

GUIDE

**ACTION STRATEGIES AND**

RESOURCES

Promoting Children's  
Mental Health Screens  
and Assessments

Children's Defense Fund

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# ACTION STRATEGIES

## Examining Children's Mental Health Screens and Assessments

**T**his Action Strategies and Resources Guide, a part of the Children's Mental Health Resource Kit, is designed to help you promote access to and the availability of mental health screens and assessments for children in your state. Please review the Fact Sheets included in the Resource Kit to familiarize yourself with key facts and background information. Use the Resources portion of this guide to find other materials and organizational support available on children's mental health. The action strategies offer you specific steps you can take to move this important agenda forward in concrete ways in your own state and community. They will help you examine what's currently available and to expand screens and assessments. We encourage you to use these action strategies with other individuals and organizations to build broad and powerful networks capable of improving children's access to mental health services.

The Children's Defense Fund developed these action strategies to help you begin to build support to increase your state's investment in children's mental health screens and assessments. Start by examining what is currently being done in your state. Collect information that will help build support for improvements in early detection, prevention, and prompt interventions for children with mental health needs.

The Action Strategies include:

- #1. Determine the status of children's mental health advocacy in your state.
- #2: Collect basic data about mental health screens and assessments.
- #3: Collect data to show how the state allocates funds for children's mental health services.
- #4: Collect personal stories from families about their experiences trying to get mental health screens and assessments for their children.

### **Strategy #1: Determine the status of children's mental health advocacy in your state.**

All states have active family groups that work to promote services and supports for children and youth with emotional, behavioral, or mental disorders and their families. Many of these family groups work in partnership with a variety of professional organizations and other advocates to promote children's mental health. Examples of information you want to know include:

- What family groups have organized to address state policies and procedures affecting children's mental health? See resources and references section of this guide for contact information for the Federation of Families for Children's Mental Health, the National Mental Health Association, and the National Alliance for the Mentally ILL. You will also want to connect with other groups working on children's mental health issues.

# ACTION STRATEGIES

- Is there an existing coalition of families and professionals working to increase attention and funding for children's mental health screens and assessments? If a coalition does not exist in your area, consider organizing one. Helpful allies include pediatricians, child psychiatrists, school psychologists and nurses, social workers, law enforcement officials, educators, and other children's health advocates.
- Do your state or local elected or appointed officials have a special interest in children's mental health issues? Individuals who have someone in their immediate or extended family with mental health problems are often the most interested in improving policies and procedures that can increase access to services and supports for this group of children and families.

## **Strategy #2: Collect basic data about mental health screens and assessments.**

You'll want to get basic data about screens and assessments along with relevant state policies and procedures.

### **Gather different types of information on children's mental health services and treatment.**

- Ask for program data, evaluations and audits.
- Get copies of any relevant state or local plans about mental health services and children's mental health services specifically.
- Ask for specific information about the children's mental health system such as waiting lists for services, descriptions of unmet needs, relevant litigation, or proposed administrative or legislative changes.

- Review formal recommendations from advisory groups or legislative committees for information about the status of children's mental health services in your state.

### **Check with the following to get the information.**

- Start with the state Medicaid Director and/or Medicaid agency staff that work on children's services.
- Ask the State Mental Health Director. Most have one individual assigned to children's mental health.
- Check with appropriate individuals in the child welfare, early intervention and pre-school, education, and juvenile justice agencies. Ask the children's mental health contact who is the best source in each of those agencies. Given the multiple funding streams for children's mental health, all of these public agencies can help increase children's access to mental health screens and assessments.
- Check with the state Mental Health Advisory Council, children's advisory councils or children's mental health advocacy groups.
- Don't forget about the family groups. They often are most active on these issues and have collected useful information.

### **Ask questions about mental health screens and assessments.**

Be specific. Examples of questions include:

- Does the state have any written policies and procedures about children's mental health screenings? If so, request copies. These documents can provide basic information for you to monitor how well the state implements its own policies and procedures.

## Examining Children’s Mental Health Screens and Assessments

- Does the state recommend a specific mental health screen for Medicaid providers to use? What is used? What, if anything, do they recommend for CHIP providers?
- For children enrolled in Medicaid managed care: Does the state Medicaid agency retain responsibility for children’s screenings or does the managed care company perform the screenings? Is this issue addressed in the managed care contract and, if so, how? If the managed care company is responsible, who monitors performance of its legal obligation to provide these screens?
- What data does the state collect about mental health screens performed by Medicaid providers? Does it show how many screens are performed? The frequency of screens for different age groups? What follow-up treatment resulted from the screens? You want all this information to monitor how the state provides the full range of EPSDT services—screens, diagnostic assessments, and treatment.

**Strategy #3: Collect data to show how the state allocates funds for children’s mental health services.**

Most states allocate more funds for residential care of children with emotional, behavioral, or mental health disorders than for preventive services or for screens or assessments. Examples of questions to ask include:

- Does the state have any written policies and procedures about how it will allocate funds for children’s mental health services? These documents can provide basic information and help you to monitor how well the state implements its own policies and procedures.
- How much does the state spend on children’s mental health screens and assessments?

- Which public agencies conduct these screens and assessments? Request this information from Medicaid, child welfare, early intervention and pre-school, education, and juvenile justice agencies. Find out if any other agencies are also involved.
- How much does the state spend for residential care for children, both in and out of the state? How many children are in residential care each year, both in and out of the state?
- Is the state actively trying to bring children home from out-of-state residential placements? What steps is it taking to do so? What services and supports are now available for these children and their families?

**Strategy #4: Collect personal stories from families about their experiences trying to get mental health screens and assessments for their children.**

At a time when budgets for human and social services are shrinking, it is more and more important that you have cost/benefit data. Although public officials need to have the dollars-and-cents data, do not overlook the power of families’ personal experiences. Tragically, the vast majority of families can back up the public policy argument that “you pay now or you pay more later,” because when they were unable to get services for their children at an earlier time, the situation often continued to get worse. The real life stories of children and families are very compelling. Whenever possible, show how the combination of data and personal anecdotes supports the policy solutions you propose.

Keep family stories focused, short and simple. They should state the facts and not place any blame. Be sure to include policy solutions for any problem described and explain how the policy change would

# ACTION STRATEGIES

produce better outcomes for the children and families. It is helpful to collect a diverse group of family stories: children of all ages (infants, pre-school, school age and adolescent); foster children; and kinship care families where grandparents or other relatives are raising children.

This Resource Kit focuses on the need to improve access to mental health screens and assessments through Medicaid and CHIP so children will be more likely to receive appropriate treatment. To help make the case for such improvements, document families' experiences in the following areas:

- Do families get Medicaid information that describes the full range of mental health services that are available? What do they get from CHIP about mental health services?
- If children qualify for Medicaid, are families told that a mental health screen is available and where to get it? How many children got their mental health screen and how often? What happened to children who got no screens?
- If children qualify for CHIP, are families offered a mental health screen? How many children got a mental health screen and how often through CHIP? What happened to children who got no screens?
- Did children receive any initial mental health screening when their problems first became evident? If not, did their mental health problems become more serious?
- Did children receive any assessment for specific treatment or services if their mental health screening indicated there was a problem to address? If not, did their mental health problems get even more serious?
- Was mental health treatment provided to children whose screens indicated the need for it? What treatment was offered? Was it home or community-based? Was it residential care only? Was the residential treatment offered in or out of state? Were parents told to go to the child welfare system for help?





# ACTION STRATEGIES

## Expanding Children's Mental Health Screens and Assessments

Once you have taken steps to examine children's mental health screens and assessments in your state, you can then take further steps to expand children's access to mental health screens and assessments. We describe five action strategies. Each strategy has several steps to consider. You may decide to pursue one or more strategies at the same time or sequentially because they require different amounts of time to plan and implement. The action strategies include:

- #1. Educate families, policymakers, and the public about the need to address children's mental health problems as early as possible.
- #2. Promote the availability and use of screening tools in settings where children and families already receive services.
- #3. Encourage prevention and early intervention services.
- #4. Expand delivery models for mental health screens and assessments.
- #5. Organize advocacy and monitoring to expand access to mental health screens and assessments.

In addition to considering these strategies, be sure to check the resources and references section of this guide for specific references to organizations, reports, and articles that can help you develop an agenda to expand access to mental health screens and assessments for children.

**Strategy #1: Educate families, policymakers, and the public about the need to address children's mental health problems as early as possible.**

Despite frequent media attention to children's increasing mental health needs, there is still an appalling lack of knowledge about the scope of these problems and the long-term serious consequences for children, their families, and communities when they are not addressed. At the local and state levels, it is important to increase awareness about the profound long-term effects of unrecognized and untreated emotional, behavioral, and mental disorders on children's development, their family and social life, their ability to learn, and even their ability to lead productive adult lives. A huge part of the public education effort must focus on decreasing the stigma of mental problems so that children and families will seek help as early as possible.

### **Organize Anti-Stigma Campaigns**

Consider working with others to organize an anti-stigma campaign in your community or state. The "Caring for Every Child's Mental Health" campaign is funded by the federal Center for Mental Health Services. It is a national public information and education campaign to increase public awareness about children's emotional, behavioral, and mental health problems and to reduce the stigma associated with them. Designed to help families, educators, health care providers, and young people, the campaign encourages early, appropriate treatment and services. See the resources and references section of this Guide for the Center's Web site where you can download an order form for its extensive collection of products,

# ACTION STRATEGIES

including brochures, fact sheets, videos, bookmarks, print public service announcements, posters, and other materials. You can order these products in quantities, and Spanish-language campaign products are also available.

## Promote Local and State Public Education Efforts

Several national organizations can help you organize local and state public education efforts. Choose a segment of your community to educate. You may want to begin by focusing on one agency, such as early childhood providers, the schools, or your child welfare or juvenile justice agency. The Federation of Families for Children's Mental Health, National Alliance for the Mentally ILL, and National Mental Health Association all have wonderful local and state contacts. See the resource and references section of this Guide for the national contact information for these organizations.

## Prepare State and Media Reports on Children's Mental Health

Some children's organizations are trying to increase public awareness about the inadequacy of children's mental health services in their states. These efforts are designed to educate the public, elected officials, and policymakers about effective strategies that may already exist in their states or ones to consider implementing. Broader children's advocacy groups are getting involved because, even if they have not traditionally focused on mental health issues, they want to ensure access to all EPSDT services (including screens) and highlight the effectiveness of early identification and early intervention strategies. Examples of recent state reports include:

- *Children's Mental Health Services in Rhode Island: An Issue Brief*. Rhode Island KIDS COUNT, October 2002. See [www.rikidscount.org](http://www.rikidscount.org).

- *Relinquishing Custody: An Act of Desperation*. Maryland Coalition of Families for Children's Mental Health, September 2002. See [www.mdcoalition.org](http://www.mdcoalition.org).
- *Speak Out for Access: The Experiences of Massachusetts Families in Obtaining Mental Health Care for their Children*. Health Care for All and the Parent Professional Advocacy League, November 2002. See [www.hcfama.org](http://www.hcfama.org) and click on "Children's Division" and then "Children's Mental Health."

In the last several years, the general media has also focused attention on the unmet mental health problems of children and the need to address them. Mainstream weekly news magazines and daily newspapers have highlighted teen suicide and depression in children as well as other related topics. Two outstanding examples include:

- *Time* magazine "Custody or Mental Health?" highlights what families face when forced to relinquish custody of their children to state child welfare systems so they can get the mental health services they need. See [www.time.com](http://www.time.com), October 22, 2002.
- *Herald News*, Portland, Maine, "Castaway Children: Maine's Most Vulnerable Kids," August 18-20, 2002. A three-part newspaper series highlighting the tremendous difficulties faced by Maine families who try to get mental health care for their children. Includes very useful charts and statistics that make a compelling case about how to redirect resources for more home and community-based care. Available at [www.portland.com/news/children/020818](http://www.portland.com/news/children/020818).

You might also use the April 2003 U.S. General Accounting Office report, *Child Welfare and Juvenile Justice: Federal Agencies Could Play a Stronger Role in Helping States Reduce the Number of Children Placed*

# Expanding Children's Mental Health Screens and Assessments

*Solely to Obtain Mental Health Services*, to generate interest in your own state about parents having to relinquish custody to get treatment for their children's unmet mental health needs. See Barriers Fact Sheet in this kit for a summary of the report.

**Strategy #2: Promote the availability and use of screening tools in settings where children and families already receive services.**

There are certain basic questions about mental health screens that can guide your efforts to explore what now exists in your state and how to improve access to screens. Consider questions like the following:

- What screening instrument is appropriate?
- How often are screens offered?
- Who administers them?
- Where are children screened?
- Is it part of a more comprehensive screen or a specialized mental health screen?
- What is the cost and who will pay for it?
- What background information is needed from children's parents or caregivers?
- Who gets the results of the screens?
- What is done to help ensure that the instruments are culturally appropriate?
- What is done to ensure screens lead to more comprehensive assessments and then to treatment?

## Types of Screens

To fulfill their EPSDT obligations, some states use one screen to ask both physical and mental health questions. Other states use specialized screens with only mental health questions. Other screening instruments have "prompts" that allow screeners to probe about possible mental health problems. We discuss options

for states to consider in the Fact Sheet, "What Do We Know about Children's Mental Health Screens and Assessments?" There, we also review the Bazelon Center for Mental Health Law's survey of state EPSDT screens. The survey showed that almost half the states had no separate mental health screening tool nor any specific mental health questions or prompts in a comprehensive screen.

## Personnel and Locations for Mental Health Screens

Some researchers have explored appropriate developmental assessments that include mental health screens for special populations of children. In recent work, both the National Center for Children in Poverty and the Georgetown University Center for Child and Human Development addressed the need for appropriate screens and assessments for very young children and those in foster care, respectively, but their findings are relevant for most children who show signs of emotional, behavioral, or developmental difficulties.

Building upon their recommendations, you might want to consider the following suggestions:

- Expand the range of professionals who provide mental health screens. For example, place clinical social workers in pediatric care settings.
- Use locations for screenings that are not threatening for children and families. Examples of locations to consider include: child care programs; pre-schools and schools; community-based provider networks and agencies; and school or community health clinics, especially for teens who are particularly aware of peer pressure. See further discussion about school-based health clinics on page 13.

# ACTION STRATEGIES

- Train a wider group of professionals to recognize early signs of mental health problems so they can make appropriate referrals for formal assessments. For example, child welfare and early intervention professionals.

The U.S. Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau, funded the development of *Bright Futures in Practice: Mental Health Practice Guide, Volumes I and II*. These guidelines, supported by more than 50 national organizations, are written for primary care health professionals and families. They consider mental health in a developmental context and emphasize the importance of early recognition and intervention. The first volume is a practice guide that discusses the need to identify emotional, behavioral, or substance use problems or disorders as early as possible and to provide appropriate intervention. *Bright Futures* provides a framework to develop and implement mental health promotion programs in a variety of settings such as primary care clinics, infant mental health programs, child care centers, school-based health centers, training programs, and parent education programs.

The second volume is a tool kit with separate sections for health professionals and families. The section for health professionals includes a recommended Pediatric Intake Form, Pediatric Symptom Checklist, and checklists for different age groups. In addition, there are guidelines for specific developmental events and mental disorders. The section for families includes suggestions about how to communicate with children and how to function effectively as a parent. To access the *Bright Futures* materials, go the Web site of the National Center for Education in Maternal and Child Health listed in the Resources and references section or through the Web site [www.brightfutures.org](http://www.brightfutures.org).

## Federal Waivers

If you begin discussions with state officials about how to provide more screens through the CHIP program, one option may be to request a federal waiver to do so.

The U.S. Department of Health and Human Services gave Minnesota permission to use its federal CHIP funds for four children's health initiatives, including two that focus on mental health screens. This waiver allows Minnesota to use federal dollars to match state money that was funding certain children's health programs. Minnesota received permission to draw \$2.5 million out of its CHIP funds, based on current state spending for these programs, to deposit into its Health Care Access Fund. One of its mental health programs provides grants to counties to provide mental health screenings for homeless children. The second one gives grants to community groups to screen children in the court system for mental health and drug dependency needs.

## Managed Care Contracts

If your state has a Medicaid managed care plan, meaning the state pays a fixed fee (called a "capitated" rate) for the bundle of services to be provided to a patient, find out how EPSDT is administered. Children in Medicaid managed care plans are still legally entitled to receive all EPSDT services, including a full developmental screen, despite the fixed fee the managed care plan receives.

- First, review the contract language regarding EPSDT used by your state Medicaid agency for its managed care plan. Sometimes the Medicaid agency retains responsibility for EPSDT services, but more likely it is part of the contract with the managed care company or plan(s). Check the contract language to make sure that full EPSDT services are required.

## Expanding Children’s Mental Health Screens and Assessments

- Second, determine if children in managed care are getting their EPSDT screens. If your state-managed care plan is “capitated” (a fixed fee per person), it may be very difficult to find out what specific services individuals use. However, states can require managed care plans to collect and report these data separately. You need the service utilization numbers (often called “encounter data”), but you should be able to tell if children are receiving screens.

The Center for Health Services, Research and Policy, at George Washington University, has useful information about Medicaid managed care contracts and different arrangements that states use. See the resources and references section of this Guide for contact information.

### Strategy #3: Encourage prevention and early intervention services.

There is growing consensus about the critical importance of a child’s earliest emotional development and its impact on his or her later years. These connections are explored in a report from the Institute of Medicine/ National Research Council, *From Neurons to Neighborhoods: The Science of Early Childhood Development* (2000). The report makes a compelling case to identify and provide appropriate early intervention services for children who demonstrate emotional and behavioral problems at a very young age. Around the country, states and local communities are recognizing that they must respond more quickly to the mental health needs of very young children and their families.

### Innovative Policy Approaches and Financing Options to Promote the Emotional Well-Being of Children and Families

The National Center for Children in Poverty (NCCP) has released four short papers in a publication series entitled, *Promoting the Emotional Well-Being of Children and Families*. These policy papers bring attention to the mental health needs of children and families and examine effective strategies and public policies to promote the emotional health of this population. The series identifies the children and families in need of services, the reasons why policy makers should invest in improving social and emotional health in young children, and sets forth a framework for community and state action. The papers focus on the particular need for early intervention in various sub-sets of children, categorized by age, placement, and risk factors. The series devotes one paper to the particular challenges facing children in foster care, and another to children at-risk between the ages of three and five. Each paper in the series employs research to support its findings and provides examples of promising strategies that promote the healthy emotional development of these children. The most recent paper in the series, *Policy Paper #4: Making Dollars Follow Sense: Financing Early Childhood Mental Health Services to Promote Healthy Social and Emotional Development in Young Children*, highlights innovative approaches to finance preventive and early intervention services and traditional treatment services for young children’s mental health. It describes specific programs, financing options, administrative structures, and common challenges and solutions to develop early childhood mental health services. See resources and references section of this Guide for ordering information.

# ACTION STRATEGIES

## **Build State Medicaid Capacity to Provide Child Development Services**

The Assuring Better Child Health and Development (ABCD) Program was organized to strengthen the capacity of the health care system to meet the early developmental needs of children from low-income families. As part of the ABCD Program, the National Academy for State Health Policy (NASHP) was asked by the Commonwealth Foundation to work with Medicaid agencies in North Carolina, Utah, Vermont, and Washington to help expand early child health and development services, including developmental screening.

The report *Early Findings from the ABCD Consortium*, found at [www.nashp.org](http://www.nashp.org), discusses each site's experience trying to improve developmental screens for infants and toddlers. All four sites acknowledged screening as a critical part of early child health services, but they all tried different approaches to encourage it for Medicaid-eligible children. The report has more details, but a quick snapshot tells you the following:

- North Carolina: Incorporated the Ages and Stages Questionnaire (ASQ), which is a low-cost reliable way to screen infants and young children for developmental delays during the first five years of life.
- Utah: Developed its own assessment of social and environmental factors affecting the family, but decided to incorporate the ASQ in the future.
- Vermont: Focused on improving skills of pediatric providers to address needs of this young population and trained a limited number of them to use Dr. T. Berry Brazelton's Neonatal Behavioral Assessment Scale for developmental screening.

- Washington: Promoted use of the EPSDT charting tool developed by its own Medicaid agency to improve the percentage of children receiving developmental screens and encouraged use of the Bright Futures guidelines.

**Strategy #4: Expand delivery models for mental health screens and assessments.**

## **Increase Consultations between Primary Care/Pediatric Services and Child Psychiatrists**

The Vermont Medicaid program initiated a pilot to increase access to child and adolescent psychiatric consultation with input from child psychiatrists, pediatricians, and state agency officials. The pilot pays for a comprehensive child and adolescent psychiatric consultation for pediatricians who want to make referrals. It includes, on average, two hours of face-to-face evaluation time for a child and two telephone consults between the psychiatrist and pediatrician. The initial target population is children under age seven who may need psychotropic medication.

The program is now working to expand the pool of referring pediatricians, add sites, and add other target populations of children. Initial feedback indicates that all children referred for the psychiatric consultation returned to their primary care physicians for on-going follow-up treatment and services. For more information, contact the American Academy of Child and Adolescent Psychiatry, Department of Government Affairs, listed in the resources and references section of this Guide.

# Expanding Children's Mental Health Screens and Assessments

## Increase Capacity of Health Care Professionals to Provide Mental Health Services

The North Carolina chapter of the American Academy of Pediatrics organized a Task Force on Mental Health Care Access and Reimbursement to address concerns in these areas and to develop an appropriate role for pediatricians to provide and coordinate behavioral health care. The Task Force, along with mental health advocacy groups, worked with the state Medicaid agency to improve access to mental health services for children. Among its successful outcomes were: obtaining reimbursement for up to six visits to a mental health/substance abuse provider without assigning a diagnosis; allowing primary care provider referrals for up to 26 annual mental health visits for children under age 21; and expanding Medicaid reimbursements to allow independently practicing licensed clinical social workers, licensed psychologists, and advanced practice nurses to bill for mental health services provided in their offices.

Background from the Task Force on the reimbursement and coordination problems and its plan of action are found at [www.ncpeds.org](http://www.ncpeds.org). See the resources and references section of this Guide for the article about the Task Force that appeared in *Pediatrics* magazine.

## Expand School-Based Health Centers (SBHC)

School-based health centers often provide comprehensive medical and mental health screening and treatment for students. Centers are designed to overcome barriers frequently cited by young people as reasons why they do not seek health care. These barriers include: concerns about confidentiality; fears that insurers will notify

parents; discomfort discussing personal health problems; cost; and lack of transportation. Many SBHC offer counseling and mental health services, such as crisis intervention, comprehensive evaluation, preventive mental health programs and individual treatment. Students and parents report satisfaction with school-based clinics. A number of professional organizations recognize the unique role these clinics can play to meet the health care needs of teens, including the American Medical Association, American Academy of Pediatrics, Society of Adolescent Medicine, and National Association of State Boards of Education.

See the resources and references section of this Guide for information about three organizations that can offer valuable assistance:

- The Center for Health and Health Care in Schools: Promotes expanding school-based health clinics and access to mental health services in them.
- The Center for Mental Health in Schools, University of California at Los Angeles: Provides information about children's mental health and psychosocial concerns and evaluates school-based mental health initiatives.
- The Center for School Mental Health Assistance, University of Maryland: Supports mental health providers and school-based mental health initiatives.

# ACTION STRATEGIES

**Strategy #5: Organize advocacy and monitoring to expand access to mental health screens and assessments and necessary follow-up services and supports for children with mental and behavioral problems and their families.**

## **Legislative Advocacy**

Sometimes legislative advocacy can create mechanisms needed to expand access to children's mental health screens, assessments, and services. Some examples illustrate the range of legislation that states could consider:

### ***Public Education***

Direct appropriate state and citizen commissions to increase public awareness about the need for families to seek help early when their children show signs of mental problems and to educate families about where help is available.

Direct your state's Medical Assistance Advisory Committee to recommend strategies to increase use of Medicaid to meet children's mental health needs.

### ***Screens and Assessments***

Direct your state Medicaid agency to consult with all appropriate professional organizations to adopt a standard mental health screen to use in the state for all children eligible for EPSDT and CHIP.

Require state agencies serving children in the juvenile justice and child welfare systems to provide age-appropriate mental health screens and assessments for all children when they enter their care.

## ***Payment and Financing***

Request that your Governor or legislature convene a state panel to develop a standard payment rate for mental health services provided to children under state contracts.

Allow Medicaid reimbursement for EPSDT screening services provided by licensed counselors, social workers, and other appropriate non-physician professionals.

Require your Department of Mental Health to explore the feasibility of applying for a federal Medicaid waiver to increase the availability of home and community-based services for children with mental health disorders and their families.

## **Legal Advocacy**

Litigation can be an effective avenue to ensure access to the legal entitlements of EPSDT. Advocates have filed lawsuits about various aspects of EPSDT, including some that have focused on mental health issues. Claims have alleged a number of violations of federal law such as: the failure to provide screening and diagnostic services; the failure to provide sufficient and timely medical and developmental health services; the failure to provide a full range of mental health services in appropriate care settings (especially home and community-based services); and the failure to provide equality of services between children with physical and mental health needs and between children with mental illness and those with mental retardation.

While litigation remains an option to consider, it is one that requires careful consideration. Over the past ten years, access to federal courts has grown more complicated. As a result, substantive claims like those raised in the litigation above are not often addressed because of procedural concerns, such as whether the court has jurisdiction to hear the case. The court may ignore substantive claims for long periods of time while the parties attempt to resolve procedural issues.

## Expanding Children's Mental Health Screens and Assessments

For the most up-to-date information about EPSDT lawsuits, check the National Health Law Program's EPSDT publication, *Toward A Healthy Future*. See the resources and references section of this Guide for ordering information.

### Monitoring

Ongoing monitoring is essential to ensure screening and assessment is in place and leads to appropriate treatment. The Connecticut General Assembly created the Children's Health Council in 1995 to ensure that all Connecticut children have access to health care services through the HUSKY program, its low-cost or free health insurance program for children that includes both Medicaid and CHIP. The Council also seeks to ensure that all children enrolled in HUSKY receive regular well-child care and all other necessary health care services—including age-appropriate screens and assessments.

Council members represent a diverse range of stakeholders including representatives from health and social service agencies, the legislature, community and professional organizations, health plans and advocacy groups. Among its functions, the Council works to ensure both accountability and access in the HUSKY program. For example, it tracks the number of children who receive specific types of mandated services. It provides community outreach workers to help families complete applications, resolve paperwork and enrollment problems, and learn how to access the health services they are entitled to receive. The Council also collaborates with state agencies to share data that can be used to evaluate and improve health care for children in state custody, children with special needs, and children at risk for lead poisoning.

The Council receives funding from the Department of Social Services and the Robert Wood Johnson Foundation's Covering Kids and Families Program. Although considered a model program and highly touted for its significance, the Council's continuation is now in jeopardy due to state budget cuts.

### Conclusion

The Children's Defense Fund hopes that implementing these action strategies in your state will help expand access to and the availability of effective mental health screening and assessment procedures for children. This is a vital first step to chart a course toward appropriate mental health treatment for children of all ages. Improvements in children's mental health will help children enter school ready to learn, perform at their full potential, and make a successful transition to adulthood. Medicaid, and CHIP in some states, offer the opportunity to get appropriate screens and assessments for many children. However, targeted and sustained advocacy is necessary to help these programs realize their potential for children. We look forward to hearing about new allies in your states as you join hands with individuals and organizations in this important endeavor. Please keep us posted about new strategies you find useful and the advances you make for children and adolescents with mental health problems. Good luck!







## RESOURCES AND REFERENCES

### Getting More Information

**T**his section lists national organizations and government agencies, as well as selected articles and reports, that we hope will be useful as you work to improve access to mental health screenings and assessments for children. The Resource Kit builds upon the very important work done by many of the organizations listed below. We cite their valuable work throughout the Resource Kit.

#### National Organizations

##### **American Academy of Pediatrics (AAP)**

141 Northwest Point Boulevard  
Elk Grove Village, IL 60007-1098  
847-434-4000  
847-434-8000 (FAX)

or

Department of Federal Affairs  
601 13th Street, NW  
Suite 400 North  
Washington, DC 20005  
202-347-8600  
202-393-6137 (FAX)  
[www.aap.org](http://www.aap.org)

For specific e-mail inquiries, see the directory at <http://www.aap.org/visit/contact.htm>

Addresses needs of children and their families through advocacy, education, and research to improve the systems through which its members deliver pediatric care. AAP also publishes “Recommendations for Preventive Health Care,” which specifies a schedule for regular screenings and developmental assessments. AAP has a number of departments, divisions, and programs to address specific issues. Their Web site offers general information for parents of children from birth through age 21 and also for clinicians.

##### **American Academy of Child and Adolescent Psychiatry (AACAP)**

3615 Wisconsin Avenue, NW  
Washington, DC 20016-3007  
202-966-7300  
202-966-2891 (FAX)  
[www.aacap.org](http://www.aacap.org)

Addresses concerns about health care and social-economic issues affecting children to improve and expand psychiatric services for them. AACAP offers public information, in both English and Spanish, for families and physicians on many mental health topics on its Web site, and provides recognized professionals as spokespersons. Contact the AACAP Executive Office for organizations or the Department of Government Affairs for legislative or related issues. AACAP provides practice parameters for children of all ages. AACAP also is working with the Child Welfare League of America on a special initiative to improve the mental health and substance abuse services provided to children in foster care.

## RESOURCES AND REFERENCES

### **The Judge David L. Bazelon Center for Mental Health Law (Bazelon Center)**

1101 Fifteenth Street NW, Suite 1212  
Washington, DC 20005-5002  
202-467-5730  
202-223-0409 (FAX)  
www.bazelon.org  
E-mail for publications: pubs@bazelon.org

Promotes the rights of people with mental disabilities. The Center produces many publications that analyze and interpret federal laws and policies affecting access to services for adults and children with mental disabilities. In 2000-2001, it conducted a study of state Medicaid policies on mental health and substance abuse screening of children and adolescents. Results of the study are reported in "Behavioral Health Screening Policies in Medicaid Programs Nationwide," R.M. Semansky, C. Koyanagi, and R. Vandivort-Warren, *Psychiatric Services*, May 2003, 54:5, 736-739. See also *Avoiding Cruel Choices*, the Bazelon Center's guide for policymakers and family organizations on Medicaid's role in preventing custody relinquishment. For additional information on this topic, see *Staying Together: Preventing Custody Relinquishment for Children's Access to Mental Health Services* (1999), a publication released jointly with the Federation of Families for Children's Mental Health.

### **Center for Health and Health Care in Schools**

1350 Connecticut Avenue, Suite 505  
Washington, DC 20036  
202-466-3396  
202-466-3467 (FAX)  
<http://www.healthinschools.org>

Promotes health services in schools. Its priorities include increasing collaboration with Medicaid and CHIP for school-based prevention and service programs and increasing access to mental health services through school-based health clinics. It is supported by The Robert Wood Johnson Foundation. On its Web site, click on "Dental and Mental Health Services" for

useful background information, resources, and financing options.

### **Center for Health Services, Research and Policy**

The George Washington University  
School of Public Health and Health Services  
2021 K Street NW, Suite 800  
Washington, DC 20006  
202-296-6922  
202-296-0025 (FAX)  
www.gwhealthpolicy.org  
E-mail: info@gwhealthpolicy.org

Works to improve access to quality, affordable health care by providing information to policymakers, public officials, and advocates. It is known for its work analyzing developments in Medicaid and CHIP and the impact of these programs on health care access, quality, and financing. The Web site has many useful publications, especially regarding Medicaid managed care.

### **Center for Mental Health in Schools (School Mental Health Project)**

University of California at Los Angeles (UCLA)  
Department of Psychology  
P.O. Box 951563  
Los Angeles, CA 90095-1563  
(310) 825-3634  
(310) 206-8716 (FAX)  
E-mail: smhp@ucla.edu  
<http://smhp.psych.ucla.edu>

Works to increase resources to improve mental health in schools; the capacity of systems and personnel; and the role of schools to address children's mental health, psychosocial and related health concerns. It offers technical assistance on-line and through personal requests. The Center, and its sister group described below, are supported by the Office of Adolescent Health, Maternal and Child Health Bureau in the Health Resources and Services Administration and the Center for Mental Health Services, Substance Abuse and Mental Health Services Administration.

## RESOURCES AND REFERENCES

### **Center for School Mental Health Assistance (CSMHA) University of Maryland, Baltimore, Department of Psychiatry**

680 W. Lexington Street, 10th Floor  
Baltimore, MD 21201-1570  
410-706-0980 or 1-888-706-0980 (toll-free)  
410-706-0984 (FAX)  
E-mail: [csmha@psych.umaryland.edu](mailto:csmha@psych.umaryland.edu)  
<http://csmha.umaryland.edu/>

Helps develop and promote interdisciplinary school-based mental health programs. It provides technical assistance and training for schools and communities that want to develop accessible, family-centered, culturally sensitive programs that are responsive to local needs. The Center is supported by the same federal agencies as described above for its sister group, the Center for Mental Health in Schools.

### **Child Welfare League of America (CWLA)**

440 First Street NW, Third Floor  
Washington, DC 20001-2085  
202-638-2952  
202-638-4004 (FAX)  
[www.cwla.org](http://www.cwla.org)

Offers resources and information on issues affecting children and families served by public and private child welfare agencies. Its Behavioral Health Division helps agencies address these particular needs of children and their families. CWLA is working with AACAP on a special initiative to improve the mental health and substance abuse services provided to children in foster care.

### **Federation of Families for Children's Mental Health (FFCMH)**

1101 King Street, Suite 420  
Alexandria, VA 22314  
703-684-7710  
703-836-1040 (FAX)  
[www.ffcmh.org](http://www.ffcmh.org)  
E-mail: [ffcmh@ffcmh.org](mailto:ffcmh@ffcmh.org)

Addresses the complex needs of children and youth with emotional, behavioral, or mental disorders and their families. It's a national family-run organization with state organizations and chapters across the country. See their Web site for local contact numbers and to learn more about their support activities for children and families and their state advocacy and public education work. From the Web site, you can also download the excellent publication, *Blamed and Ashamed: The Treatment Experiences of Youth with Co-Occurring Substance Abuse and Mental Health Disorders and Their Families*. For information on custody relinquishment, see *Staying Together: Preventing Custody Relinquishment for Children's Access to Mental Health Services* (1999), a publication released jointly with The Judge David L. Bazelon Center for Mental Health Law.

### **Georgetown University Center for Child and Human Development**

3307 M Street NW, Suite 401  
Washington, DC 20007  
202-687-5000  
202-687-1954 (FAX)  
<http://gucdc.georgetown.edu>

Works on issues related to children's health, mental health, early intervention, and foster care. To read the two publications, *Meeting the Health Care Needs of Children in the Foster Care System: Summary of State and Community Efforts—Key Findings* (Jan McCarthy), and *Meeting the Health Care Needs of Children in the Foster Care System: Strategies for Implementation* (Maria Woolverton), go to <http://gucdc.Georgetown.edu/foster.html>. These reports describe what communities and states can do to provide developmental and mental health screenings, assessments, and treatment for foster care children, but their recommendations apply beyond that group.

## RESOURCES AND REFERENCES

### **National Academy for State Health Policy**

50 Monument Square, Suite 502  
Portland, ME 04101  
207-874-6524  
207-874-6527 (FAX)  
www.nashp.org  
E-mail: info@nashp.org

Coordinates an early childhood development program through four state Medicaid programs. See the Web site for their report, *Early Findings from the ABCD Consortium*, discussing ways to increase access to developmental screens for Medicaid-eligible infants and toddlers.

### **National Alliance for the Mentally ILL (NAMI)**

Colonial Place Three  
2107 Wilson Boulevard, Suite 300  
Arlington, VA 22201  
703-524-7600  
NAMI Helpline: 1-800-950-6264  
www.nami.org

Works to improve the lives of persons with severe mental illnesses including schizophrenia, bipolar disorder (manic-depressive illness), major depression, obsessive-compulsive disorder, and severe anxiety disorders. It's a national grassroots advocacy organization with local affiliates across the country that sponsor support groups for individuals and their family members. Some larger affiliates have an advocacy and education agenda. NAMI issued a report on custody relinquishment titled, *Families on the Brink: The Impact of Ignoring Children with Serious Mental Illness* (1999).

### **National Association of State Mental Health Program Directors (NASMHPD)**

66 Canal Center Plaza, Suite 302  
Alexandria, VA 22314  
703-739-9333  
703-548-9517 (FAX)  
www.nasmhpd.org

Represents the interests of State Mental Health Authorities and their directors at the national level. Association staff members have information about national, state, county, and local issues relating to mental health services. Check their Web site for the staff members designated to represent their states in the Association's Children, Youth & Families Division.

### **National Center for Children in Poverty (NCCP)**

Mailman School of Public Health, Columbia University  
154 Haven Avenue  
New York, NY 10031  
212-304-7100  
212-544-4200 or 544-4201 (FAX)  
www.nccp.org  
E-mail: nccp@columbia.edu

Identifies and promotes strategies that prevent child poverty in the United States and improve the lives of low-income children and their families. It emphasizes preventing or alleviating poverty among children under age six because of the particularly serious risks to children's healthy growth and development during those years. The Center has done extensive work to address the social and emotional needs of young children and has a number of useful publications listed on its Web site. The policy paper series entitled, *Promoting the Emotional Well-Being of Children and Families*, includes *Policy Paper #4: Making Dollars Follow Sense: Financing Early Childhood Mental Health Services to Promote Healthy Social and Emotional Development in Young Children*, which describes innovative ways to finance preventive and early intervention services and traditional treatment services for young children's mental health. Other titles in the series are: *Policy Paper #1: Building Services and Systems to Support the Healthy Emotional Development of Young Children: An Action Guide for Policy Makers*; *Policy Paper #2: Improving the Odds for the Healthy Development of Young Children in Foster Care*; and *Policy Paper #3: Ready to Enter: What Research Tells Policymakers About Strategies to Promote Social and Emotional School Readiness Among Three- and Four-Year-Old Children*.

## RESOURCES AND REFERENCES

### **National Center for Education in Maternal and Child Health (NCEMCH)**

Georgetown University  
Box 571272  
Washington, DC 20057-1272  
202-784-9770  
202-784-9777 (FAX)  
www.ncemch.org

The National Center for Education in Maternal and Child Health provides national leadership to the maternal and child health community in three key areas—program development, education, and state-of-the-art knowledge—to improve the health and well-being of the nation's children and families. *The Bright Futures in Practice: Mental Health Practice Guide, Volumes I and II*, can be accessed through the NCEMCH Web site or by going to [www.brightfutures.org](http://www.brightfutures.org).

### **National Center for Mental Health and Juvenile Justice (NCMHJJ)**

Policy Research Associates  
345 Delaware Avenue  
Delmar, NY 12054  
1-866-962-6455 (toll free)  
518-439-7612 (FAX)  
www.ncmhjj.com  
E-mail: [ncmhjj@prainc.com](mailto:ncmhjj@prainc.com)

Promotes awareness about the mental health needs of youth in the juvenile justice system and works to improve policies and programs based on the best available research and practice. It has major support from the John D. and Catherine T. MacArthur Foundation and the U.S. Department of Justice, Office of Juvenile Justice and Delinquency Prevention.

### **National GAINS Center for People with Co-Occurring Disorders in the Justice System (GAINS Center)**

Policy Research Associates  
345 Delaware Avenue  
Delmar, NY 12054  
1-800-311-4246  
518-439-7612 (FAX)  
www.gainsctr.com  
E-mail: [gains@prainc.com](mailto:gains@prainc.com)

Serves as a national center to collect and disseminate information about effective services for adults and juveniles with co-occurring disorders who have contact with the justice system. Funded by the federal Substance Abuse and Mental Health Services Administration.

### **National Health Law Program (NHeLP)**

2639 South La Cienega Boulevard  
Los Angeles, CA 90034-2675  
310-204-6010  
310-204-0891 (FAX)  
www.healthlaw.org  
E-mail: [nhelp@healthlaw.org](mailto:nhelp@healthlaw.org)

Works to improve health care for America's working and unemployed poor, minorities, the elderly, and people with disabilities. Provides back-up and technical assistance to legal services programs, community-based organizations, the private bar, providers, and individuals who represent low-income people. In April 2003, NHeLP published *Toward A Healthy Future: Medicaid Early and Periodic Screening, Diagnostic and Treatment Services for Children and Youth*, which includes annotations on EPSDT cases.

# RESOURCES AND REFERENCES

## **National Mental Health Association (NMHA)**

1021 Prince Street  
Alexandria, VA 22314-2971  
703-684-7722  
1-800-433-5959 (TTY)  
703-684-5668 (FAX)  
Mental Health Information Center: 1-800-969-6642  
(Mon.-Fri., 9-5 EST)  
[www.nmha.org](http://www.nmha.org)

Works to improve the mental health of all Americans through advocacy, education, research, and service. It runs a Mental Health Information Center and provides pamphlets on many topics, including children's mental health.

## **Government Agencies**

### **Center for Mental Health Services (CMHS)**

Substance Abuse and Mental Health Services Administration  
U.S. Department of Health and Human Services  
P.O. Box 42557  
Washington, DC 20015  
[www.mentalhealth.org/cmhs](http://www.mentalhealth.org/cmhs)  
National Mental Health Information Center:  
1-800-789-2647

Leads federal efforts to help states improve and increase the quality and range of their treatment, rehabilitation, and support services for people with mental illness, their families, and communities. It runs a National Mental Health Information Center that provides linkages and referrals to consumer and family advocacy organizations; federal, state, and local mental health agencies; and other resources. The Child, Adolescent and Family Branch funds state and local service programs, statewide family networks, and a national anti-stigma campaign, the "Caring for Every Child's Mental Health" campaign. Go to <http://www.mentalhealth.org/publications/allpubs/CA-0000/>

[orderform.pdf](#) to get an order form.

## **National Institute of Mental Health (NIMH)**

NIMH Public Inquiries  
6001 Executive Boulevard, Rm. 8184, MSC 9663  
Bethesda, MD 20892-9663  
301-443-4513  
301-443-4279 (FAX)  
[www.nimh.nih.gov](http://www.nimh.nih.gov)  
E-mail: [nimhinfo@nih.gov](mailto:nimhinfo@nih.gov)

Leads the federal government's effort to conduct research about mental illness. It has many useful reports available through its Web site.

## **Office of Juvenile Justice and Delinquency Prevention (OJJDP)**

U.S. Department of Justice  
810 Seventh Street, NW  
Washington, DC 20531  
202-307-5911  
202-307-2093 (FAX)  
[www.ojjdp.ncjrs.org](http://www.ojjdp.ncjrs.org)  
[Askjj@ncjrs.org](mailto:Askjj@ncjrs.org)

## **Juvenile Justice Clearinghouse**

P.O. Box 6000  
Rockville, MD 20849-6000  
1-800-638-8736  
301-519-5212 (FAX)  
[askjj@ncjrs.org](mailto:askjj@ncjrs.org)

Provides national coordination and resources to prevent and respond to juvenile delinquency and victimization. It supports states and local communities in their efforts to develop and implement effective and coordinated prevention and intervention programs and to improve the juvenile justice system. Its Web site offers useful information and links to relevant state and national resources.

## RESOURCES AND REFERENCES

### **President's New Freedom Commission on Mental Health**

[www.mentalhealthcommission.gov](http://www.mentalhealthcommission.gov)

Began work in April 2002 to recommend improvements in the mental health service system for adults with serious mental illness and children with serious emotional disturbances. The Commission's final report is due in May 2003. It will be available, along with the Commission's minutes, other reports and testimony, on its Web site.

### **Additional Articles, Reports & Reference Materials**

*Pediatrics*, Volume 110, Number 6, December 2002, pp. 1232-1237, "Working to Improve Mental Health Services: The North Carolina Advocacy Effort."

U.S. Department of Health and Human Services. Health Resources and Services Administration. Maternal and Child Health Bureau, *Bright Futures in Practice: Mental Health Practice Guide, Volumes I and II*, 2002. Available at [www.brightfutures.org/mentalhealth/index.html](http://www.brightfutures.org/mentalhealth/index.html)

U.S. Department of Health and Human Services. *Mental Health: A Report of the Surgeon General*. Substance Abuse and Mental Health Services Administration, Center for Mental Health Services, National Institutes of Health, National Institute of Mental Health, 1999.

U.S. Department of Health and Human Services. *Report of the Surgeon General's Conference on Children's Mental Health: A National Action Agenda*. U.S. Public Health Service, 2000.

U.S. Department of Health and Human Services. *Mental Health: Culture, Race and Ethnicity*. Substance Abuse and Mental Health Services Administration, Center for Mental Health Services, National Institutes of Health, National Institute of Mental Health, 2001.

U.S. Department of Health and Human Services. *Youth Violence: A Report of the Surgeon General*. U.S. Public Health Service, 2001.

U.S. General Accounting Office. *Medicaid: Stronger Efforts Needed to Ensure Children's Access to Health Screening Services*. GAO-01-749, July 2001. See Appendix II for examples of promising EPSDT practices adopted by states as a result of legal settlement agreements. Available at [www.gao.gov](http://www.gao.gov).

U.S. General Accounting Office. *Medicaid and SCHIP: States Use Varying Approaches to Monitor Children's Access to Care*. GAO-03-222, January 2003. Available to download at [www.gao.gov](http://www.gao.gov).

U.S. General Accounting Office. *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*. GAO-03-397, April 2003. Available to download at [www.gao.gov](http://www.gao.gov).



## About The Children's Defense Fund

**T**he mission of the Children's Defense Fund is to *Leave No Child Behind*<sup>®</sup> and to ensure every child a *Healthy Start*, a *Head Start*, a *Fair Start*, a *Safe Start*, and a *Moral Start* in life and successful passage to adulthood with the help of caring families and communities.

CDF provides a strong, effective voice for *all* the children of America who cannot vote, lobby, or speak for themselves. We pay particular attention to the needs of poor and minority children and those with disabilities. CDF educates the nation about the needs of children and encourages preventive investments before they get sick, into trouble, drop out of school, or suffer family breakdown.

CDF began in 1973 and is a private, nonprofit organization supported by foundation and corporate grants and individual donations. We have never taken government funds.



Children's Defense Fund

25 E Street, NW  
Washington, DC 20001  
202-628-8787  
[www.childrensdefense.org](http://www.childrensdefense.org)