

A Citizens League Research Report.
Prepared for the Minnesota Department of Health
and the Minnesota Department of Human Services.

Meeting Every Child's Mental Health Needs: A Public Priority

Final Report of the Citizens League
Committee on Children's Mental Health

Marcia Avner and Keith Halleland,
co-chairs

January, 2001

CITIZENS LEAGUE
708 S. Third St., Suite 500, Minneapolis, MN 55415
ph: 612/338-0791 fax: 612/337-5919
info@citizensleague.net www.citizensleague.net

Executive Summary

In 1989, the Minnesota legislature passed the Children's Mental Health Act – landmark legislation that outlined a state supervised / county administered system for delivering mental health services to Minnesota's 1.2 million children. The goal was to ensure access to a continuum of services that would address the unique needs of individual children, in a manner sensitive to their cultural differences and special needs. Early screening and prompt intervention were to be available to all children. The services provided by social service, health, education and juvenile justice systems were to be coordinated and complementary. The entire system was to be “unified, accountable, [and] comprehensive.”

The Act also authorized the creation of local Children's Mental Health Collaboratives to bring together the numerous people and organizations that provide services to children with emotional disturbances. The Collaboratives were charged with “designing, developing and implementing” an integrated service system by calling on the resources and strengths of all of the collaboratives' members to meet the needs of children with emotional disorders efficiently and effectively. The idea was that the collaboratives would help eliminate some of the red tape and create a coordinated, seamless system focused more on meeting the needs of the child and their family than who is responsible for providing or who is going to pay for a particular service.

More than ten years after its passage, the mission of the Children's Mental Health Act remains utterly unfulfilled. The mental health services a child receives, and the degree to which those services are coordinated and easily obtainable, depends largely on what county the child lives in and the persistence of parents and family members. Education, prevention and early intervention efforts range from limited to virtually nonexistent. No one is held accountable when a child's mental health needs go unmet – and Minnesota's children are suffering the consequences.

The results achieved by the Collaboratives have been questionable, at best. While some appear to be running smoothly, others are either bogged down in arguments or lacking participation from key stakeholders. Factors such as the size of a county or the individual personalities of those involved appear to play a significant role in the success or failure of each collaborative. In many cases, the local collaborative seems to be adding another layer of bureaucracy rather than coordinating those that already exist.

As with many public challenges, more money and good intentions will not fix Minnesota's children's mental health system. A fundamentally different approach is required.

Recommendations

- 1. In order to ensure that every child's mental health needs are appropriately identified and met, Minnesota must take a public health approach to childhood mental illness.**

Core functions of a public health approach include community assessment ("knowing what needs to be done"), policy development and program planning ("being part of the solution") and assurance ("making sure it happens"). Taking "a public health approach" will provide a focus on the

population as a whole and an emphasis on both primary and secondary prevention, which the children's mental health system desperately needs.

In the area of children's mental health, the vision is a public health approach that will result in ...

- A new emphasis on prevention and early intervention.
- Increased efforts in the area of public education and parent education.
- A focus on the child population as a whole, rather than just those with most serious illnesses or fewest resources.
- Utilization of existing ties with the medical community and private insurance/managed care systems to improve coordination and cooperation in the area of children's mental health.
- Establishment and dissemination of a set of "best practice" treatment strategies and delivery models.
- Increased accountability.
- Increased data collection regarding outcomes and consumer satisfaction in both the public and private sector.

2. The state must take a stronger leadership role in order to ensure that the mental health needs of Minnesota's children are being met and that various systems are working together.

Voluntary collaboration is admirable, but strong top-level leadership is needed to bring together the large, bureaucratic systems involved in children's mental health. The state must play a stronger role and lead by example. This means ensuring that the children it insures through Medicaid and Minnesota Care receive the level and quality of mental health services it expects the private sector to provide its enrollees.

3. Within state government, the resources and authority for children's mental health should largely be shifted to the Department of Health (MDH).

The Department of Health is the best choice to lead a public health approach. It should be given the necessary resources and responsibility for increasing and improving education, prevention and early intervention efforts, broadening the focus to include all kids, bringing the private sector to the table, and collecting data and using it to hold public and private service providers accountable.

4. The policy of depending on voluntary Children's Mental Health Collaboratives to bring together major systems should be re-evaluated. The legislature should authorize and fund an independent evaluation of the Collaborative system to be completed by the 2003 legislative session.

This evaluation should focus on comparing outcomes for children in counties with collaboratives and outcomes in counties without collaboratives, in order to determine a set of best practices. It should also include a consumer satisfaction element in order to determine whether the collaboratives have been successful in reducing red tape and creating a more seamless system.

The Cost of Doing Nothing

For children, their families and our society, the costs of continuing on the current path are extremely high – in both financial and human terms. Our failure to prevent or intervene early in a child's mental health problems results in:

- Higher K-12 education costs and dramatically lower graduation rates.
- Increased use of expensive "deep-end" mental health services.
- Increased health care costs.
- An increased number of children in the juvenile justice system and other out-of-home placements.
- Suicide – the second leading cause of death among Minnesota children ages 10 and up.

Clearly, strong evidence exists to support early investments in a child's mental health. It not only saves money, but also reduces the human pain and suffering experienced by Minnesota's children and families. It is the smart thing to do – and the right thing to do.

Introduction

In the fall of 2000, the Minnesota Department of Human Services (DHS) and the Minnesota Department of Health (MDH) commissioned the nonprofit, nonpartisan Citizens League to gather citizen input on the children's mental health system. More specifically, the Citizens League Committee on Children's Mental Health was charged with examining the following issues:

1. What policies and strategies should Minnesota pursue to ensure that every child's mental health needs are appropriately identified and met? How can major systems be brought together to do the best job in identifying children's mental health needs?
2. Who is getting diagnosed and who is not? Where and when are children being diagnosed, and by whom? What are the systemic problems related to diagnosis and how should they be addressed?
3. How should we approach fears related to "labeling" children?
4. What resources are needed to guarantee access to appropriate services for children in all communities? How can we pay for the services needed?
5. What are the costs to society when we fail to prevent or intervene early in a child's mental health problem?

A committee of engaged citizens, working over the course of several months, researched these issues and produced the following findings, conclusions and recommendations, in response to the Departments' charge.

Background

According to the U.S. Census Bureau, there were approximately 1.2 million children living in Minnesota in 1999. We know that 47 percent are under the age of 8, and 53 percent are between the ages of 9 and 17. Most are white (89%), but a growing number are African American, Hispanic, and Asian/Pacific Islander. We know that approximately 20 percent live in Hennepin County, and another 10 percent reside in Ramsey County. We also know that about 6 percent, or approximately 72,000 children, have a serious mental disorder.

A recent report by the U.S. Surgeon General defines mental disorders as "health conditions that are characterized by alterations in thinking, mood, or behavior (or some combination thereof) associated with distress and/or impaired functioning." In children, these disorders are often referred to as "emotional disturbances."

Children are diagnosed with a "mental disorder" or "emotional disturbance" when the combination and intensity of their symptoms meets the criteria for a disorder listed in the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (DSM-IV). Disorders listed in the DSM-IV include:

- Anxiety Disorders
- Attention-Deficit and Disruptive Behavior Disorders
- Autism and Other Pervasive Developmental Disorders
- Eating Disorders
- Elimination Disorders
- Learning and Communication Disorders
- Mood or Depressive Disorders
- Schizophrenia
- Tic Disorders

When these disorders are "of such duration and severity that they substantially interfere with or limit a child's role or functioning in family, school or community activities," the child is considered to have a "serious emotional disturbance." National prevalence rates estimate that five percent of children ages 5 through 8 and nine percent of children ages 9 through 17 have a serious emotional disturbance. According to the Department of Human Services, applying these numbers to Minnesota's population yields the above estimate that six percent, or 72,000 Minnesota children, have a serious emotional disturbance.

Financing

In 1996, the United States spent \$69 billion on the diagnosis and treatment of mental illness. Of this \$69 billion, public dollars accounted for roughly 53 percent (\$37 billion) and private dollars accounted for roughly 47 percent (\$32 billion). About \$18 billion, or slightly more than half of the private expenditures, were made by the private insurance and managed care industries, while the remaining \$14 billion was the result of out-of-pocket payments, which include co-payments from individuals with private insurance, co-payments and prescription drug costs not covered by Medicare, and payments made by the uninsured or the insured who choose not to use their insurance coverage for mental health care.

In fiscal year 1999, Minnesota's public sector spent \$144 million on children's mental health services alone. This is in addition to the public dollars spent on adult mental health services and the private dollars spent on children and adults. Of this \$144 million, 30 percent came from the federal government, 27 percent from the state and 40 percent from county governments. Ultimately, this \$144 million resulted in mental health services for approximately 22,000 Minnesota children, or 30 percent of those believed to have a serious emotional disorder.

The Public System

In Minnesota, publicly funded mental health services for children are provided through a state-supervised / county-administered system using federal, state and local tax dollars. The Minnesota Department of Human Services provides the state supervision.

The basis for the existing system is the state's Children's Mental Health Act, which was passed in 1989. The act requires all counties to develop a children's mental health system with 12 components. However, as a result of our state-supervised / county-administered approach and the

fact that counties finance such a large portion of the system, each county is given a significant amount of discretion in determining priorities and allocating resources.

The 12 components that every county is supposed to provide, include:

- education and prevention services;
- identification and intervention services;
- emergency services;
- outpatient services;
- family community support services;
- day treatment services;
- residential treatment services;
- acute care hospital inpatient treatment services;
- screening;
- case management;
- therapeutic support of foster care;
- professional home-based family treatment.

Furthermore, the act specifies that education and prevention services must be available to all children residing in the county, and identification and intervention services must be available to "meet the needs" of all children residing in the county. The other ten services on the list are to be made available to children with "severe emotional disturbances." There is, however, no requirement that a child be from a low-income family in order to receive these services.

In addition to outlining the desired service system, the Children's Mental Health Act also authorizes the creation of local Children's Mental Health Collaboratives. These collaboratives were intended to bring together the numerous people and organizations that provide services to children with emotional disturbances. At a minimum, the law requires that each collaborative include a representative from the county, the juvenile justice system, one local school district or special education cooperative, and one mental health clinic or treatment provider. Some collaboratives also include parents of children with emotional disorders, mental health advocates, and representatives of various consumer, community, civic and religious organizations.

Overall, these collaboratives are supposed to "design, develop and implement" an integrated service system that calls on the resources and strengths of all of the collaboratives' members to meet the needs of children with emotional disorders efficiently and effectively. The idea is that the collaboratives will help eliminate some of the red-tape and create a coordinated, seamless system that is focused more on meeting the needs of the child and their family than who is responsible for providing or who is going to pay for a particular service.

It is important to note, though, that these collaboratives are voluntary and currently there are only 38 collaboratives serving 45 of Minnesota's 87 counties. Furthermore, it is very difficult to describe the "typical" Children's Mental Health Collaborative because there is so much variation from one county to the next. Some collaboratives are largely county-run and controlled, while others operate as completely separate entities. Some collaboratives have their own staff and provide programs and services directly to clients, while others work largely behind the scenes to

develop relationships and build linkages between their members' programs. Some collaboratives appear to be running smoothly, while others are either bogged down in arguments or lacking participation from key stakeholders.

Findings, Conclusions and Recommendations

The mission of the Children's Mental Health Act reads "*the commissioner of human services shall create and ensure a unified, accountable, comprehensive children's mental health service system that ...*

- *identifies children who are eligible for mental health services;*
- *makes preventive services available to all children;*
- *assures access to a continuum of services that:*
 - *educate the community about the mental health needs of children;*
 - *address the unique physical, emotional, social and educational needs of children;*
 - *are coordinated with the range of social and human services provided to children and their families by the departments of children, families and learning, human services, health, and corrections;*
 - *are appropriate to the developmental needs of children; and*
 - *are sensitive to cultural differences and special needs;*
- *includes early screening and prompt intervention to:*
 - *identify and treat the mental health needs of children in the least restrictive setting appropriate to their needs; and*
 - *prevent further deterioration;*
- *provide mental health services to children and their families in the context in which the children live and go to school;*
- *addresses the unique problems of paying for mental health services for children, including:*
 - *access to private insurance coverage; and*
 - *public funding;*
- *includes the child and the child's family in planning the child's program of mental health services, unless clinically inappropriate to the child's needs; and*
- *when necessary, assures a smooth transition from mental health services appropriate for a child to mental health services needed by a person who is at least 18 years of age.*

More than ten years after the passage of the Children's Mental Health Act, this mission remains utterly unfulfilled. Education, prevention and early intervention efforts range from limited to virtually nonexistent. The mental health services a child receives, and the degree to which those services are coordinated and easily obtainable, depends largely on what county the child lives in and the persistence of parents and family members. No one is held accountable when a child's mental health needs go unmet. The accountability for outcomes that is supposed to come with a system of local control is absent. And Minnesota's children are suffering the consequences.

1. What policies and strategies should Minnesota pursue to ensure that every child's mental health needs are appropriately identified and met? How can major systems be brought together to do the best job in identifying children's mental health needs?

A. In order to ensure that every child's mental health needs are appropriately identified and met, Minnesota must take a public health approach to childhood mental illness.

Core functions of a public health approach include community assessment ("knowing what needs to be done"), policy development and program planning ("being part of the solution") and assurance ("making sure it happens"). Taking "a public health approach" means a focus on the population as a whole and an emphasis on both primary and secondary prevention.

Primary prevention means "preventing disease and disability before they occur" by "promoting positive attitudes, skills and behaviors." In the case of diseases that cannot be prevented altogether, a public health approach provides secondary prevention, which focuses on "early detection and intervention to prevent an existing problem from causing serious or long-term effects." There is growing evidence that both are possible for a whole range of mental disorders.

In addition to creating an emphasis on education, prevention and early identification, labeling mental and emotional wellness a "public health issue" makes a clear statement. It lets people know it is an important issue, a health care issue, and an issue that affects society as a whole. It prioritizes the issue, grants a sense of urgency, and starts people thinking about solutions.

In the area of children's mental health, we envision a public health approach that will result in ...

- **A new emphasis on prevention and early intervention.** As in other areas mandated by the Children's Mental Health Act, education and prevention and early identification and intervention efforts vary widely from one county to another. Some counties have decided, either directly or indirectly, not to invest heavily in early identification because they don't have the resources to serve the additional children that would be identified. Other counties operate programs to screen specific groups of children, like those in homeless shelters or those involved in the juvenile justice system, and a few others are working to incorporate a mental health screening tool into the pre-kindergarten screening provided to every child.

Overall, of the \$137 million in public funds devoted to children's mental health in 1998, *only 3 percent* went to early identification and intervention efforts. This represents an extremely short-sighted use of public resources.

Some childhood mental illnesses can be prevented. Many others can be prevented from causing long-term damage. But this will only happen with early identification and intervention. Failure to identify and treat early has extreme costs – in both human and financial terms.

It is imperative that all children be screened for mental health problems at numerous points in their development, so that potential problems and illnesses can be detected early. We cannot wait to identify children until the public resources to serve them become available. Children and families have a right to know, and in some cases will be able to access treatment and services outside the public system. And unfortunately, there will probably never be additional resources until decision makers are presented with the cold hard facts regarding the level of unmet need.

- **Increased efforts in the area of public education and parent education.** Public education is a key component of any public health campaign. One of the primary messages that needs to be conveyed is that mental illnesses are medical conditions that result from both biological and environmental factors. There is also a need for public education regarding the prevalence of mental illness, the early signs and symptoms, and the risk and protective factors. When it comes to parent education, the need to have children screened for mental illness as part of regular health check-ups should be stressed.
- **A focus on the child population as a whole, rather than just those with most serious illnesses or fewest resources.** This is another hallmark of the public health field. Mental disorders afflict children of all ages, races, cultures and incomes. Therefore, the system needs to take a broader approach, rather than just focusing on those who are “the responsibility of the public sector.”
- **Utilization of existing ties with the medical community and private insurance/managed care systems to improve coordination and cooperation in the area of children’s mental health.** The mental health needs of Minnesota’s children are not going to be met by the public sector alone. The private sector – especially individual pediatricians/family practitioners and insurance companies/HMOs – must be brought to the table. The two sectors need to come to an explicit understanding of common goals in the area of children’s mental health. A public health approach is more likely to have success in this area than the old social service model.
- **Establishment and dissemination of a set of “best practice” treatment strategies and delivery models.** In recent years, medical science has made significant advances in its understanding of both the human brain and child development. There is a great deal of academic research about the effectiveness of various prescription drugs and therapeutic approaches. This information needs to be incorporated into useful delivery models and better distributed to the mental health professionals and general practitioners providing front-line care. Best practices in the delivery of culturally competent care are especially needed.
- **Increased accountability.** This is the assurance or “making sure it happens” element of a public health approach. Currently, no one is in charge of Minnesota’s mental health system. Many would say there is no “system” at all. No one is held accountable when a child’s mental health needs go unmet. No one has the ability to bring together all of the players

and get results. As it stands now, families in need of services and citizens looking for accountability just get a lot of passing of the buck -- between the public and the private sectors and between the counties, school districts and juvenile justice system. In any service system, the whole idea of local control is to allow increased flexibility in return for meeting high standards of accountability in outcomes. *The children's mental health system is not being held to high standards of accountability.*

- **Increased data collection regarding outcomes and consumer satisfaction in both the public and private sector.**

B. Stronger public sector leadership is needed in order to ensure that the mental health needs of Minnesota's children are being met and that various systems are working together.

Voluntary collaboration is admirable, but strong top-level leadership is needed to bring together the large, bureaucratic systems that have a role in children's mental health. The state must play a stronger role. Currently, there is too much variation between counties and not enough oversight. The services a child receives, and the degree to which those services are coordinated and easily obtainable, depends largely on what county and school district they live in. This is unacceptable.

Furthermore, there is a need for strong public sector leadership of the entire system, to make sure that the mental health needs of Minnesota's children are being met in both the public and the private sectors. First and foremost, the state must lead by example. This means ensuring that the children it insures through Medicaid and Minnesota Care receive the level and quality of mental health services it expects the private sector to provide its enrollees. The first step in achieving this is to fix the Early, Periodic Screening, Diagnosis and Treatment (EPSDT) program.

The EPSDT program makes comprehensive health check-ups available to all children, age birth to 21, who are eligible for Medicaid and Minnesota Care. This federally mandated service is known as Child & Teen Check-ups in Minnesota.

The program is optional on the part of families, so parents have to decide if they want their child to receive an EPSDT check-up. But there is no cost to the family and assistance is available to set-up appointments and arrange transportation.

The check-ups are intended to occur at 1, 2, 4, 6, 9, 15, 18 and 24 months and at 3, 4, 5, 6, 8, 10, 12, 14, 16, 18 and 20 years of age. Components of the EPSDT program include:

- **Early** assessment of a child's health so that possible disease and disabilities can be prevented or detected;
- **Periodic** assessment of a child's health at critical points in physical and mental development;

- **Screening** tests and procedures to determine whether further examination of the child needs to occur because of a physical (including dental) **or mental condition**;
- **Diagnostic** tests and procedures to determine the nature and cause of condition identified through screenings;
- **Treatment** services that control, correct or reduce physical **and mental health** problems.

Approximately 305,000 Minnesota children are eligible for these regular, comprehensive check-ups at no cost to them or their family. The state is spending \$7 million a year on outreach efforts to encourage families to take advantage of this program. The results? According to a recently published external review commissioned by the Department of Human Services, only 6 percent of eligible kids are getting the complete check-up, with all of the components mandated by law.

This, too, is unacceptable.

Despite the Department of Human Services' weak claims that a "mental health screen is not specifically required," the EPSDT program clearly includes mental health. This is an ideal opportunity to screen 305,000 Minnesota children and provide early intervention for those exhibiting signs of mental illness. *And it is going to waste!*

The Department of Human Services has received a great deal of feedback and recommendations from the State Advisory Council on Mental Health and the Office of the Ombudsman for Mental Health and Mental Retardation on how to address this problem. These recommendations must be taken seriously and the problem solved.

C. Within state government, the resources and authority for children's mental health should largely be shifted to the Department of Health (MDH).

The Department of Health is the best choice to lead a public health approach. Therefore, it should be given the necessary resources and then made responsible for increasing and improving education, prevention and early intervention efforts, broadening the focus to include all kids, bringing the private sector to the table, and collecting data and using it to hold public and private service providers accountable. The Department of Health should also be given the authority to coordinate children's mental health initiatives and programs housed at other departments, such as Human Services; Children, Families and Learning (CFL); and Corrections. However, the publicly funded service delivery system, which provides direct services to individual children, should continue to be overseen by the Department of Human Services – but in a more assertive manner.

D. Minnesota should re-evaluate the policy of depending on voluntary Children's Mental Health Collaboratives to bring together major systems.

More than a decade after the Collaborative concept was authorized, the results have been questionable, at best. After months of study, this committee was unable to sort out the numerous conflicting reports and arrive at a definitive evaluation of the collaboratives. Factors such as the size of a county or the individual personalities of those involved appear to play a significant role in the success or failure of each collaborative. In many cases, the local collaborative seems to be adding another layer of bureaucracy rather than coordinating those that already exist. And there appears to be plenty of players interested in controlling the collaboratives, but few interested in leading.

- **Therefore, the legislature should authorize and fund an independent evaluation of the Collaborative system to be completed by the 2003 legislative session.**

This evaluation should focus on comparing outcomes for children in counties with collaboratives and outcomes in counties without collaboratives, in order to determine a set of best practices. If this evaluation determines the collaboratives are seizing the opportunity for local control to produce better outcomes for kids, then the state needs to commit to this strategy more fully by increasing the incentives and the accountability, and seeing that they spread throughout the state.

This evaluation should also include a consumer satisfaction element. After all, one of the primary reasons for establishing collaboratives was to create a more seamless system and reduce the amount of red tape that children and families have to cut through in order to get their needs met. Standardized reporting systems generally don't capture this. Only consumer feedback can uncover whether a parent had to call five different places to get a question answered or had to fill out tons of paperwork every time they entered a new office.

2. Who is getting diagnosed and who is not? Where and when are children being diagnosed, and by whom? What are the systemic problems related to diagnosis and how should they be addressed?

Unfortunately, there is no centralized reporting system that combines data from both the public and private sector to paint a clear picture of who is and who is not getting diagnosed and treated for mental disorders. There is some information about the children being served through the public system, but there is no publicly available information about the number of Minnesota children being diagnosed and treated in the private sector, not to mention the gender, race/ethnicity, geographic location, or income level of these children.

Based on data collected by the Department of Human Services, we do know that children of color are disproportionately represented in the population of children receiving publicly funded mental health services. (See Table 1.) However, we cannot assume that the children being served in the public sector are representative of all children receiving mental health services. It could be that white children are being diagnosed and treated in the private sector, while children of color are

being diagnosed and treated in the public sector. The data to answer these questions just isn't available.

Table 1: Racial/Ethnic Breakdown of Children Receiving Publicly Funded Mental Health Services via Children's Mental Health Collaboratives, 1999.

Race/Ethnicity	% of State Population	% of those receiving publicly funded services	% of those receiving "intensive" services
White	89%	80%	71%
African American	4%	9%	16%
Asian/Pacific Islander	3%	2%	1%
Hispanic	2%	3%	6%
American Indian	2%	4%	5%

However, even without clear demographic data about who is and who is not having their mental health problems diagnosed, it is clear that there are several systemic problems related to diagnosis. Overall, this is not a problem of some children being served well by our current system, while others are not. As it stands now, the system is failing all types of children – black-white, urban-rural, native-immigrant.

The barriers to timely assessment and accurate diagnosis include ...

- **Limited understanding and buy-in from pediatricians and family practitioners regarding the importance of mental health.** Evaluation of a child's mental health should be a standard component of any check-up. Unfortunately, the necessary "buy-in" from pediatricians and family practitioners that would make this a reality is lacking. Too few pediatricians and family practitioners take the time to inquire about their patient's mental health. Given the shortage of mental health professionals and the fact that general practitioners are the only doctors many children ever see, this results in countless children's mental health problems going unrecognized.
- **A shortage of child and adolescent psychiatrists.** The Minnesota Medical Association has a roster of 8,000 doctors practicing in Minnesota. Of these 8,000 individuals, 354 list their specialty as psychiatry and 31 list their specialty as child psychiatry. The Minnesota Society of Child and Adolescent Psychiatry lists 93 current members, although many of them divide their time between children and adults. Regardless of which number you look at, this is insufficient to meet the needs of the estimated 72,000 Minnesota children with a serious emotional disturbance. And the problem is particularly acute if you live in Greater Minnesota or need culturally specific care. This shortage is passing much of the responsibility for diagnosis to generalists -- either pediatricians and family practitioners or psychiatrists that don't specialize in children and adolescents.
- **Numerous financial and insurance barriers.**
- **Absence of assessment tools appropriate for children and failure to employ those that do exist.**

There is no doubt that accurately diagnosing childhood mental illness is a very difficult task. Even more so than in adults, the potential signs and symptoms seen in a child must be evaluated within the context of their development and their environment. Arriving at an accurate diagnosis takes time and requires input from the child, their parents and family members, teachers and daycare providers, and the child's primary care physician.

Removing the existing barriers to quality diagnosis will require both short-term and long-term strategies. In the short-term, pediatricians and family practitioners need more training in order to recognize the signs and symptoms of childhood mental illness, they need to take the time to inquire about their patient's mental health and they need to see it as their duty to recognize and act upon any early signs and symptoms.

In the long-term, steps must be taken to increase the number of qualified mental health professionals practicing in Minnesota – especially child and adolescent psychiatrists. This will require creating an environment where these individuals want to practice – an environment that places a priority on children's mental health, and devotes resources accordingly.

3. How should we approach fears related to “labeling” children?

Unfortunately, labels are a fact of life in our society, especially when it comes to qualifying for public benefits. Therefore, in order to reduce fears about “labeling” children with mental disorders, the labels used must first be de-stigmatized at a societal level.

The terms “cancer” and “diabetes” are both labels for serious medical conditions, yet they don't carry the same negative connotations as “bi-polar disorder” or “schizophrenia.” This is the result of society's general understanding of diseases like cancer and the medical profession's increasing ability to treat them. In order to de-stigmatize the labels associated with mental disorders, we must invest in public education efforts so that society starts to see mental disorders as treatable medical conditions rather than abnormal behavior, personality or intelligence.

In addition to de-stigmatizing mental health labels at the societal level, the specific fears and concerns of parents must also be addressed. Parents need to view a mental health diagnosis as the first step toward helping their child, rather than a condemnation of their own parenting skills.

In order for labels to be better received, they must . . .

- **Be clearly and uniformly defined.** The parent of a recently diagnosed child, or even an average citizen, hears terms like “mental disorder,” “emotional disturbance,” “severe emotional disturbance,” “*serious* emotional disturbance,” and “emotional/behavioral disorder,” and wonders, “what the heck is the difference?” Furthermore, the federal government defines these terms differently than the state Department of Human Services, who defines them differently than the K-12 education system, etc. And while the difference between these labels can be the determining factor in eligibility for a particular social service or education program, none of them are specific or diagnostic enough to suggest a course of treatment for the child.

- **Be clearly explained to the child and their parents.** When a child receives a mental health diagnosis, the child (when age appropriate) and their parents need the same information that is regularly provided following the diagnosis of a physical illness. What does the diagnosis mean? What are the pros and cons of the recommended treatment and alternative treatments? What is the prognosis for treating and managing the disorder?
- **Yield something of value.** We don't want to label children just for the sake of labeling them. Labels should yield something of value, either by suggesting a course of treatment or opening the door to a useful service.
- **Come from a trusted/respected and culturally competent source.** No parent wants to hear a nonprofessional offer a diagnosis of their child's mental health. This is a particularly important issue for children and families from diverse racial, ethnic and cultural backgrounds who bring unique views and perspectives to the field of mental health. It is essential that labels applied to children of color come from a culturally competent source.
- **Be correct the first time, whenever possible.** There are countless stories of children who receive a new diagnosis every time they visit a new clinic. After labels have been applied and discarded several times in the course of a few years, it is no wonder that parents view the most recent label with some suspicion. While recognizing that what is a correct diagnosis for a child at age five might no longer be correct at age 14, the continuous revising of labels and diagnosis must be minimized. This can be accomplished, in part, by ensuring that professionals refrain from diagnosing beyond their level of competence.

4. What resources are needed to guarantee access to appropriate services for children in all communities? How can we pay for the services needed?

Additional human, financial and informational resources are desperately needed in order to meet the mental health needs of Minnesota's children.

Human Resources – There is an overall shortage of child and adolescent psychiatrists practicing in Minnesota and an acute shortage of people with the cultural competency to treat children of color. As mentioned above, additional incentives are needed to increase the number of child and adolescent psychiatrists. This might include offering fellowships to allow experienced psychiatrists to gain an additional specialty in child and adolescent psychiatry, internships and job shadowing programs designed to encourage undergraduates to attend medical school with the specific goal of becoming a psychiatrist, and special residency programs to draw medical students to Minnesota.

Financial Resources – While there is no question that additional financial resources – from both the state and the private sector - will be necessary if we are going to meet the mental health needs of all Minnesota children, the first step is to use existing resources more wisely. Smarter investments in prevention and early intervention would yield measurable savings on the other end of the spectrum. Secondly, enforcement of existing parity laws can help ensure that insurance and managed care companies are not withholding resources from the children's mental health system.

The committee does see a special need for additional state resources in two specific areas. The first is in the Department of Health, which currently has no appropriations to address mental health and will require an investment of state resources in order to initiate a public health approach. Once again, though, it is important to remember that a public health approach, with special emphasis on prevention and early intervention, will yield savings down the road – but it is going to take time to see the return on this investment.

Secondly, in order to address the shortage of professionals willing to provide mental health treatment to Minnesota's children, additional state resources must be devoted to increasing Medicaid reimbursement rates for children's mental health care. To build support for additional state funding, firm evidence must be available regarding the level of unmet need.

Informational Resources – When a child is diagnosed with a mental disorder, parents are faced with countless decisions to make and numerous questions of their own. They need a more structured place to turn for information. Therefore, a formal information and referral service for families should be developed. This service could be built and supported by an expanded Office of the Ombudsman for Mental Health and Mental Retardation and might take a form similar to the state's existing Senior Linkage Line

Additionally, the professionals who work with children – including teachers, school counselors and social workers, pediatricians and family practitioners – need additional information about the signs and symptoms of childhood mental illness and where they can direct the families of children exhibiting these signs and symptoms.

5. What are the costs to society when we fail to prevent or intervene early in a child's mental health problem?

When we fail to prevent or intervene early in a child's mental health problem, the costs to that child, their family and our society are extremely high – in both financial and human terms. For example:

- **Higher K-12 education costs.** Children with emotional and behavioral disorders are often placed in special education programs, which cost more money per student than regular classroom programs. The Department of Children, Families and Learning estimates that it costs \$7600 per year to educate a child with a disability – roughly twice what it costs for a child without a disability.
- **Dramatically lower graduation rates.** Children with emotional and behavioral disorders who are in special education programs have a graduation rate of only 22 percent for a four year high school program. This is even lower than the overall four year graduation rate from special education programs, which stands at 45 percent. In today's economy, it is very difficult for individuals who don't have at least a high school diploma to find fulfilling employment and earn a living wage. From society's perspective, individuals without a high school diploma can be expected to pay less in taxes and receive more social service and welfare benefits than those with a high school diploma.

- **Use of expensive "deep-end" mental health services.** It costs less to treat a child's mental health problems early, or to prevent them altogether, than to wait until they need crisis services and inpatient or residential treatment. For example, estimates suggest it costs \$43,000 per year to provide residential treatment to a child with a serious emotional disturbance compared to just \$3,000 per year to provide home visits for a family.
- **Increased health care costs.** Individuals with untreated mental illness often consume excessive amounts of general health care services. This includes multiple trips to their primary care physician with complaints of an upset stomach, headache, difficulty sleeping and general aches and pains when the real problem is an undiagnosed mental disorder. The American Psychological Association estimates that "50 to 70 percent of usual visits to primary care physicians are for medical complaints that stem from psychological factors."

A recent study conducted by the Mayo Clinic in Rochester followed 4,880 Minnesota children for nine years. The study found that children with Attention Deficit Hyperactivity Disorder (ADHD) were more likely to have asthma, suffer major physical injuries and receive hospital inpatient, outpatient and emergency care services than children without ADHD. From a financial standpoint, children with ADHD were found to have average health care costs of \$4,306 compared to \$1,944 for their peers without ADHD.

- **Increased number of children in the juvenile justice system and other out-of-home placements.** Of the children with serious emotional and behavioral disorders who drop out of school, 73 percent are arrested within five years, according to the Children's Defense Fund. They also estimate that 60 percent of teenagers in juvenile detention facilities have behavioral, mental or emotional disorders.

It costs Minnesota taxpayers approximately \$50,000 per year for every child kept in a juvenile correction institution, where they may or may not be receiving the mental health treatment they need. This is in addition to the court costs associated with prosecuting and defending these children, and the costs paid by the victims of juvenile crime.

Additionally, mental health is a significant issue for the 11,800 Minnesota children in out-of-home placements such as foster care. Out-of-home placement is a rapidly increasing expense for most counties, and a traumatic experience for children and families.

- **Suicide.** When we fail to prevent or successfully intervene in a child's mental health problems, that child often ends up paying the ultimate price. Suicide is the second leading cause of death among Minnesota children ages 10 and up. According to the U.S. Surgeon General, 90 percent of the children and adolescents who commit suicide have a mental disorder. In 1998, the Minnesota Student Survey found that 19 percent of girls and 15 percent of boys in the 12th grade had thought about committing suicide in the past year, while 4 percent of girls and 3 percent of boys had actually attempted suicide in the past year.

Clearly, strong evidence exists to support early investments in a child's mental health. It not only saves money, but also reduces the human pain and suffering experienced by Minnesota's children and families. It is the smart thing to do – and the right thing to do.

Appendix: Work of the Committee

Background

The U.S. Surgeon General's recent report on mental health outlines a number of issues and concerns related to the diagnosis of mental health problems that first occur in childhood or adolescence. Many of these revolve around the need for specialized professionals who are capable of sorting out serious problems from the many variations on normal behavior that occur during development.

There are not enough of these providers; the reimbursement system is discouraging the preparation of adequate numbers of them for the future; they are geographically distributed in ways that make access difficult for many families; and too few of them represent or are competent in dealing with children from communities of color.

As a consequence, some children's needs are missed altogether; some receive inappropriate diagnoses or are diagnosed on partial criteria; diagnoses may follow regional or profession-specific trends or diagnoses may follow from available treatment methods rather than leading them.

While there may be cases in which diagnosis is primarily a gateway to services and these concerns are secondary, for many specific mental health problems, these are serious issues and need the attention of both public and professional forums.

Charge to Task Force

The Department of Human Services and the Department of Health charge the task force to study the following questions:

1. What policies and strategies should Minnesota pursue to ensure that every child's mental health needs are appropriately identified and met? How can major systems be brought together to do the best job in identifying children's mental health needs?
2. Who is getting diagnosed and who is not? Where and when are children being diagnosed, and by whom? What are the systemic problems related to diagnosis and how should they be addressed?
3. How should we approach fears related to "labeling" children?
4. What resources are needed to guarantee access to appropriate services for children in all communities? How can we pay for the services needed?
5. What are the costs to society when we fail to prevent or intervene early in a child's mental health problem

Committee Membership

The Children's Mental Health Study Committee was co-chaired by Marcia Avner and Keith Halleland. A total of 22 individuals took an active part in the work of the committee. In addition to the chairs, they were:

Brad Brown	Judy McDonald
Lou Burdick	Todd Otis
John Colonna	Beverly Propes
Bright Dornblaser	Dennis Schapiro
Susan Fisher	Ann Cullen Smith
Emma Foss	Joy Sorenson Navarre
BraVada GarrettAkinsanya	Robert Stepaniak
Virginia Greenman	Mary Tambornino
Kay Gudmestad	Parker Trostel
Roger Israel	Jack Wallinga

Meetings and Resource Testimony

The committee met for the first time on October 16, 2000 and concluded its deliberations on January 29, 2001. The committee met thirteen times, studied a large and varied amount of printed materials and heard from the following resource speakers:

Don Allen - MN Dept. of Human Services, Children's Mental Health Division
Jannina Aristy - MN Dept. of Human Services, Children's Mental Health Division
Boyd Brown - Office of the Ombudsman for Mental Health & Mental Retardation
Dr. William Dikel - Consultant
Dr. Norena Hale - Office of Special Ed, MN Dept of Children, Families & Learning
Lois Harrison - MN Dept. of Health
Joel Hettler - Ramsey County, Children's Mental Health Department
Kathy Kosnoff - Disability Law Center
Vicki Kunerth - MN Department of Human Services
Dr. James Moore - Southdale Pediatrics
Judy Parr - Wilder Foundation
Tonja Rolfson - MN Dept. of Human Services, Children's Mental Health Division
Jose Santos - Director, La Familia Guidance Center
Rob Sawyer - Olmsted County, Division of Children and Family Services
Mary Jo Verschay - Ramsey County, Children's Mental Health Collaborative
Jill Weise - MN Dept. of Human Services, Children's Mental Health Division

Staffing

This report was prepared by Kristine Lyndon Wilson. Administrative support was provided by Trudy Koroschetz and Gayle Ruth.