Policy Debate

CHILD AND TEEN MENTAL ILLNESSES AND THE NATIONAL HEALTHCARE CRISIS

by
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America's mental health system is in shambles.
- -Letter to President Bush from Michael F. Hogan, Ph.D., Chairman, President's New Freedom Commission on Mental Health, dated October 29, 2002.[1]

Students participating in the National Forensic League's policy debate contests have a unique opportunity to share in the ongoing national dialogue on the crisis in the mental health system for children and teens – apart from just the broader system. The highest levels of the federal government — including the White House, the Department of Health and Human Services (HHS), the Department of Justice (DOJ), the Department of Education (DOE), and the Surgeon General's Office have focused attention on the crisis. But attention so far has not been enough; we need real leadership and a real investment to see any change in the status quo that has existed for more than 20 years.

The burden of suffering experienced by children with mental health needs and their families has created a health crisis in this country...

--Surgeon General David Satcher (Report of the Surgeon General's Conference on Children's Mental Health, 2001)

The national media has also seized on the crisis and focused attention on the increasing prevalence of childhood mental illnesses and the lack of effective treatment systems. Most recently, Time Magazine featured a cover story entitled *Young and Bipolar* (August 19, 2002), and followed up with another article entitled *The Secret Sacrifice* (October 28, 2002), an article that exposes the practice of some states requiring families to give up custody of their child to secure services. Newsweek also recently featured a cover story on Teen Depression. (October 7, 2002) U.S. News and World Report followed suit with a story entitled *The Demons of Childhood – Young brains break. Then comes the broken care system.* (November 11, 2002) NAMI is pleased to lend its voice to this ongoing national dialogue and to share information that may be useful to students participating in the National Forensic League (NFL) debates.

The National Alliance for the Mentally Ill (NAMI) is the leading family member and consumer grassroots membership organization in the nation dedicated to improving the lives of children and adults with severe mental illnesses and their family members. NAMI supports education, outreach, advocacy and research on behalf of persons with serious mental illnesses such as schizophrenia, bipolar disorder, major depression, severe anxiety disorders and major mental illnesses affecting children and adolescents. The group that NAMI represents, those with severe and persistent mental illnesses, constitutes more than 5% of all adults, and nearly 10% of all children.

Our nation has abandoned people with mental illnesses – Especially children

The prevalence rates of youth with mental illnesses are staggering. Approximately 7-9% of all children have a diagnosable serious mental disorder, which translates into millions of youth and one or two of the children in every classroom.
- -New Freedom Commission's Interim Report, October 2002

NAMI is deeply concerned with the information recently reported to the President in the New Freedom Commission's Interim Report. It is consistent with the research and information in the Surgeon General's 2001 report on children's mental health. According to the Surgeon General's report, 1 in 10 children and adolescents in the United States suffers from a mental illness severe enough to cause impairment while fewer than 1 in 5 of these children receives needed treatment. The World Health Organization Global Burden of Disease Study indicates that by the year 2020, childhood neuropsychiatric disorders will rise proportionally by over 50% to become one of the five most common causes of morbidity, mortality, and disability among children. (WHO, 2001) The WHO report shows that when compared with all other diseases, including cancer and heart disease, mental illness ranks first in causing disability in the U.S., Canada and Western Europe.

[1] On October 29, 2002, the President's New Freedom Commission on Mental Health issued an Interim Report to the President that describes the critical problems in our nation's fragmented and broken mental healthcare system. All references in this article to the "Commission's Interim Report, October 2002" apply to that report which is available online at *www.mentalhealthcommission.gov*.

One thing is patently clear — too many children with mental illnesses are not receiving any services. The circumstances are even worse for African-American, Latino and other youth from ethnically and culturally diverse communities. Tragically, they often bear a significantly greater burden from unmet mental health needs and thus suffer a greater loss in overall health and productivity. (Surgeon General 2001 Report on Mental Health: Culture, Race, and Ethnicity)

What are the consequences for the roughly 80% of youth with mental illnesses who fail to receive services? The long-term consequences are staggering in both human and fiscal terms. Suicide is the third leading cause of death in adolescents aged 15 to 24. (Centers for Disease Control, 1999) Over 30,000 lives are lost each year to suicide. (Commission's Interim Report, October 2002) The evidence is strong that as many as 90% of children and adolescents who commit suicide have a mental disorder (Institute of Medicine Report, 2002 and Surgeon General, 1999).

Consequences of Untreated Mental Illnesses in Children and Adolescents--

- Suicide - 3rd leading cause of death in youth;
- 30,000 people lose their lives to suicide each year;
- 90% of those who commit suicide have untreated mental illness;
- Youth get locked up -- 80% of youth entering the juvenile justice system have a diagnosable mental disorder;
- Children end up in foster care where it is estimated that 85% of children have an emotional disorder or substance use disorder;
- Dramatically high rates of school failure and drop-out;
- 20% of families surveyed by NAMI gave up custody of their child to the state to secure services;
- Youth frequently turn to substance use to self-medicate;
- Youth are socially isolated from their peers.

Youth with untreated mental illnesses also tragically end up in the criminal justice system. An astounding 80% of children entering the juvenile justice system have a diagnosable mental disorder. (Commission's Interim Report – citing Cocozza and Sowyra article entitled *Youth with mental disorders: Issues and emerging responses*, Juvenile Justice Journal, April, 2000) The prevalence rates of children and adolescents with mental illnesses in the juvenile justice system is a moral outrage and speaks to our nation's failure to build a mental health treatment system.

Often, children end up in foster care – where it is estimated that up to 85% of children have significant mental health problems. (*Values and Principles for Mental Health and Substance Abuse Services and Supports for Children in Foster Care*, American Academy of Child and Adolescent Psychiatrists and Child Welfare League for America, June 5, 2002). For children, the failure to diagnose and treat a mental illness early often results in the loss of critical developmental years. Many children fail in school, fail to develop friendships and social skills. They also become isolated from their peers. Their inability to participate in school results in their failure to earn a diploma 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.

What is the impact of untreated and poorly treated mental illnesses in children on families? Simply put – devastating. Stigma and shame drives many families away from the treatment system. Suicide severely impacts the families left behind – who often wrongly live with extreme shame and guilt over not having prevented the death of their loved one.

NAMI is frequently contacted by families across the country who have struggled to get treatment for their child, and in the process attempted to navigate a fragmented, broken and underfunded system. Often these families have long since exhausted their private insurance benefits for mental health coverage (nearly all health insurance plans place restrictive and discriminatory caps on mental health benefits) and paying for intensive service is simply not financially feasible. Most of these families do not qualify for Medicaid benefits. Many families are told by state agencies and others that they can access critically needed treatment by relinquishing custody of their child to the state. This causes unthinkable stress for families, hit at their most vulnerable moment.

NAMI's 1999 report – *Families on the Brink, The Impact of Ignoring Children with Serious Mental Illness* – documents the prevalence of the custody relinquishment problem. In *Families on the Brink*, 23% of respondents to NAMI's national survey of parents and caregivers, reported being told that they would have to relinquish custody of their child to access services. 20% of the respondents reported they ultimately relinquished custody of their child to the state. Understandably, families are devastated to learn that their family must be torn apart and they must hand custody of their child over to the state to get care. Children who are turned over to the state often feel abandoned and unwanted. Imagine a family with a child with cancer or diabetes or any other major illness being told that they must give up custody of their child to get health care treatment.

Some families also report being told that to access treatment or services for their child, they should either call the police and have their child arrested or leave the child at a hospital or treatment center. An arrest means that the child *may* receive services through the juvenile justice system and parental abandonment means that the child will be referred to the child welfare system for possible treatment.

It is now well recognized that mental or emotional disorders are not "just a stage" or simply a function of poor parenting or crowded classrooms, but are real brain illnesses. We know with certainty that children do experience serious mental illnesses as well as a range of emotional and behavioral disorders that require and respond to treatment in the same way as other illnesses do. If properly treated, these children can experience a fairly typical childhood. They can establish friendships, learn in school, and improve their life chances dramatically.

The Federal Government must take a leadership role to overcome this national crisis

Our Nation's failure to prioritize mental health is a national tragedy.

- -New Freedom Commission's Interim Report, October 2002

The federal government must make the same commitment to childhood mental illnesses that it has made to childhood immunizations and screening for vision, hearing, lead and other health related issues. The federal government – including the U.S. Congress and federal agencies charged with research, oversight and the delivery of mental health services to youth with mental illnesses (HHS, DOE, DOJ, NIMH) — must take the lead to overcome this health care crisis, by addressing the following, which are described more completely below:

- Invest in redesigning the fragmented and broken service system and develop a national campaign to combat stigma;
- Work with state and local governments and families and mental health consumers to build an effective and accountable unified mental health service system to serve the needs of children and adolescents;
- Enforce and implement the federal laws that were enacted to remedy the civil injustices that have historically existed for those with mental illnesses (Individuals with Disabilities Education Act and Medicaid);
- Increase funding for research on early-onset mental illnesses and effective treatments; and
- Enact federal legislation to address discriminatory health insurance coverage for mental illness treatment (Mental Health Parity); health care coverage for families when children require intensive treatment (Family Opportunity Act); legislation to address the profound shortage of mental health treatment providers for children and the juvenile justice crisis.

States lack the resources and scope of understanding to do it alone. When the states cannot solve such problems, the federal government has a responsibility to act – as a partner in our federal system.

The various levels of government and different agencies must stop the finger pointing of responsibility that so often interferes with children receiving services. Families suffer greatly from the lack of treatment options – while one community may have an innovative mental health system for children and adolescents another state or community may have no available services. The system for delivering mental health services to children and their families is complex; the patchwork of providers, interventions and funding streams contributes to the lack of treatment. There is a desperate need for appropriately trained child psychiatrists, psychologists and social workers.

In addition to the need for an effective treatment system, we must stop the stigma surrounding mental illnesses. A national campaign should be established that includes partnerships with youth, families, media, the health care system (mental health and other treatment providers), schools (educators, counselors and other school personnel), community leaders and advocacy groups. We must reach children early. Education is the key to understanding and combating stigma and giving children with mental illnesses an equal chance in life.

Federal special education law—a good "IDEA" but not well implemented

Children with mental disorders who are identified for special education services have higher levels of absenteeism, higher drop-out rates, and lower levels of academic achievement than students with other disabilities.

- -New Freedom Commission's Interim Report, October 2002

The United States Congress enacted the Individuals with Disabilities Education Act (IDEA) as a civil rights statute in response to the neglect and failure of school systems to meet the most basic education needs of children with disabilities, including students with mental and emotional disorders. Students were routinely denied equal opportunity to fully participate in the educational system. The statutory provisions included in IDEA are strong and could be effective. Unfortunately, the federal government has failed to adequately implement and enforce the provisions of this critically important legislation, thereby denying students with mental illnesses their fundamental right to a free and appropriate public education. (National Council on Disabilities, *Back to School on Civil Rights*, January, 2000). The federal government should set the standard for state and local education agencies by enforcing implementation of IDEA. (See also, *A New Era: Revitalizing Special Education for Children and Their Families*, a report of President Bush's Commission on Excellence in Special Education – available at www.ed.gov/inits/commissionsboards/whspecialeducation/index.html) Enforcement and implementation of the federal law would improve the outcomes of students with mental illnesses.

The U.S. Congress also promised to fund IDEA up to 40% of the average per pupil expenditure for each special education student, but has never lived up to that promise. Congress has never funded more than 15% for special education. The new Congress just elected in 2002 should live up to the promise of full funding. Most schools fail to provide school personnel with basic training and education to understand the early warning signs and symptoms of mental illnesses, despite the high prevalence rates of the disorders. Without an adequate investment in education for students with disabilities, especially those with mental illnesses, and an investment in the appropriate training of school personnel, we will continue to see unacceptably poor outcomes for these students.

We know that for many children, their mental illnesses go undetected and thus, untreated. The federal government should ensure that states and local school districts have the resources for early identification and appropriate intervention to maximize the ability of students with mental illnesses to benefit from their education. They should also increase and encourage collaboration between state and local government agencies that serve children and adolescents (like community mental health centers, child welfare, juvenile justice and others) and schools. These systems must accept the financial and service responsibility for meeting the needs of children and adolescents with mental illnesses and their families.

Federal Medicaid law requires broad healthcare coverage for children who qualify – but kids still do not get the care that they need

Medicaid is a joint federal and state program that finances

health care coverage for 21 million, or more than 1 in 4 of our nation's children. Medicaid has been an effective healthcare program for millions of lower-income families who need basic healthcare. Despite the assistance that it has provided to many families, there are important components of the Medicaid program that require reform. One of the central services that federal Medicaid law requires states to provide is the screening of children to detect various conditions early and to treat them before the conditions worsen. The Medicaid early screening requirement is commonly referred to as "EPSDT" – which stands for Early and Periodic Screening, Diagnosis and Treatment.

Unfortunately, all too often, states fail to meet the EPSDT federal mandate and children in the program fail to be screened for early detection of illnesses – including mental illnesses. Research shows that the percentage of children receiving preventive care and screening of any kind through the Medicaid EPSDT requirement is low. (National Health Law Program, 2001 – National Review of EPSDT – information available at www.healthlaw.org, see also; U.S. General Accounting Office, 2001 – Report on *Medicaid: Stronger Efforts Needed to Ensure Children's Access to Health Screening Services* – information available at www.gao.gov; and Bazelon Center for Mental Health Law — Report on *Where to Turn: Confusion in Medicaid Policies on Screening Children for Mental Health Needs* – information available at *www.bazelon.org*.)

States also routinely fail to inform families that they are eligible for Medicaid. Moreover, for those families who are fortunate enough to be identified and enrolled, unduly complicated federal and state rules, procedures and other administrative barriers often exist in the Medicaid program. This prevents families from accessing the critically needed screening and follow-up services that are required by the EPSDT mandate. The failure of states to identify children with mental illnesses through the Medicaid EPSDT mandate is consistent with the deeply troubling research and information in the Surgeon General's 2001 report that showed that less than 20% of children who need treatment receive it.

What can be done at the federal and state levels of government to ensure that Medicaid eligible families receive the treatment and services that children with mental illnesses often require and are entitled to receive under the federal law –

- The federal government holds the purse strings and must take action to hold states accountable for providing mandated services for children with mental illnesses;
- The federal government, through the Center for Medicare and Medicaid Services (CMS) – the federal agency with oversight responsibility for the Medicaid program — must work with states to conduct outreach to Medicaid eligible families to make them aware of the EPSDT mandate;
- CMS must also maintain closer oversight of state Medicaid agencies to hold them more accountable for providing EPSDT services and to promote state EPSDT compliance – this includes requiring states to provide data on mental health referrals for children – something that is not currently required;
- CMS should identify states that are performing well in providing EPSDT services and other innovative service programs and share information with other states on what policies and procedures have been adopted to meet the EPSDT requirements and to address the needs of youth with mental illnesses;
- Both CMS and states should encourage state-sponsored physician and provider education programs to ensure that mental health treatment providers under the scope of the EPSDT requirements;
- Both the federal and state governments must provide adequate reimbursement to mental health treatment and service providers to increase the profound shortage of child and adolescent treatment providers participating in the Medicaid Program;
- CMS and state government should ensure family inclusion at every point of outreach, screening, diagnosis, treatment planning and implementation phases to ensure the best chance for the recovery of children with mental illnesses.

The Medicaid program *should* offer real hope for families with children with mental illnesses. Unfortunately, like so many other well meaning programs, it has not been well enforced or implemented at the federal or state levels and thus has failed in its purpose to identify children with illnesses early and to get them treatment. The program is simply not meeting the needs of many families across the country with children with mental illnesses. This contributes greatly to the crisis.

Scientific advances offer hope — our nation must continue to invest in research on early-onset mental illnesses

> *Research confirms that recovery from mental illness is real: there are a range of effective treatments, services, and supports to facilitate recovery. Medical science has devised treatments and services that work …*
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> - - New Freedom Commission's Interim Report, October 2002

Research is our best hope for the future. Science is giving us new and effective treatments every year. Years of hard work and investments in research have begun to pay off. Scientists have made breakthrough discoveries on how the brain works and that has resulted in new medications that help the brain work better at regulating emotions and thoughts. These medicines — when combined with cognitive behavioral therapy, home and community-based services, family education, wrap-around services, respite care – give children and adolescents with mental illnesses the chance to recover from their illnesses and enjoy a full and normal childhood. We must continue to invest in and support research on early-onset mental illnesses. This includes research on the use of psychopharmacology for children and adolescents with mental illnesses.

It is critical that Congress appropriates significant increases in federal funding of research at the National Institute of Mental Health (NIMH) – especially research focused on mental illnesses in children. The research funding for these illnesses should directly correlate to the disease burden and the high prevalence rates of mental illnesses in children and adolescents.

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 benefits outweigh the risks. Children and adolescents who are taking psychotropic medications must be closely monitored and frequently re-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. Many families report that medication and therapy has 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 will adversely affect a child's overall physical and mental development, including the ability to learn, socialize and function in the community.

Efforts must be undertaken at the federal level to bridge the gap between research and practice by disseminating information and promoting effective communication and appropriate sensitivity between and among healthcare and mental health providers, researchers, youth and families. We know that too often children and adolescents are not getting the best evidence-based treatment available because of the information gap.

NAMI is well aware of those who suggest that children and adolescents are being over diagnosed with mental illnesses and over treated with medications. These arguments largely recycle bad science and trivialize the need for early identification and treatment of mental illnesses in children and adolescents. Public policy involving treatment of mental illnesses in children and adolescents must be founded on science and shaped by research and scientific evidence, not science fiction or religious ideology. Research and science have disproved the baseless arguments of those who claim that we are over diagnosing and over medicating children.

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 should exist across all 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. There must be a coordinated effort to break down the barriers to appropriate identification and recognition of children with mental health needs and the factors that interfere with access to appropriate treatments and services. Research increasingly is showing that the failure to intervene and provide early treatment for many mental illnesses accelerates the course of the illnesses and may actually result in increased damage to the functioning of the brain.

Rather than focus on scientifically unfounded assertions, attention must be paid to the legacy of failure in this country to treat childhood mental illnesses and efforts must be made to fix the fragmented and broken system.

The U.S. Congress must show leadership by enacting federal legislation that will help to alleviate the mental health crisis in this country

Mental Health Parity

The health insurance policies of most Americans include adequate coverage for what have typically been called "medical or physical illnesses." That is not so for mental health coverage. Most policies include extremely restricted and discriminatory mental health coverage. There is simply no scientific or medical justification for insurance coverage of mental illness treatment to be so unfairly restricted in comparison to the terms and conditions for other diseases. Discriminatory insurance coverage of mental illness bankrupts families and places a tremendous burden on taxpayers through suicide, homelessness and the inappropriate "criminalization" of children and adolescents, as well as adults, with mental illnesses. The enactment of a federal mental health parity bill would change that by requiring insurance plans to provide coverage for mental illnesses at the same level or amount as coverage for other illnesses.

The good news is that parity is affordable! The Congressional Budget Office (CBO) estimates that the current Senate-passed parity bill (Senate Bill 543) would only increase insurance premiums by 0.9% (a finding that is consistent with numerous previous studies that demonstrate how non-discriminatory coverage is affordable). (To review the text of S 543 and the Senate Committee reports — visit — *thomas.loc.gov*)

Mental illnesses are real illnesses of the brain – treatment works, if you can get it – in fact, the treatment efficacy rates for most severe mental illnesses exceed those for heart disease and diabetes. There is simply no scientific or medical justification for allowing employers and insurers to continue to arbitrarily restrict and limit insurance coverage of mental illness treatment. The United States Congress simply should do the right thing and enact a federal parity law. To do otherwise will only serve to prolong the crisis.

Family Opportunity Act

This landmark federal legislation (Senate Bill 321) is intended to end the financial devastation that families too often encounter in attempting to access quality treatment for their children with mental illnesses. As many NAMI members know firsthand, families are often tragically forced to give up custody of their children to obtain the most appropriate treatment and services for them. This legislation offers the chance for stability and recovery for children with severe and chronic disabling disorders, including early-onset mental illnesses. It is a measure that will help put an end to the horrible choice – of forcing families to give up custody of their child to secure services — that loving and caring families must make in cases where there has been no abuse or neglect.

Under the bill, states would be able to offer Medicaid coverage to children with severe disabilities living in middle income families through a buy-in program. Cost sharing on a sliding scale up to the full premium cost will be required within certain guidelines that protect lower income families. Currently, families must stay impoverished, place their child in an out of home placement or simply give up custody in order to secure the health care services their child needs under Medicaid.

Federal Action is needed to address the profound shortage of mental health providers and for juvenile justice reform

A crisis exists in the shortage of qualified child and adolescent mental health providers in virtually every region of this country. This shortage is pronounced in rural and poor communities and disproportionately exists in our public mental health systems. Families are often told that they must travel tremendous distances to get mental health treatment for their ill child. This presents an incredible hardship for families who are already suffering from the burden of having a loved one with a mental illness.

According to a report of the American Academy of Child & Adolescent Psychiatrists, there are currently approximately 6,300 child and adolescent psychiatrists in this country and, given the existing prevalence rates of childhood mental illnesses, the need is currently at 30,000. (For more information, visit the American Academy of Child & Adolescent Psychiatrists web site at *www.aacap.org)*. The disparity between the number of psychiatrists and the need is projected to substantially increase in the years ahead. The shortage of children's mental health providers is not limited to psychiatrists it includes psychologists, social works and other professionals.

According to the National Center for Education Statistics in the Department of Education, there are approximately 513 students for each school counselor in United States schools, a ratio that is double the recommended ratio of 250 students for each school counselor. (For more information visit the National Center for Education Statistics web site at *nces.ed.gov*)

Congress must develop incentives, through legislation or programs, to attract more qualified professionals to child and adolescent mental health services and treatment. Legislation might include loan forgiveness and scholarship programs for new children's mental health professionals, grants for graduate programs to create or expand children's specialties and grants for community providers to train paraprofessionals, among other things.

On the juvenile justice front, the federal government, either through the U.S. Congress or the Department of Justice must take a leadership role in developing effective approaches to divert youth with mental illnesses out of the criminal justice system and into treatment systems. It is simply a moral outrage that our jails and prisons have become our nation's defacto mental health treatment system. This issue is intentionally included last to make the point that if we work to reform our mental health **treatment** system for children and adolescents – then we should not have to focus our reform efforts on the juvenile justice system. We would not tolerate treating children and adolescents with other serious illnesses – such as cancer or diabetes – like this and we should refuse to tolerate treating children with mental illnesses with this deliberate neglect and abandon.

Conclusion

Children and teenagers represent our nation's hope for the future. Those with mental illnesses deserve to experience accomplishments in childhood and to thrive in nurturing environments. Mental illnesses, like all childhood illnesses, should be detected early and children should receive appropriate treatment and services targeted to their specific needs. Without proper attention and a real commitment to change at the federal, state and local levels — the tragedies that result from unidentified and untreated mental illnesses in children and adolescents will continue.

*(**Darcy E. Gruttadaro**, is Director of the National Alliance for the Mentally Ill Child & Adolescent Action Center)*

NFL Executive Secretary

The NFL seeks applicants for the position of **Executive Secretary**, to begin effective August 1, 2003.

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