERAL

GENERAL

As a parent of an autistic child, we need the wraparound services for our children to help them to keep learning and being taught those things needed to learn and be mainstreamed. These services are not and cannot just be gotten anywhere else, the cost cannot be left to the families to pay, because unfortunately most families do not make enough to cover these costs. The government needs to be helping to pay for these costs, all the money given for drug rehabs and services for people that can work, such as alcoholics, druggies, suicidal individuals, and welfare bums, let them go clean up the streets, flip burgers, help at the soup kitchens. OUR CHILDREN DID NOT ASK FOR THESE PROBLEMS, BUT LET'S PUT THE MONEY WHERE IT IS NEEDED.

Submitter : Ms. Marian Dezelan

Date: 10/01/2007

Organization : Ms. Marian Dezelan

Category : Individual

Issue Areas/Comments

GENERAL

GENERAL

Without CMS coverage of wraparound therapy for my autistic son, I am certain he will not continue to develop his ability to speak. He is living proof that autism is treatable through applied behavior analysis, and these services are critical in order for him to become a productive member of society. Without them, there is no hope.

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

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,

Mary Logan
Student, consumer and supporter of NAMI.

Submitter :

Date: 10/02/2007

Organization :

Category : Consumer Group

Issue Areas/Comments

GENERAL

GENERAL

See attachment

CMS-2261-P-232-Attach-1.DOC

Marvin Lim
6654 Wandering Way
Norcross, GA 30093

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:

Thank you for providing opportunities for individuals living with mental illness and their family members to provide comments on the proposed rule regarding coverage for rehabilitative services under the Medicaid program. I am writing as a member of The National Alliance on Mental Illness (NAMI), the nation's largest grassroots organization representing individuals living with serious mental illnesses and their families. As members of NAMI, we have lived experience with mental illness and bring that unique perspective to our comments on these rules.

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.

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.

We appreciate the emphasis on recovery in the rules. All individuals with mental illness and their families want the system to make it easier to recover. We also like the provisions about the participation of the individual and their family in the rehabilitative plan and receiving copies of the plan so we can hold the system accountable. We would like to see some flexibility to make sure that providers can still do outreach and provide crisis care, but we very much appreciate the agency's intent to encourage communication between providers, the individual and family members.

However, we have a few areas of deep concern where we hope 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:

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 health 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.

Conclusion:

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,

Marvin Lim