

# **NAMI POLICY RESEARCH INSTITUTE TASK FORCE REPORT**

## **CHILDREN AND PSYCHOTROPIC MEDICATIONS**

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## Executive Summary

In 2003, NAMI's Policy Research Institute (NPRI) convened a task force of experts and stakeholders to consider issues related to the use of psychotropic medications for children and adolescents. Since then, the issue has exploded in the nation's headlines, but not necessarily with the kind of precision that medical issues require.

Our nation is currently experiencing a public health crisis in the number of youth with mental illnesses that fail to receive any treatment or services. The U. S. Surgeon General has warned that approximately 80% of youth with mental illnesses fail to receive any treatment or services. We have made major scientific advances in understanding how to properly diagnose and treat mental illnesses in children, but more needs to be done.

The prevalence of mental illnesses in children and adolescents is significant and on the rise. About 1 in 10 children in the U.S. suffers from a mental illness severe enough to cause impairment. Research shows that reaching children with mental illnesses early with appropriate treatment significantly improves their long-term prognosis. Conversely, the failure to provide treatment has tragic consequences. After careful deliberations, the task force developed the following four recommendations to guide policy, legislation and research:

1. The National Institute of Mental Health (NIMH) must make research on early onset mental illnesses and the use of psychotropic medications in children a priority and increase funding, accordingly. On this point, another NPRI Task Force on Serious Mental Illness Research has issued a separate report noting that for children and adolescents, there is "little correlation" between what treatments are known to work and what is actually implemented in the mental health care system." See *Roadmap to Recovery and Cure* (February 2004).
2. One size does not fit all when it comes to treating mental illnesses. All children and adolescents with mental illnesses must have access to evidence-based assessments and interventions (EBI) and quality care. The EBI system should require clinicians to continually improve care by using the most current evidence and research to make decisions about the most appropriate medication and treatment **on an individualized basis**.
3. Families, child-serving professionals and other stakeholders must receive information and education about the diagnosis and treatment of early onset mental illnesses. This should include information about the early warning signs of these illnesses and the appropriate use of psychotropic medications for children:

***Psychotropic medications for young children should be used only when anticipated benefits outweigh risks. Parents should be fully informed and decisions made only after carefully weighing these factors. Children and adolescents must be closely monitored and frequently evaluated as the side effects common to some medications can be particularly difficult for children. At the same time, psychotropic medications can be lifesaving.***

4. Policymakers generally should **not** interfere with the right of access to treatment, the patient-provider relationship, or the promotion of partnerships for treatment between parents, providers, and other child-serving professionals. Any legislative or regulatory consideration related to the use of psychotropic medications for children and adolescents must be guided by science. Action should be taken **only after** obtaining testimony from qualified and well-recognized medical and mental health professionals and on the basis of sound scientific research.

Children and adolescents represent our nation's hope for the future. Mental illnesses, like all childhood illnesses, should be detected early and children should receive effective and appropriate care targeted to their individual needs. Our nation should protect children from harm, while also ensuring that those with mental illnesses receive the most effective treatment and services. Their future depends on it.

## **NAMI Policy Research Institute**

The NAMI Policy Research Institute (NPRI) is one of the nation's foremost consumer- and family-oriented policy groups dedicated to addressing mental illness issues across the life span. The Institute's mission is to shape national, state, and local debates on reforms and investments in the nation's mental illness delivery and financing system. As part of its mission, the Institute provides technical assistance to NAMI state organizations and local affiliates on pivotal issues such as Medicaid financing, access to medications, and children's delivery issues. The Institute brings together policymakers, advocates and scientists through various forums, including special task forces, to develop solutions and expand support for science-based, recession-proof early intervention, treatment and recovery oriented systems and supports.

### **Purpose of the Task Force**

NAMI created the Task Force on Children and Psychotropic Medications to help NAMI examine pertinent issues and to develop information that can be shared with the NAMI Board of Directors, grassroots leaders and state and federal policymakers on this topic. Although there were many issues that the Task Force could have focused on relative to this topic, including the profound shortage of children's mental health providers and overall trends in the use of psychotropic medications for children and others, NAMI identified the need to address legislative and policy actions that are being taken that threaten to restrict access to the most effective treatments for children based on misinformation, overreaction or ideological agendas. These mental illnesses include, but are not limited to early onset

bipolar disorder, childhood onset schizophrenia, obsessive compulsive disorder, major depressive disorder, anxiety disorders, attention-deficit/hyperactivity disorder, tourette's syndrome, and autism.

### **Introduction and Background**

The prevalence of mental illnesses in children and adolescents is significant and is on the rise according to the latest research and information. An estimated 1 in 10 children and adolescents in the United States suffers from mental illness severe enough to cause some level of impairment. Fewer than 1 in 5 of these ill children receives treatment.

Research shows that early identification and comprehensive treatment (multi-disciplinary) can improve the long-term prognosis of children with mental illnesses. Research on effective treatments is our best hope for the future. We must apply the most current knowledge gained from research in the care and treatment of children and their families.

***An estimated 1 in 10 children and adolescents suffer from mental illness severe enough to cause some level of impairment. Fewer than 1 in 5 of these ill children receives treatment.***

Much has been learned in the last decade about treating children with various mental illnesses, however much remains to be done. There are a number of effective treatment options available to mental health providers for children and adolescents with mental illnesses. These include cognitive behavioral therapies, home and community-based services, behavioral strategies, family psycho-education and support and psychotropic medications.

There has been a steady increase in the use of psychotropic medications to treat children. Despite scientific advances in the proper diagnosis and treatment of mental illnesses in children, the parameters for the use of psychotropic medications for children remain unclear. There is a bit of a catch-22 when it comes to children and psychotropic medications. On the one hand, some suggest that psychotropic medications should not be prescribed to children until adequate research is done. On the other hand, others express concern that children are being inappropriately enrolled as subjects in research studies on psychotropic medications. Obviously, adequate research about the efficacy and safety of medications for children requires their enrollment in research studies.

In the meantime, thousands of children who are suffering from severe mental illnesses need immediate help.

The issue of children and the use of psychotropic medications received considerable attention in June 2003, when the British Medicines and Healthcare Products Regulatory Agency (the British equivalent of the FDA) and the U.S. Food and Drug Administration issued formal warnings advising against the use of Paxil (an SSRI) to treat depression in children and adolescents. In December 2003, British regulators issued a second advisory statement indicating that the broader class of serotonin reuptake inhibitor (SSRI) medications should not be prescribed to youth under the age of 18 years for the treatment of depression, with the exception of fluoxetine (Prozac). In February 2004, the FDA began an intensive review of its own on the use of SSRIs for children and adolescents for the treatment of depression. As part of that review, the FDA asked Columbia University to re-analyze existing

data to try to determine whether SSRIs raise the risk of suicide in children. The FDA committee reviewing the use of SSRIs to treat depression in youth is expected to continue through the summer of 2004 before an official recommendation is made to the FDA.

***There are a number of effective treatment options available to mental health providers for children and adolescents with mental illnesses.***

In the field of mental health, new studies are needed to identify the best treatments for children with mental illnesses and to better understand psychopharmacology – particularly polypharmacy in children. Children are in a state of rapid change and development. The diagnosis and treatment of mental disorders must be approached with these changes in mind. While some problems may be short-lived and may not require treatment, others may be persistent and quite serious, and may require immediate treatment and medications. Many psychotropic medications that are prescribed for children and adolescents are not FDA approved for use in children, but are routinely used off-label, a common practice among physicians and psychiatrists.

***Thousands of children who are suffering from severe mental illnesses need immediate help.***

At the same time, special consideration and attention must be paid to the complex ethical issues associated with research on children and the complexities raised by child development. Psychotropic medications for young children with mental illnesses should be used only when the anticipated benefits outweigh the risks. Parents and family

members should be fully informed of the risks and expected benefits associated with medications prescribed for children and decisions about whether to use medication for a child should only be made after carefully weighing these factors. Children and adolescents who are taking psychotropic medications must be closely monitored and frequently evaluated by qualified mental health providers. The side effects common to some medications can be particularly difficult for children.

At the same time, psychotropic medications can be lifesaving for some children with mental illnesses. Families often report that medication and therapy have allowed their child to participate in school like other children, to live at home and to develop friendships with peers. We also know that lack of treatment for a child who needs it will adversely affect the child's overall physical and mental development, including the ability to learn, develop self-esteem, socialize and function in the community.

***Medications for young children with mental illnesses should be used only when the anticipated benefits outweigh the risks.***

## **Costs and Consequences of Untreated Illness**

The long-term consequences of untreated mental illnesses in youth are staggering. Suicide is the third leading cause of death in adolescents aged 15 to 24. (Centers for Disease Control, 1999) Evidence strongly suggests that as many as 90% of those who commit suicide have a diagnosable mental disorder. (Institute of Medicine Report, 2002 and Surgeon General, 1999) Youth with untreated mental illnesses also tragically end up in the criminal justice

system. According to a recent study – the largest ever undertaken -- an alarming 65% of boys and 75% of girls in juvenile detention have at least one psychiatric diagnosis. (Teplin, L. *Archives of General Psychiatry*, Vol. 59, December 2002) Also, NAMI's 1999 report *Families on the Brink* showed that in over 36% of the cases, youth were placed in the juvenile justice system to access mental health services.

Many children with untreated mental illnesses fail in school, fail to develop friendships and social skills.

***Psychotropic medications can be lifesaving for some children with mental illnesses.***

They also become isolated from their peers. Their inability to succeed in school results in their failure to complete their education, obtain meaningful employment and ultimately in the chance to lead an independent and productive life. The devastating reality is that youth with untreated mental illnesses have a greatly diminished future as citizen and worker. The negative impact on our youth, their families — who report experiencing enormous stress, divorce, the loss of housing, excessive absenteeism from work, and social isolation -- and communities cannot be overstated.

***Many children with untreated mental illnesses fail in school, fail to develop friendships and social skills.***

In contrast, some claim that there is a widespread practice of inappropriately labeling children as mentally ill and drugging them with "heavy, mind-altering

drugs.”<sup>1</sup> These assertions are not supported by either existing research or science. In fact, the available evidence shows that even while increased prescription of medications for children has occurred, the much more pressing issue is the number of children with mental illnesses that are not being diagnosed and treated.<sup>2</sup> Public policy addressing the treatment of mental illnesses in children and adolescents must be founded on science and shaped by research and scientific evidence, not political or religious ideology or stigma and discrimination that persists against mental illnesses. In fact, scare tactics can only harm the public health.

***Public policy addressing the treatment of mental illnesses in children and adolescents must be founded on science.***

There is emerging scientific evidence that early treatment interventions significantly improve the long-term outcomes for children and adolescents with mental illnesses.

Early assessment and identification of mental health needs does not exist in most of the systems designed to serve children and their families, including but not limited to primary health care, schools, community centers, child welfare, juvenile justice, substance use treatment systems and others. Research increasingly is showing that the failure to intervene and provide early and

<sup>1</sup> Citizens Commission on Human Rights was established by the Church of Scientology in 1969. The quote is from their web site -- [www.fightforkids.com](http://www.fightforkids.com).

<sup>2</sup> *Is ADHD Overdiagnosed and Overtreated? A Review of the Epidemiological Evidence.* Emotional & Behavioral Disorders in Youth, Fall 2002. Research in the U.S. Surgeon General’s report shows that only 1 in 5 children with a mental illness receives treatment.

comprehensive treatment (whether it is medication, psychosocial interventions or some combination of the two) for many mental illnesses accelerates the course of the illnesses.

## **State Legislative Action on Children and Psychotropic Medications**

Anti-psychiatry groups have fueled the debate in many state legislatures on the use of psychotropic medications for children with unfounded assertions. Legislators have responded to these scientifically unfounded assertions with legislation that restricts the role of school personnel in helping to identify children who may need a mental health intervention. This will likely lead to personnel refusing to raise legitimate concerns with families about the educational needs and overall well being of students.

***There is emerging scientific evidence that early treatment interventions significantly improve the long-term outcomes for children and adolescents with mental illnesses.***

The Citizens Commission on Human Rights (CCHR), established by the Church of Scientology, has been a critic of the use of psychotropic medications in children and has expended significant resources on claims that psychiatric diagnoses in children are “fraud.” The group does not recognize mental disorders such as Attention Deficit/Hyperactivity Disorder (ADHD) as a legitimate illness. They have been active in attempting to convince state and federal legislators and policymakers that our nation is “drugging” and inappropriately labeling millions of children. At their request, in September 2002, the United States House of



Representatives Committee on Government Reform held a hearing entitled “Attention Deficit Hyperactivity Disorders – Are Children Being Over Medicated?” – during which CCHR supporters testified that we are legally “drugging” millions of children with “heavy, mind-altering drugs.”

CCHR has pushed “model state legislation” that threatens to cause school personnel to refuse to talk with families about the need for an evaluation for their child. Their model legislation includes the following language:

*This Act would establish rules and regulations prohibiting school personnel from identifying or diagnosing unwanted classroom behaviors or slow learning as disorders or suggesting or recommending psychotropic drugs for any child.*

Although the legislative language seems to permit school personnel to talk with families about a student’s need for a mental health evaluation, NAMI families report that in the states that have enacted this type of legislation, it has had a chilling effect on the willingness of school personnel to talk with families about these issues.

***Anti-psychiatry groups have fueled the debate in many state legislatures on the use of psychotropic medications for children with unfounded assertions.***

The issue of medicating youth also received significant media scrutiny after it was revealed that one of the youth responsible for the Columbine shootings had been taking psychotropic medication. After Columbine,

<sup>3</sup> The model legislation can be founded online at [www.fightforkids.com](http://www.fightforkids.com).

the state of Colorado considered banning the use of psychotropic medications in schools for youth. Instead, the Colorado Board of Education passed a resolution that promotes academic and classroom management solutions for behavior problems rather than relying on psychotropic medications.<sup>4</sup> Such resolutions are in effect discriminatory.

The past four years have seen legislative activity on issues related to the use of psychotropic medications and children. The issues fall into several general categories, the following list represents some of the types of legislation and resolutions that have been enacted or passed:

- The U.S. House passed H.R. 1170, the Child Medication Safety Act – legislation that would require, as a condition of receiving federal education funds, that states develop policies and procedures that prohibit schools from requiring a child to use psychiatric medication as a condition of attending school. The Senate introduced similar legislation – S. 1390.
- Resolution to create a committee of the state legislature or a committee appointed by state officials to study the use of psychotropic medications in children (Georgia – 2000).
- Resolution promoting school personnel to use academic and management solutions to resolve

<sup>4</sup> The Colorado State Board of Education resolution, adopted November 11, 1999, is available online at [www.cde.state.co.us/cdeboard/bdresolution.htm](http://www.cde.state.co.us/cdeboard/bdresolution.htm). A similar resolution adopted in Texas, is available online at: [www.tea.state.tx.us/sboe/minutes/sboe/2000/0011resolve.html](http://www.tea.state.tx.us/sboe/minutes/sboe/2000/0011resolve.html).

- behavior problems rather than a psychiatric approach (Colorado Board of Education – 1999, Texas Board of Education – 2000).
- Resolution or legislation requiring the tracking and monitoring of the number of children in state custody or in the state being diagnosed with a psychiatric disorder and using psychiatric medication (Washington legislation – 2000, Hawaii resolution, also requires state to examine non-medication alternatives – 2001, Illinois legislation introduced but not enacted – 2001, California law enacted requiring state to adopt regulations for the administration of medications to kids in state custody – 2000, Florida law enacted -- 2000, North Carolina law enacted – 2001).
  - Enactment of state law prohibiting school personnel from recommending the use of psychotropic medications for any child and providing that the refusal of a parent to use such medications shall not constitute grounds for removing the child (Connecticut law enacted – 2001, Virginia law enacted that directs the Board of Education to develop and implement policies that prohibit school personnel from recommending the use of psychotropic medications for students – 2002).

***Children with mental illnesses deserve to have their illness identified and treated with the most appropriate -- evidence-based treatments available.***

The legislative activity outlined above represents just some of the recent activity. It is likely that states will continue to introduce and consider state legislation around the issue of psychopharmacology and children.

Children with mental illnesses deserve to have their illness identified and treated with the most appropriate -- evidence-based treatments available. Science and years of research have demonstrated that in many cases – that will include the use of psychotropic medications, along with other treatment modalities.

## **The Outlook**

State legislatures are likely to continue to consider legislation addressing the diagnosis and treatment of mental illnesses in children.

***Significant scientific advances have been made and continue to be made in understanding and treating mental illnesses in children.***

This is particularly true because anti-psychiatry groups are fueling “model legislation” that targets these issues. Tough decisions lie ahead. Scientists, mental health and medical professionals, and families must provide impact information and the latest research and science based information to policymakers. We must stress to legislators and policymakers that well-documented studies and reports make

clear that we have repeatedly failed to provide gravely needed treatment and services to many children and adolescents with mental illnesses across most of the systems designed to meet their needs. Significant scientific advances have been made and continue to be made in understanding and treating mental illnesses in children; however despite those advances, we need to continue to build our knowledge base. For some children, the use of psychotropic medication is appropriate and has dramatically improved the quality of their life. For others, it has saved their lives.

## **NAMI Policy Research Institute Task Force Policy Recommendations**

After reviewing the background information and based on further deliberations, the task force developed the following recommendations to guide NAMI policy and grassroots efforts on children and psychotropic medications.

### **Policy Recommendation 1**

**NAMI calls on the National Institute of Mental Health (NIMH) to make a significant investment in research on early onset mental disorders and the use of psychotropic medications in children and adolescents. With so many children being prescribed psychotropic medications, we need research and science to help guide the safe and effective use of these medications.**

**NIMH must develop a complete portfolio of basic, clinical, and intervention services research on children's mental disorders – with families involved in the design, implementation and outcome measures of the research.**

**Federal funding from the research and services agencies should focus on additional research to identify evidence-based home and community-based service approaches and on building incentives to disseminate those approaches into communities – where appropriate.**

There are significant gaps in research on the treatment of childhood mental disorders. There is very little research on children and the use of psychotropic medications, outside of research that has been done on the use of stimulants for children with mental disorders. Also, the limited research that has been done has focused on the short-term effects and efficacy of the medications, without focusing on the long-term effects and safety of the medications for children.

*Families should be an integral component of all research that is done to better understand childhood mental illnesses and effective treatments.*

NAMI recognizes that NIMH has faced challenges in recruiting children to participate in research and clinical trials related to the use of psychotropic medications. NIMH is supporting a model for large simple trials related to the use of psychotropic medications with children. This model will involve recruiting community mental health professionals who are treating children with mental disorders in their practices. The participating providers will relay data used in their clinical practice that will be used to better understand the effectiveness of treatment approaches – including psychotropic medications. This research should help to address the essential need for more data on the long-term effects and safety of psychotropic medication use in children.

Families should be an integral component of all research that is done to better understand childhood mental illnesses and effective treatments.

Mental health and primary care providers and the research community should heed the recommendations included in President Bush's New Freedom Commission report that call for families and consumers to be at the center of all mental health service delivery models. (New Freedom Commission, 2003)

## **Policy Recommendation 2**

**NAMI believes that children should only be diagnosed and treated by the best-qualified mental health professionals and properly trained medical professionals. NAMI supports efforts to protect children from inaccurate diagnoses by ensuring that primary care and mental health providers are better informed and educated on the proper diagnosis and treatment of childhood mental disorders.**

**The mental health treatment and service system should adopt an evidence-based assessment and intervention approach (much like the "evidence-based medicine" model widely used in other areas of medicine) that calls for clinicians to continually improve care by using the most current evidence and research to make decisions about the most appropriate care on an individualized basis. This approach for the diagnosis and treatment of mental disorders in children should be used by medical professionals – in close consultation with parents, caregivers and youth (when appropriate) – when making decisions about whether psychotropic medications are appropriate for the treatment of a child's mental disorder.**

**NAMI believes that the debate on children and the use of psychotropic medications must also address the critical need to ensure that *all* children and adolescents with mental disorders have access to evidence-based assessments and interventions – with quality clinical care as an integral part of all aspects of the service delivery system.**

It is critical to develop consensus around the most efficacious treatment and interventions – both psychopharmacology and psychosocial interventions -- for children and adolescents with mental disorders.

This includes a focus on developing and implementing appropriate treatment algorithms, care mapping, and other empirically sound approaches that provide the most appropriate interventions for children and families.

*It is critical to develop consensus around the most efficacious treatment and interventions -- for children and adolescents with mental disorders.*

There is clearly a need for both primary care and mental health providers to become better informed about current research findings in children's mental health and to work to implement the most efficacious treatment approaches. The task force recommended that mental health and primary care providers be trained in and routinely retrained in evidence-based treatment interventions and quality treatment approaches to ensure that the most appropriate services are provided to children and families. These professionals should also be willing to adopt evidence-based interventions. We know a lot about evidence-based interventions for children

with mental disorders, unfortunately most of the interventions are not implemented – policy makers, funders and advocates should focus on building incentives for implementation.

Training and education of professionals should also focus on how medications and other forms of therapy should be combined and strategies to avoid either under- or over-medication of youth.

***We know a lot about evidence-based interventions for children with mental disorders, unfortunately most of the interventions are not implemented.***

It is also crucial that primary care providers and child-serving agencies receive appropriate training to recognize the early warning signs of mental disorders and apply screening and early recognition tools -- such as normed questionnaires that function like the blood pressure cuff of mental health care. In this way, children will be identified as at risk and appropriately diagnosed as early as possible to prevent prolonged delays in receiving appropriate treatment.

Mental illnesses in children and adolescents should be treated as all other illnesses in youth. We should look at the whole person when evaluating the health and well being of a child – and not separate out mental illnesses. This is true when it comes to treatment approaches, financing/insurance coverage and other issues. This discussion raised the issue of where responsibility for treatment and services related to childhood mental illnesses should reside. Policy consideration should be paid to whether responsibility should reside in the primary care setting with triage to mental health providers or with mental health providers. Effective models currently exist that place a

mental health provider in a primary care setting.

The task force believes that the role of family members and caregivers as educators, advocates and participants in the treatment process is critically important. It is imperative that clinicians work more effectively with families when treating children with mental disorders. Research has demonstrated that treatment is improved when family members are educated about treatment.

“Shared decision-making” provides a new framework for family member and caregiver participation that is critical for more informed decision-making and ultimately results in more effective care.

***For some children, the use of psychotropic medication is appropriate and has dramatically improved the quality of their life. For others, it has saved their lives.***

Shared decision-making is a process in which providers present information about the risks and benefits of treatment options to children, adolescents and their family members. This treatment information and the family preferences are used to reach a health care decision based on mutual agreement.

***Research has demonstrated that treatment is improved when family members are educated about treatment.***

The shared approach to the decision permits an open exchange of information that allows the provider to present and consider all treatment alternatives, thereby enhancing the quality of the decision made. This dialogue promotes willingness and acceptance of the

decision because the child or adolescent and the family member have participated in the treatment decision process. The key characteristics of the relationship that contribute to collaborative decision making are:

- [ Partnership;
- [ Respect;
- [ Open Communication;
- [ Knowledge;
- [ Cultural Competence;
- [ Flexibility;
- [ Best Practices, and;
- [ Responsibility.

### **Policy Recommendation 3**

**NAMI believes that families and all professionals that work with children should receive appropriate information and education about early-onset mental illnesses – including how to recognize the early warning signs. Families and all professionals working with children should also receive education and information on the latest research related to the use of psychotropic medications for children and other evidence-based and science-based treatment and services.**

The task force recommended that, whenever possible, NAMI should disseminate the most current research and evidence-based treatment and diagnostic information on childhood mental illnesses.

Education of school-system professionals is also extraordinarily important and necessary so that they are better able to recognize serious mental illnesses in children and link them to appropriate services.

NAMI calls on schools to take the following steps to meet the needs of students with mental disorders:

- Educate administrators, teachers, and general staff about the nature of mental disorders in children;
- Ensure that schools have appropriately trained healthcare professionals (nurses and counselors) who are qualified to assess a student’s need for a psychiatric intervention;
- Implement a curriculum to teach students about mental disorders, just as schools teach children about other illnesses;
- Hire appropriately trained staff to teach students with mental disorders to improve the educational outcomes of these students;
- Gain a better understanding of the requirements included in the federal special education law (The Individuals with Disabilities Education Act – IDEA) to ensure that students with mental illnesses receive a free and appropriate public education, as required by IDEA;
- Identify and implement best practices for creating positive school climates that are inclusive of students with mental disorders and that reduce stigma (i.e. positive behavioral intervention and supports -- PBIS);
- Train school professionals to use “family wrap-around” practices as an effective model for delivering services for students with mental disorders and their families; and
- Develop better alliances with families with children with mental illnesses.

## Policy Recommendation 4

**Policymakers generally should not interfere with the right of access to treatment, the patient-provider relationship, the promotion of treatment, partnerships between parents, providers and other professionals serving the child. Any legislative or regulatory consideration related to the use of psychotropic medications for children and adolescents must be guided by science. Action should be taken only after obtaining testimony and input from qualified and well-recognized medical and mental health professionals and families and on the basis of sound scientific research.**

The task force recommended that advocates deliver the following messages to policy makers and legislators considering action that would restrict children's access to medications and treatment:

- Given the unacceptably high number of youth with mental illnesses that are not identified and receiving treatment (approximately 80%) and the crisis that has ensued, the focus should be on better education and training of providers, school professionals and families to address this crisis of under-identified children and adolescents;
- Legislators and policy makers do not attempt to address clinical issues or make clinical decisions related to the treatment of **other** childhood illnesses and should not do so with mental disorders without first obtaining input from well-recognized and respected mental health experts on the likely impact of their actions;
- Decisions that are made based on anecdotal information and without

appropriate consideration of the likely greater impact -- present the real risk of imposing harm to a large group of children; and

- Lawmakers should not inappropriately interfere with the patient/provider relationship and the rights of parents and caregivers to make medical decisions for their child, absent a clear showing that the parent's actions may cause harm to the child.

*Nearly 80% of youth with mental illness are not identified and receiving treatment. This is an unacceptable number.*

The task force recommended that NAMI develop model legislation for children's mental health that helps to ensure appropriate access to evidence-based and science-based treatment and service interventions.

### Other Considerations

In addition, the task force also considered the most effective way to refocus the debate on the failure to identify and treat children with mental disorders. The task force recommended that NAMI explore whether there is a link between the failure to identify and treat children with mental disorders and growing concern over barriers to learning and increased school failure.

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## NOTES