



THE BARRIERS

Why is it So Difficult for Children to Get Mental Health Screens and Assessments?

“...A fragmented services system is one of several systemic barriers impeding the delivery of effective mental health care. Our interim report describes other problems, including...our failure to intervene early in childhood, and our Nation’s failure to recognize mental health care as a national priority.”

Michael F. Hogan, Ph.D, Chair, President’s New Freedom Commission on Mental Health, 2002.

It is estimated that nationally four out of five children with mental health needs do not receive any help. Many of these children are not adequately screened or assessed so that they can receive appropriate treatment, services, and supports. Why don’t children get screens? Below we describe four different types of barriers they face and provide examples of each: service delivery issues, federal and state policy problems, family difficulties, and challenges in serving special populations of children.

Barriers: Service Delivery Issues

I. Lack of Clarity about Why, When, and How Children Should be Screened or Assessed

- There is inadequate attention paid to the importance of early screening for potential emotional, behavioral, or mental health problems.
- There is no single approach or agreed upon set of approaches for pediatric professionals to use for mental health screens.
- It is very difficult for children to get help even when families recognize that there are emotional, behavioral, or mental health difficulties. Children generally first need a specific diagnosis to receive services or supports.

II. Lack of Coordination of Multiple Systems

- Even under the best circumstances, it is difficult to coordinate services between public and private health care systems. Medicaid managed care further complicates the situation unless the specific roles and responsibilities of all participating public agencies and private companies are clearly defined.
- The service system is very fragmented as a result of different funding streams for children’s services and different eligibility requirements. Often families are left to coordinate their children’s services while trying to deal with the personal, family, and financial stress brought on by the child’s condition.
- When mental health services or treatment are delayed, families may turn to the child welfare system for help because they are overwhelmed by their children’s needs. Sometimes, children’s behavior gets so destructive that they end up in the juvenile justice system even before they receive an assessment.

III. Lack of Resources

- The demand for services and supports for children of all ages far exceeds the available resources. Resources are often concentrated on children with the greatest and most expensive needs. It is difficult to redirect public funds to make the appropriate investments in early prevention, detection, and intervention.
- A philosophical shift in programmatic and funding priorities is essential. Expanding resources for screens and assessments to detect children who can benefit from services and supports early on will help avoid much more expensive and extensive treatment later. Although residential treatment centers are used by a small percentage of treated children (8 percent), nearly one-fourth of the national expenditures for children’s mental health is devoted to care in these settings. [U.S. Surgeon General’s Report, 1999]

IV. Lack of Providers and Inadequate Reimbursement

- The demand for treatment, services, and supports for children of all ages far exceeds the number of available providers.
- Doctors and other health professionals do not receive adequate reimbursement for screenings.
- Non-mental health professionals who screen children need more information about the full array of mental health services and levels of care that are available in the community so they can recommend the most appropriate intervention. Specialized training would improve their ability to recognize warning signs of emotional, behavioral, and mental health difficulties and to provide appropriate guidance to families when serious problems are indicated.

“Our review...leads us to the united belief that America’s mental health service delivery system is in shambles... There are so many programs operating under such different rules that it is often impossible for families and consumers to find the care that they urgently need. The efforts of countless skilled and caring professionals are frustrated by the system’s fragmentation. As a result, too many Americans suffer needless disability and millions of dollars are spent unproductively in a dysfunctional service system that cannot deliver the treatments that work so well.”

Michael F. Hogan, Ph.D, Chair, President’s New Freedom Commission on Mental Health, 2002.

Barriers: Federal and State Policies

I. Lack of Early Detection and Early Intervention

- Program priorities and funding do not emphasize the value of early detection and intervention. As a result, emotional, behavioral, and mental health difficulties

often escalate and require more expensive services and supports.

- States too often view the Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) program as a program separate from Medicaid, although legally that is not true. This creates a situation where all children are not screened through EPSDT despite their legal entitlement to these services.
- State flexibility to design CHIP programs means that there are no standard benefits packages. There is no guarantee that children will receive full developmental screens that include mental health, as required by EPSDT in the Medicaid program.
- There is inadequate data to monitor screens and assessments. Data are lacking in a number of areas: number of well-child visits; frequency of mental health screens; follow-up with assessments; and referrals for appropriate treatment. Other important data needed include meaningful indicators to track family satisfaction and the quality of assessments.

II. Lack of Follow-Up

- Contrary to federal law, children who receive EPSDT screens that indicate a need for treatment do not always get the required follow-up. Federal law requires states to provide all “medically necessary” treatment that is indicated by a child’s screen. Instead, states often limit treatment to services listed in their Medicaid state plans.

III. Lack of Coordination

- There is little coordination or integration between state Medicaid and state mental health systems.
- There is little coordination between mental health services for children and adults. This is especially a problem for adolescents who “age out” of children’s services, but still need treatment and support services from the adult mental health system.

Full citations are included in the Action Strategies and Resources Guide.

Barriers: Family Difficulties

I. Lack of Access

- Families face a host of problems when attempting to access any health service. They may have trouble getting adequate information if they cannot read or do not speak English as their primary language. They may have difficulty getting to the service location if transportation is not provided or public transportation is limited. They may have difficulty finding necessary child care for their other children.
- Some families are reluctant to discuss emotional or mental health issues. They may view these as very private matters that should not be discussed outside the family. The situation is exaggerated when parents do not have consistent access to the same health care provider with whom they can develop a relationship of trust.

II. Inadequate Follow-up

- Families report that even if they successfully enroll their child in Medicaid, they often do not get complete information about the full scope of mental health benefits available through EPSDT.
- When children are released from residential treatment settings, their families are often left scrambling to find appropriate community services and supports to help their reentry into family, school, and community life.

III. Fear of Losing Custody of Their Children

- Families have tremendous fear about losing custody of their children if they acknowledge any challenges in caring for them at home. Advocates estimate that one in five families who has a child with a mental disorder has surrendered custody in exchange for treatment or services. This situation reflects the inadequacy of public and private insurance to meet children's mental health needs. Limits on mental health coverage in private insurance plans mean that even middle-class families cannot afford long-term care for their children. Children who qualify for Medicaid often cannot get services because there are not enough providers who accept Medicaid. This creates pressure on families to relinquish custody of their children to the public child welfare agency because, under federal child welfare laws, most children in state care are automatically entitled to Medicaid and its comprehensive screening, assessment, and treatment benefits. The Bazelon Center for Mental Health Law, the National Alliance for the Mentally Ill, a number of state organizations, and most recently, the U.S. General Accounting Office (GAO) have documented the custody relinquishment problem across the country, and it has attracted national media attention.

GAO Reports that Parents and Caregivers Must Relinquish Custody to Obtain Mental Health Services for Their Children

The U.S. General Accounting Office (GAO), in April 2003, released a report, *Child Welfare and Juvenile Justice: Federal Agencies Could Play a Stronger Role in Helping States Reduce the Number of Children Placed Solely to Obtain Mental Health Services*. It documents that the problem of parents having to relinquish custody of their children in order to obtain appropriate services for their mental health needs is extensive, affirming earlier findings by both the Bazelon Center for Mental Health Law and the National Alliance for the Mentally III. In some cases, the lack of available, appropriate, and affordable services for children leaves parents with no alternative but to place their children in the custody of the child welfare or juvenile justice system in order to get them the mental health treatment they need. Residential and other specialized out-of-home care can cost over \$250,000 a year for one child.

Based on interviews with child welfare directors in 19 states and juvenile justice officials in 30 counties, the GAO estimated that in fiscal year 2001, parents placed more than 12,700 children into the child welfare or juvenile justice system so that their children could receive treatment. Comprehensive national data on the number of children relinquished to these systems are not currently available, since many states and local jurisdictions do not track the number of children placed solely for the purpose of receiving mental health treatment. The GAO also heard from groups of officials that neither of these systems is designed to accommodate children who have not been abused or neglected or committed delinquent acts.

The GAO reported that parents have to turn to the child welfare or juvenile justice system because of the limitations of both public and private health insurance in covering comprehensive mental health treatment; the inadequate supply of appropriate mental health services; the limited availability of mental health services through schools; difficulty in meeting mental health service eligibility requirements; and lack of coordination among different child-serving agencies.

Barriers: Challenges in Serving Special Populations of Children

I. Diverse Cultural Views about Mental Illness

- Different racial and ethnic groups may have different views about disabilities and when it is necessary to seek professional help. Mental illness still carries a certain stigma in some cultures and may make families reluctant to seek help.

II. Lack of Access by Immigrant Children

- Families who come to live here from other countries may fear that getting mental health services through Medicaid or CHIP might jeopardize the family's ability to become citizens or to remain in the country.

III. Special Challenges for Teens

- Teens are especially sensitive to peer pressure. The stigma of “getting help” may make it very difficult for them to tell anyone how troubled they are. Sadly, some teens report that it is easier to admit substance abuse problems than mental health ones.
- Teens who want to get help often want assurances from their doctors about confidentiality. This is an age group that may not want their families to know that they sought help for mental health or drug or alcohol problems.

Full citations are included in the Action Strategies and Resources Guide.

- There are inadequate services and supports in most communities for adolescents, especially those making the transition from residential treatment.

IV. Children Who are Homeless

- Homelessness may be both a symptom and a cause of mental health problems. Regardless, children and families who are homeless often have very limited access to health or mental health services. It is not difficult to realize the impact on a child's mental health of having no home and facing tremendous daily stress.

V. Children in the Juvenile Justice System

- There is growing recognition about the increasing number of youths with mental health disorders who enter the juvenile justice system. Many also have co-occurring substance use disorders.
- Reports in recent years document that youth in the juvenile justice system receive inadequate, and often inappropriate, care and treatment.
- There is growing concern about an over-reliance on the juvenile justice system to provide mental health and substance abuse services to youth who might get more appropriate treatment in a community-based setting.

VI. Children in the Child Welfare System

- Emotional, behavioral, and mental health problems are particularly widespread among children in the child welfare system for a variety of complex family, social, and environmental reasons. These reasons include child abuse, drug exposure or drug use, teen pregnancy, school failure, family violence, and conduct disorders. Some parents may have mental health problems for

which they never received appropriate care. Children's experiences while in foster care, including frequent moves, may also exacerbate emotional problems.

- Approximately 60 percent of all children in out-of-home care have moderate to severe mental health problems. A substantial number of them have psychological problems so serious that they require residential placement. Yet, despite these needs, less than one-third of children in the child welfare system receive mental health services.

VII. Children Exposed to Violence in Their Homes, Communities, and through the Media

- Growing up in a violent home can affect all aspects of children's lives and development. It can make them less likely to succeed in school, more likely to commit and be victimized by violence, and more likely to face health and mental health problems that may last throughout their lives.
- Children growing up with domestic violence in the home may risk facing violence themselves. The overlap between domestic violence and child abuse is well-documented.
- Experts agree that children who see a lot of violence often show signs of increased stress and anxiety. Sometimes they also may show more aggressive behavior. They can benefit from mental health counseling to keep these concerns from escalating into more serious problems.