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Welcome

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Mental Health Board Trustee



Welcome to the Spring 2002 issue of *How's YOUR Mental Health?* The City of St. Louis Mental Health Board of Trustees (MHB) developed this quarterly e-zine to help St. Louis residents become better informed about mental health and substance abuse. Many people know relatively little about these topics, even though an MHB study found that 31 percent of city voters surveyed have an alcoholic in their immediate family, 22 percent have a relative addicted to other drugs and 25 percent have a close relative who is mentally ill. Directly or indirectly, these are problems that touch all of us.

Each edition of “*How's YOUR Mental Health?*” focuses on a topic that impacts the lives of many St. Louisans. This issue is devoted to serious emotional disturbance (SED), which is of particular interest to MHB because it affects children and their families in such devastating ways. The stories that follow describe:

- What SED is, its symptoms and causes
- The impact of SED on children and their families
- The services children with SED require
- The tragedy of bureaucracy that may require parents to relinquish custody of a child to obtain adequate treatment for SED
- A commentary focusing on a recent report on SED that **has** lead to helpful legislation
- A link to MHB's board and staff
- Links to useful web sites and other sources of information

MHB hopes you will find these stories informative and useful. And we hope this e-zine will help readers to be more aware of the signs of potential trouble and where to get appropriate assistance.

The Goal Is Appropriate Services Based in the Child's Home and Community

A Special Commentary by:

Joe Squillace, Health Policy Analyst, Citizens For Missouri's Children



In 1982, Jane Knitzer noted in her book, *Unclaimed Children*, that two million of the three million children and youth experiencing a serious emotional disturbance and their families were not receiving adequate services. Eleven years later, the situation was even worse. According to the National Mental Health Association and the Federation of Families for Children's Mental Health, from 66 to 80 percent of children with a serious emotional disturbance were not receiving appropriate services in 1993.

It is a problem that is a growing concern in St. Louis. An editorial in the Post-Dispatch on May 12 spelled out the tragedy that can result when appropriate services are not available. And tragically, for many Missouri families, the only means of getting services today — two decades after Knitzer's book appeared — is to give up custody of their child or to place the child in an institution.

Anticipating the statewide funding deficit changes that will make a bad situation even more desperate, a St. Louis-based organization called Citizens for Missouri's Children (CMC) addressed this situation in March 2002 in a policy brief titled "A Choice That Parents Should Never Face: Relinquishing Custody of their Child to Obtain Mental Health Care." It emphasizes that obtaining appropriate mental health services for children in the private market is a difficult, if not impossible, task for many Missouri families, especially those with low or moderate incomes.

If a family has health insurance, they usually turn first to that resource for help, only to find that mental health services are often not covered or limited. Instructed to try the Missouri Department of Mental Health, they are discouraged to learn that inadequate funding means that DMH can serve only 20 percent of the children who potentially qualify for state-funded services. Families may be placed on a waiting list or just turned away.

The child's school, although involved with his/her problems on a daily basis, may not offer needed services because the district discourages schools from providing mental health services or because appropriate mental health services were not included in a

child's Individual Education Plan (IEP). Also, parents may be reluctant to have their child receive special education services for fear that he/she will be stigmatized.

The Goal Is Appropriate Services Based in the Child's Home and Community, continued

In desperation, families may turn to the Division of Family Services (DFS). In numerous conversations with families and mental health professionals, CMC interviewers found that DFS caseworkers, police officers, workers in residential treatment facilities, mental health providers and even judges often advise parents that their child's mental health needs can be met if the family is willing to relinquish custody of the child to the state. Parents are then deprived of the authority to make medical, educational and other important decisions about their children's lives. While this is distasteful, it is often the last resort for many families struggling with managing their child's mental health.

In 1998, the National Alliance for the Mentally Ill (NAMI) and the Federation of Families for Children's Mental Health conducted a national survey of families interested in or dealing with issues related to children's mental health. Among the significant statistics that emerged were:

- 23 percent of families responding had been told by a government official that they should relinquish custody of their child(ren) in order to obtain necessary mental health services.
- 20 percent of respondents actually **did** relinquish custody.
- About half of the families responded that managed-care organizations limited or denied necessary treatment for their child, resulting in a negative impact on the child's health.
- 36 percent of the families had children that were placed in juvenile justice facilities because adequate mental health services were not available.

Services Available in Missouri for Children with SED

One resource for Missouri children with the most severe forms of SED is the Division of Comprehensive Psychiatric Services (CPS) in the Department of Mental Health. CPS operates residential treatment, inpatient hospitalization, therapeutic foster care, respite care, targeted case management and day treatment services. Unfortunately, due to extremely limited funding, it is difficult for families to access these programs. Of the

approximately 52,900 children with severe needs who would qualify for these services, CPS can serve just over 20 percent, or 11,041. This

The Goal Is Appropriate Services Based in the Child's Home and Community, continued

leaves about 42,000 families struggling with private insurance or Medicaid, reluctant — and often ill-prepared — schools, the juvenile justice system or the option of going without services altogether.

Citizens for Missouri's Children has become aware of increasing reliance on residential treatment children and teens. While this is an appropriate placement for some children, many people believe that residential facilities are an overused placement for troubled children and teens. Children with SED often require a high level of intensive and coordinated mental health treatment and behavior management which may not be available in a contained facility.

No single treatment service — residential treatment, outpatient family therapy or targeted case management — should be considered wholly appropriate for all children with mental health needs. And regardless of the type of treatment or placement required, parents should never be forced to relinquish legal custody of the child in order to obtain these services.

Under Missouri law, if a parent is unable to obtain adequate and affordable mental health services for the child — either home-based or out-of-home placement — the court can order DFS to provide any and all necessary services. In the past, in order for the courts to get involved, there had to be a charge of neglect or abandonment against the parent. If this occurs, the courts could order DFS involvement by taking legal custody of the child.

Physical custody — where the child will live — can either remain with the parent, with DFS providing home and community-based services, or be given to DFS, with the agency moving the child to a residential facility, foster home or other DFS placement.

By law, the court should consult with all relevant state agencies and private practitioners involved with the child before assigning legal custody to DFS. However, this is an extremely difficult statute to uphold because of the lack of coordination among public and private agencies. Missouri law also mandates that all efforts be made toward family reunification by identifying and planning for necessary services for the child and family. In general, this is meant to apply to DFS services and programs. In the case of children with SED, these necessary services could include case management, wrap-around services and other long-term home and community-based services. These are not the types of treatment that DFS normally purchases, which means that the child and family find themselves in a system that is unable to meet the child's needs.

The Goal Is Appropriate Services Based in the Child's Home and Community, continued

Effects of Custody Relinquishment

When a family gives up legal custody of their child in order to obtain the mental health services he/she needs, these are the negative consequences that occur:

- The parent has no control over where, how and when their child is treated. **The child may be sent to live across the state or even out of state without parental consent.**
- **In the past, a permanent mark of child neglect or abandonment has been put on the parent's record** — despite no neglect or abandonment having been committed. Not only is this ethically questionable, but it prevents parents from holding jobs working with children, including teaching and early care and education. **Recent action by the Missouri Legislature, awaiting the Governor's approval, will change this.**
- Depending on familial income, the parent may also be required to make "child support" payments to the State of Missouri while their child is in treatment. **Not only would the family pay for a service they may not want their child to participate in, but their already limited resources would be further depleted.**
- **Parents often feel guilt or loss.** The inadequacy of the mental health delivery system forces them to make an otherwise unthinkable choice between retaining responsibility for their often unmanageable child or giving decision-making authority and control to a state agency to obtain the help their child desperately needs.
- **Separation is especially difficult for children with SED. It may cause them to believe they have been abandoned by their families and may contribute to their feelings of worthlessness.**
- Relinquishing custody sometimes forces children into expensive residential placement, rather than allowing them to remain with their families with lower cost in-home or community-based services being provided. It wastes public funds by keeping children wards of the state when their basic needs could otherwise be provided by their families.

The Goal Is Appropriate Services Based in the Child's Home and Community, continued

There is, finally, hope for progress. In response to CMC's policy brief, legislation has been introduced in both the Missouri and the U.S. House of Representatives that would make it possible for parents to relinquish custody of a child to secure necessary mental health services without being charged with neglect or abandonment. MHB urges everyone concerned with the provision of adequate mental health services for children to let their state and national representatives know that they strongly endorse this legislation. We also encourage you to:

- Advocate for legislation that supports these other important goals . . .
 - Ensuring that children and youth receive the mental health services they need
 - Making it unnecessary for parents to have to relinquish custody in order to get DFS to pay for mental health services

- Lobby DMH officials . . .
 - To extend the Home and Community-Based Waiver to apply to children with SED and disregard parental income when considering financial eligibility

 - To extend the Sarah Jian Lopez Waiver to apply to children with SED

 - To fully enforce delivery of all mental health services mandated under federal Medicaid Early and Periodic Screening, Diagnosis and Treatment laws

 - To review cases in which parents relinquished custody to obtain mental health services to assess whether the MC+ Medicaid managed-care companies had been providing children with appropriate services.

Working together, we can make life easier for children with SED and their families.

*Based on information from "A Choice that Parents Should Never Face:
Relinquishing Custody of Their Child to Obtain Mental Health Care"
Policy Brief Citizens for Missouri's Children
March 2002
and
ARCH Fact sheet Number 34
ARCH National Resource Center for Crisis
Nurseries and Respite Care Services
May 1994*

How SED is Identified

Serious emotional disturbance (SED) is a term used to describe a combination of emotional, behavioral or mental disorders. The Individuals with Disabilities Education Act (IDEA) defines SED as a condition exhibiting one or more of the following characteristics over a long period of time and to such a marked degree that educational performance is adversely affected:

- An inability to learn that cannot be explained by intellectual, sensory or health factors
- An inability to build or maintain satisfactory interpersonal relationships with peers and teachers
- Inappropriate types of behavior or feelings under normal circumstances
- A general pervasive mood of unhappiness or depression
- A tendency to develop physical symptoms or fears associated with personal or school problems

It is important to note that SED is **not** a diagnosis. Rather, it is used to describe a combination of conditions in especially severe forms. IDEA's definition includes schizophrenia, but does not apply to children who are socially maladjusted, unless it is determined that they have serious emotional problems.



In the U.S. Department of Education's annual report to Congress in 2000, it was noted that 463,172 children and youth with SED were receiving services in the public schools during the 1998-99 school year. As is the case with most psychological illnesses, it can be assumed that the incidence of SED is both under-reported and vastly under-served.

Various factors, including heredity, brain disorder, diet, stress and family functioning, have been suggested as causes of SED, but research has not shown any of them to be directly related. Despite on-going research, the causes have not been adequately explained.

Children with SED display such characteristics and behaviors as:

- Hyperactivity (short attention span and impulsiveness)

- Aggression/self-injurious behavior (acting out/fighting)
- Withdrawal (failing to initiate interaction with others; retreating from exchanges of social interaction; being excessively fearful or anxious)
- Immaturity (inappropriate crying, temper tantrums, poor coping skills)
- Learning difficulties (performing academically below grade level)

Children with the most serious emotional disturbances may exhibit distorted thinking, excessive anxiety, bizarre motor acts and abnormal mood swings and are sometimes identified as having a severe psychosis or schizophrenia.

Of course, many children who do **not** have emotional disturbances may display some of these behaviors at various times. Perfectly normal youngsters sometimes act impulsively, cry and squabble with their playmates. But when these behaviors continue over long periods of time, signaling that a child is unable to cope with his/her environment or peers, a serious emotional disturbance may be indicated.

*Adapted from Fact Sheet No. 5
National Information Center for Children and Youth with Disabilities
December 2001*

How SED Affects Children and Their Families

There are approximately 53,000 children in Missouri with emotional disturbances serious enough to qualify for state services, but only about 11,000 of them - just under 21 percent - are actually receiving assistance from state-funded agencies. Many families do not have health insurance and, even those who do often find that their coverage, including Medicaid/MC+, excludes the cost of services for a child with SED.



Typical behaviors that a child with SED may exhibit are included in these hypothetical cases:

~Jason is eight. He has no apparent physical ailments, and his test scores indicate he has normal intelligence, but he does not complete his work in class and his grades are poor. He has difficulty staying on task and often interrupts the teacher and other students with inappropriate outbursts that sometimes escalate into temper tantrums. His behavior is a problem, both in the classroom and on the playground. He won't follow rules, doesn't like to share or take turns and is often aggressive - fighting, spitting and using bad language. More than once, his teacher has caught Jason stabbing his arms and legs with a sharp pencil. It's no surprise that other children avoid him.

~Sarah, who's ten, is a shy, quiet child. Her parents and teachers can't understand why her grades are poor when ability tests indicate she is brighter than average. She is never disruptive in class, but it's obvious her mind is often not on her work. When Sarah is called on, she has trouble expressing herself or maintaining eye contact. Other children try to draw her into their activities, but she prefers to watch from the sidelines. She often begs to stay home from school, saying she has a stomachache or headache, and frequently requests to go to the school nurse's office. She cries easily when she's frustrated - and often for no apparent reason at all. Sarah told a counselor she's afraid something might happen to her parents while she's at school.

~Two real-life stories about families with children with SED reveal the violence that can occur. Justin, 14, has been raised by his grandparents. Serious trouble at school for threatening classmates and teachers and frequent fighting led to court-ordered probation and a stay at a mental health facility. Under a waiver for Medicaid Home Community Base Services (HCBS) - available in three states, including Kansas for children with SED - Justin now sees a case manager from a mental health center on a regular basis, is in therapy with a psychologist at the center and sees a physician who prescribes medication. They have helped Justin learn to control his temper and stop instigating fights, but he still doesn't understand why his anger flares up so violently.

~Robert, who's nine, gets along well with other children, but has serious trouble with adults. He goes berserk when anyone touches him. The major disruptions he caused at school often resulted in his removal from the classroom. The principal wanted him hospitalized. His mother says that, because Robert is a very bright little boy, "He can figure out where your buttons are and push with the best." Therapy and home schooling are helping him learn to stop and think before acting out. His behavior in Jiu-jitsu class has improved so much that they can't believe it's the same kid.

A report issued in 1994 by the U.S. Department of Education Office of Special Education and Rehabilitative Services Office of Special Education Programs revealed that students with SED have lower grades than any other group of students with disabilities and fail more often to be promoted. Forty-four percent received one or more failing grades in their most recent school year, compared to 31 percent for all students with disabilities. Of those who took minimum competency tests (22 percent were exempted), 63 percent failed some part of the test.

Eighteen percent of students with SED are educated outside of their local schools, compared to six percent of all students with disabilities. Of those in their local schools, fewer than 17 percent are placed in regular classrooms, in contrast with 33 percent of all students with disabilities.

Forty-eight percent of students with SED drop out of grades 9 through 12, as opposed to 30 percent of all students with disabilities and only 24 percent of all high school students. Forty-two percent of youth with SED earn a high school diploma, compared with 50 percent of all youth with disabilities and 76 percent of youth in the general population.

Twenty percent of students with SED are arrested at least once before they leave school, as opposed to nine percent of all students with disabilities and six percent of all students. Fifty-eight percent of youth with SED are arrested within five years of leaving school, as opposed to 30 percent of all students with disabilities. Of students with SED who drop out of school, 73 percent are arrested within five years of leaving school.

Without appropriate help, these young people will carry their problems, likely magnified, into adulthood. The next story, "Services for Children With SED and Those Who Care for Them Need," describes the help they should receive - help that is too often not available.

Services for Children With SED and Those Who Care for Them Need



As early as 1994, the U.S. Department of Education's Office of Special Education and Rehabilitative Services Programs issued a "National Agenda for Achieving Better Results for Children and Youth with Serious Emotional Disturbance." It began with a statement that failing to address their needs threatens the success of the nation's educational objectives and limits life-long opportunities for many individuals. The report included the information that

their families are more likely to be blamed for the student's disability and are more likely to make tremendous financial sacrifices to secure services for their children. It was also noted that teachers and aides who work with students with SED are more likely to seek reassignment or to leave their positions.

A new program for children and youth with SED was authorized by Congress in 1990 under Part C of the Individuals with Disabilities Education Act, mandating the provision of a free, appropriate public education. Seven interdependent strategic targets were identified for improving the educational experience for students with SED:

- Expand positive learning opportunities and results
- Strengthen school and community capacity
- Value and address diversity
- Collaborate with families
- Promote appropriate assessment
- Provide ongoing skill development and support
- Create comprehensive and collaborative systems

These targets are based on the assumption that a flexible and proactive continuum of services must be built around the needs of children with SED and their families, that the services must be comprehensive and sustained and that they collaboratively engage children with SED, their families and service providers. Finally, family-centered, cross-agency, school- and community-based relationships must be characterized by mutual respect and accountability.

In terms more meaningful to laymen, this is what children with SED and their families need:

- Early recognition of the problem, before it escalates out of control

- Intervention that focuses on self-control, self-management, self-advocacy and conflict resolution skills for the child
- Except as a last resort, using intervention tactics other than removing the student from the regular classroom, which does not solve the problem and may prevent him/her from developing the academic and social competencies required for success throughout life.
- Mentoring and training for parents, classroom teachers, special educators and service providers to help them understand the needs of children with SED, along with field-based workshops to give them the opportunity to share information, experiences and ideas for working successfully with these students. Class size may need to be reduced. Mental health specialists can be used as trainers, consultants and in-school resources.
- Recognition that families are a child's most intimate support system and that they must be allowed to advocate for their child and be included in planning and providing services. This family-responsive approach should include:
1) designating a single person to coordinate services for the family; 2) establishing single-point-of-entry intake procedures for all services; 3) staffing technical assistance centers with family members; 4) expanding the role of families and care givers at IEP meetings and placing a family report on the agenda for these meetings; and 5) including families in outreach planning and cultural competency training.
- Appropriate, ongoing assessment - tied to services rather than labels - that is capable of capturing a child's changing developmental needs. Results should identify the support and modification necessary for the successful integration or re-integration of students with SED into regular education settings.
- Respite care for temporary relief in severe cases to help families avoid placing their child in an institution.
- Appropriate mental health services available to every family at a cost they can afford.

Some schools are "ahead of the curve" in dealing with children with SED. For example, special education teachers in the Radford (Virginia) City Schools met at the beginning of the 1997-98 school year to discuss the characteristics of SED and developed a web page to help parents and others understand the disability. Families with a child between two and 21 who exhibits the symptoms described on the web page are invited to contact the school's Child Study Team, who will review the referral and assist with remedial strategies or make a referral for an initial evaluation.

In most cases, a child with SED will require services beyond what the school is able to provide. Change must occur in the system that in many communities requires parents to

attempt to maneuver through a fragmented, confusing and overlapping aggregation of services in education, mental health, health, substance abuse, welfare, youth services, correctional and vocational agencies, where they must endure competing definitions, regulations and jurisdictions. Coordination among agencies must increase and improve.

Most of all, families need reassurance that their child's problems are not their fault, along with the promise of understanding, compassion and cooperation from other caregivers and service providers. They also need the financial assistance necessary to keep their child at home when at all possible and to retain the right to make decisions in his/her best interest. Tragically, this does not always happen. The commentary which follows deals with this issue and the possibility of remedying it.

*Some material adapted from
"A National Agenda for Achieving Better Results
for Children and Youth with Serious Emotional Disturbance"
U.S. Department of Education
Office of Special Education and Rehabilitative Services
September 1994*

Resources:



Where to call for mental health help or to get more information:

Citizens for Missouri's Children www.mokids.org	314-647-2003
National Information Center for Children and Youth with Disabilities www.nichcy.org	1-800-695-0285
National Mental Health Association www.nmha.org	1-800-969-NMHA
American Academy of Child and Adolescent Psychiatry www.aacap.org	1-202-966-7300
Council for Exceptional Children http://ericec.org	1-800-328-0272
Federation of Families for Children's Mental Health www.ffcmh.org	703-684-7710
National Clearinghouse on Family Support and Children's Mental Health www rtc.pdx.edu	1-800-628-1696
Behavioral Health Response (BHR) 24-hour crisis hotline staffed by professional counselor www.bhrstl.org	314-469-6644
City of St. Louis Mental Health Board of Trustees www.stlmhb.com	314-535-6964
City of St. Louis Mental Health Board Comment Line	314-658-3603

Help with Gambling

1 800-BETS-OFF

Life Crisis Service

314-647-4357

24-hour hotline staffed by trained volunteers

www.lifecrisis.org

**Missouri Department of
Mental Health**

314-877-0370

Eastern Region Office

dmhmail@mail.dmh.state.mo.us

**The Greater St. Louis
Treatment Network**

1-888-287-6060

stlouis.missouri.org/gsltn

**Substance Abuse Mental Health Information
Online (SAMHI)**

<http://stlouis.missouri.org/samhi/>

- A fact sheet with general information and links to other resources provided by National Information Center for Children and Youth with Disabilities
<http://www.nichcy.org/pubs/factshe/fs5txt.htm>
- Research and Training Center on Family Support and Children's Mental Health
<http://www.rtc.pdx.edu/> The four web sites below are provided by this center at Portland State University in Oregon.
- The Virtual Clearinghouse contains links to organizations that provide information regarding: child, adolescent, and family support and support organizations in all fifty states; advocacy; information on specific disabilities and disorders; legislation, legal issues and the rights of children with emotional and behavioral disorders; community support; education for children with emotional and behavioral disorders. <http://www.rtc.pdx.edu/pgClearinghouse.shtml>
- eResearch: Finding and Evaluating Internet-based Information is a guide to finding quality, useful information about the mental health field on the Internet. eResearch offers information that is at an introductory level; however, eResearch also provides links to Internet tools, tutorials and other resources that can help even experienced Internet users become more effective at searching for and evaluating information. <http://www.rtc.pdx.edu/pgeResearchMain.shtml>
- Youth Resources features a comprehensive list of youth-focused web sites, useful for youth, parents, researchers, and service-providers. Sites are organized

into 13 categories, including advocacy, peer support, youth-led research and programs, youth art production and stories, and web pages specifically for youth.
<http://www.rtc.pdx.edu/pgYouthResources.shtml>

- Written in accessible, user-friendly language, the sources linked to Glossaries, Dictionaries, and Tutorials are helpful for decoding and demystifying acronyms, jargon, statistical concepts and research terminology. This page also contains links to sites, which describe some of the tests and
- evaluations, which are often administered to children with emotional and behavioral disorders. <http://www.rtc.pdx.edu/pgGlossaries.shtml>
- Web site of the Bazelon Center for Mental Health Law, with references to a number of useful publications, including Making Sense of Medicaid for Children with Serious Emotional Disturbance. <http://store.bazelon.org/skuCM1.html>
- A fact sheet on respite care for families with children experiencing a serious emotional disturbance from the National Respite Network and Resource Center. <http://www. chtop.com/arch/archfs34.htm>
- "Listening to the Voices Of Adolescents With Serious Emotional Disturbance," case studies from the Pennsylvania Department of Public Welfare http://www.dpw.state.pa.us/omhsas/CASSPNews/SEP/omhCassp_ListenEmotionalDist.asp
- The Pacer Center in Minneapolis has published several books that may be helpful to parents, including A Guidebook for parents of Children with Emotional or Behavior Disorders and Honorable Intentions: A Parent's Guide to Educational Planning for Children with Emotional or Behavioral Disorders, both by D. Jordan. <http://www.pacer.org/publications/ebd.htm>
- Random House/Times Books in New York is the publisher of It's Nobody's Fault: New Hope and Help for Difficult Children by H. S. Koplewicz. <http://www.randomhouse.com/catalog/display.pperl?isbn=0812929217>