



Family Guide

to Systems of Care for Children
With Mental Health Needs



U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
Substance Abuse and Mental Health Services Administration
Center for Mental Health Services
www.samhsa.gov

Family Guide to Systems of Care for Children With Mental Health Needs

Caring for Every Child's Mental Health Campaign is a national public education initiative emphasizing attention to children's and adolescents' mental health. It supports the *Comprehensive Community Mental Health Services for Children and Their Families Program*, in place in communities across the Nation, which is demonstrating the effectiveness of systems of care in meeting the services needs and improving the lives of children with serious emotional disturbances (SEDs) and their families. This campaign is managed by the Center for Mental Health Services, Substance Abuse and Mental Health Services Administration, U.S. Department of Health and Human Services. The guide is intended to help parents and caregivers seek help for children with mental health needs. Information is provided on what parents and caregivers need to know, ask, expect, and do to get the most out of their experience with systems of care.

For information about child and adolescent mental health, contact:

SAMHSA's National Mental Health Information Center
P.O. Box 42490
Washington, DC 20015
Toll-free: 1.800.789.2647 (English/Spanish)
TDD: 1.866.889.2647
www.mentalhealth.samhsa.gov

**SMA05-4054
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About the Family Guide

This bilingual family guide was first printed in December 1998 with the support of the Child, Adolescent and Family Branch of the Center for Mental Health Services, part of the Substance Abuse and Mental Health Services Administration. One of the most popular print publications of the *Caring for Every Child's Mental Health Campaign*, the Family Guide is intended to inform caregivers and families about how to seek help for children with mental health problems. Information is provided on what caregivers and families need to know, ask, expect, and do to get the most out of their experience with systems of care.

The content and format of the guide was determined by families from across the country, and it was written by a diverse team of experts led by the Federation of Families for Children's Mental Health. The initial text for the guide was developed by Families and Communities Equal Success of Stark County, OH. Rhode Island Parent Support Network of Warwick, RI, field-tested the guide's content, relevance, usefulness, and format.

The Spanish version of the guide was initially adapted by a contractor to the Federation of Families and was reviewed for readability and cultural relevance by staff from Roxbury Unites for Families and Children, Inc. of Massachusetts; Parents for Behaviorally Different Children of New Mexico; and Abriendo Puertas of Florida.

In 2005, the guide was updated to reflect the current state of the science in mental health service delivery, as well as to ensure that it supports the recommendations called for in the report of the President's New Freedom Commission on Mental Health.

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Why Read This Guide?

You may have decided to read this guide because you are concerned that your child needs help getting along with others, controlling his or her behavior, or expressing emotions. Depending on your child's needs and your family's situation, you might look for help from schools, health clinics or hospitals, health insurance providers, community mental health centers, social service programs, and, possibly, the courts. When different agencies work together and include you and your family as a team, this is the beginning of developing a *system of care*.

Working with several different providers can be confusing, even overwhelming, unless they partner with you as a team to focus on your goals, *strengths*, and needs. In a *system of care*, each family defines its own *strengths*, the things it wants to change, and the kinds of help and support needed to reach the family's goals.

Families who have received help from *systems of care* participated with the Federation of Families for Children's Mental Health in creating this guide. In seeking appropriate care for their children, family members reported having felt overwhelmed, alone, intimidated, or even blamed. They found strength by sharing their experiences with other families. They have used their experiences to help develop this guide. This guide can help you figure out:

- What you need to know;
- What questions to ask;

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- What you can expect; and
 - What you can do.

Some words in this guide are printed in *italics*; these words are defined in the Glossary (page 21).

The words “you” and “your” in this guide refer to family members and others who are raising a child with a behavioral or emotional disturbance.

Finding Services for Your Child

Get help early. If you have concerns about your child's behavior or emotions, tell your doctors, teachers, counselors, social workers, spiritual advisers, friends, and relatives who know about child and adolescent development and mental health. Ask for their help to find out what the problem is and where to get services.

Explore all options available to meet your child's and family's needs. Check your library, the health department, and the social service section of the telephone book for places that might offer the kinds of help you are looking for. A large amount of information can be found on the Internet. Many family-run organizations have resource centers and advocates or mentors who know about available services and whether a *system of care* is being developed in your community.

What you need to know

You are the expert when it comes to your child. You know your child better than anyone else. You know:

- How your child responds to different situations;
- Your child's *strengths* and needs;
- What your child likes and dislikes;
- What has worked to help your child; and
- What has not worked.

You are the person who decides what services and supports your child and family will receive.

Include your child in the decisionmaking process. Your child needs to understand what is going on in order to actively participate in his or her care.

Every child is different, yet there are children similar to yours. You are not alone. Other families have faced similar problems, shared the same experiences, and are willing to help you.

What to ask

- What do I need to know and to do to help my child?
- What agencies in the community have programs or services that can help my child and other members of my family? How do I get services from them?
- How will my child's health, growth and development, social interaction, and ability to learn be affected by the problems we face?
- What has helped other children like mine?

What you can expect

- You will hear and learn many new words and technical terms. Ask for definitions and explanations.
- Because *systems of care* are youth-guided and *family-driven*, your entire family may be asked to participate in the services you are offered.

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- There may be waiting lists for some services. Find out how to get some help while you are waiting for a particular service.

What you can do

Gather all the information you have about your child. Keep track of everything and start a notebook or file to organize:

- Reports of tests and evaluations;
- *Service plans* and information about the providers, programs, and services you are using;
- Instructions from doctors, teachers, social workers, and others working with your child and family;
- Changes in your child's behavior;
- Medications—note dates that medications are prescribed and changed, and any differences in your child's physical and/or mental health;
- Appointments, conversations, and meetings, including notes of what was discussed;
- Requests you have made for supports such as child care, transportation, and flexibility in scheduling appointments; and
- Letters about meetings and services—note the date they were received.

Ask for information and written materials in the language you speak and ask for explanations of anything you don't understand.

Find other parents or family-run organizations where you can get information and support by sharing ideas and experiences.

Preparing for the First Visit

The first step to getting involved with the *system of care* usually is called an *initial referral* or *intake*. This is when you and the staff of the program or service find out about each other. This first visit may be at your home, at your child's school, or at an agency office. This meeting could last a while—maybe as long as 2 hours.

What you need to know

- Most programs and services have *eligibility criteria*.
- You may be asked to bring your child to the first visit.
- Someone may want to talk with your child alone. Do not agree to this before both you and your child feel comfortable and have agreed to participate in the program.
- Most programs have a handbook that explains how they do their work. The intake worker should give you one.
- People who work in *systems of care* really do want to help your child and family. They will encourage you to speak up and ask questions on behalf of your child and family.

What to ask

- What services and supports are available, and when and where can my child and family get them?
- How is eligibility for services determined?
- How much do services cost and where can I get help to pay for them?

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- Who will watch my children while I complete the paperwork and go to meetings?
 - How often will my child and family get services and how long can we continue?
 - How do I get help if there is a crisis, especially at night or on the weekend, when the office is closed?
 - How do I find *respite care* and other support to help me care for my child at home?

What you can do

Schedule the first visit at your (and your child's) convenience.

Bring:

- Someone you trust with you (for example, a *parent advocate*) to the first visit, and to any meetings later on;
- Your folder or notebook of information and some identification, such as driver's license, social security number, or birth certificate; and
- Proof of medical insurance, a Medicaid card, or evidence of your need for financial assistance (such as a pay stub or rent receipt).

Answer questions honestly and give accurate information about your child's *strengths* and needs.

Remember that there is no such thing as a "dumb" or "foolish" question.

Request information, and ask anything you want to know more about or do not understand.

Write down your questions before you go to the meeting.

Write down the answers to your questions and the names and phone numbers of people you want to get in touch with, and of those who will be working with your child and family.

Get a brochure or write down information about the agency's services, fees, payment options, procedures, and *appeal process*.

Request a written explanation if you are told that your child and family are not eligible for services.

Do your own homework. Get another opinion, and ask for a referral to another service or program that could help you.

What you can expect

You will be asked many questions about your child and family. The intake worker will want to know things such as:

- What things your child does well;
- What you think the problems are, and how they affect your family;
- What you want help with;
- What kind of insurance you have or how the services will be paid for; and
- Who or what has been helpful in the past.

You will be asked to sign many forms such as:

- Permission for your child to be tested;
- Permission to gather or release information; and
- Agreement to accept and pay for services.

It's okay if you feel tired and a bit stressed when the first visit is over.

Set a date to meet with your *service planning team*.

Partnering With Service Providers

Your child and family will be working with individual service providers and a *service planning team*. Building partnerships among families, individual providers, and *service planning teams* is hard work. Everyone has to be courteous and honest to gain the respect and confidence of others.

You are the customer and the client. Tell your *service planning team* and service providers what services and supports you need. Be clear about your family's *strengths*, your needs, and what you think will help your child and family the most.

What you need to know

You and your *system of care service planning team* will work together to write a *service plan* specifically designed for your child and family, including:

- Goals to achieve;
- Services and supports provided as close to home as possible;
- Services and supports that match your family's lifestyle and culture; and
- Regular progress reports and an ongoing communication plan for the service providing team.

A *service coordinator* or *case manager* can help organize services so they are easy for you to use, and can help provide your

family with guidance and support. In some *systems of care*, you can be your family's *service coordinator*.

All providers may not agree or recommend the same services and supports for you and your family. You can disagree with a provider, get a second opinion, or reject a service provider's advice.

Providers and services that are considerate and respectful of your family's language, spiritual beliefs, and cultural values must be accessible to you.

What to ask

- How will the services and supports in the plan help my child and family?
- What are the service provider's qualifications? Does he or she have special training and a track record of working with children and families like mine?
- Can I call service providers at any time of the day or night if there is a crisis?
- How do I change services or providers if things aren't working out as planned?

What you can expect

- You have the opportunity to speak up, be listened to with respect, and not be judged.
- Most service providers will talk to you and your child in a clear, courteous, respectful, and sensitive manner in the

language you use at home. Ask for an interpreter if you need one—do not let your children translate for you.

- Service providers who work with your child may have a different view of your child and family from yours. Carefully consider the evidence for what they are saying before reacting. Most service providers are just as eager to see progress as you are.
- Insist that service providers meet when and where your child and family feel comfortable.
- Service providers may ask for your feedback and suggestions. Be honest when you reply.
- Most service providers will help you advocate for the services and supports that will help your child and family achieve goals that you set.
- You may be asked to sign something that says you agree to the *service plan* and are accepting the services offered. You can refuse to sign if you do not agree with the plan. Ask for a copy of the *service plan* if it is not given to you.

What you can do

Pick your *service planning team* members carefully, and be an active participant on the team. Choose people who:

- Respect and trust you;
- Know your child and family and have been supportive;
- Have a track record of success managing the kinds of problems you are facing; and

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- Know about services in the community.

Share the future you envision for your child and explain how others can help achieve it.

Let service providers know your child's and family's *strengths*, needs, wants, and expectations, and tell them about your family's preferences and priorities. You could talk with someone you trust before the meeting so you are confident about what you say.

Write down short- and long-term goals for your child and family, and watch for progress toward these goals.

Tell your *service coordinator* or *case manager* as soon as you realize that some part of the plan isn't working as you expected. Get your *service planning team* together again to make changes.

Rights and Responsibilities

In a *system of care*, your child and family have specific rights and responsibilities. Other families, as well as advocates and providers, can tell you about these and can help you understand how and when to use them. Become a strong advocate for your child and family. Exercise your rights.

What you need to know

- Discrimination in the provision of services on the basis of race, religion, ethnicity, gender, religion, age, or disability is illegal.
- If your child is being evaluated for special education, you have special rights and responsibilities. Ask the school to tell you about them and get a copy of them in writing.
- You can choose service providers who respect and value your language, culture, and spiritual beliefs.
- Services and supports need to be provided in your community, so your child and family can be involved with others from your neighborhood.
- You can refuse any service offered to you without being penalized. Get help from family advocates if you are penalized for making a legitimate complaint or refusing services that you believe could harm your child or family.
- Responsible providers will notify you before they change or stop providing any service. Ask for a written notice and explanation of the change if you are not given one.

What to ask

- How do I review and get copies of my child's and family's records?
- How is my child's and family's privacy protected, and who has access to confidential records?
- How do I get help exercising my rights—especially if I want to file a complaint?

What you can expect

- Schools and agencies will give you a guide that explains all of your rights. The guide should be in the language you understand best, or a professional or advocate who speaks your language can interpret and explain it to you.
- You will be told details of what confidential information will be disclosed to others and under what circumstances. Make sure you review information before giving permission for anything to be released to another school, provider, or agency.
- You can exercise any and all of your rights without punishment in any form. If you experience otherwise, seek help from an organized advocacy group or family-run organization.
- Expect to be treated with courtesy, consideration, and respect. See the resource list in this guide (p. 24) to assist in identifying a family-run support organization.

What you can do

- Get to know and understand your rights and all the terms or conditions that apply to the services your child and family are using.
- Read everything carefully. Be sure that you understand and really do agree with anything that you are given before you sign it.
- Remember that although you may be under a great deal of stress, you are your child's best advocate. Clearly, you should listen to the advice of others on your *service planning team* who know something about your child's needs. Ultimately, you must decide what help is needed, where you want to go for it, and when and how often you need to have a service.
- Take control of the flow of information about your child and family. Carefully consider what reports go to which person, agency, school, and so forth. Think about this before you sign permission for information to be collected or given out.
- Resolve disputes promptly. If you disagree with a decision, speak first to the person most immediately involved. If that doesn't solve the problem, speak to your *service coordinator* or the provider's supervisor before you file a complaint.
- Request help from advocates who know the rules, understand the *system of care*, and have experience with the providers who are working with you and your family.

Glossary

Appeal process: These are the steps you must follow to get a decision about services reviewed and changed. Usually this process involves proving why the decision was wrong or how it will harm your child and family. Often, you can appeal to a higher level if the first appeal does not get the result you want. You should be given information about the appeal process when you first start getting services. You should learn how to make an appeal and how to get help doing so.

Eligibility criteria: These are the admission criteria or the basis on which children and families are allowed to get services from an agency or program. These criteria usually include age, disability, and income. They also can include where you live, whether your child is male or female, what kind of medical insurance you have, or what other kinds of problems your family is managing.

Family-driven: A family-driven *system of care* gives priority to family and youth voices in making decisions. Family-driven *systems of care* actively demonstrate their partnerships with all families and youth by sharing power, resources, authority, and control with them. Family-driven *systems of care* ensure that families and youth have access to sound professional expertise so they have good information on which to base the choices they make.

Initial referral or Intake: This is the process an agency or program uses first to find out about your child and family, and to determine your eligibility for services.

Parent advocate: This is an individual who has been trained to help other families get the kinds of services and supports they need and want. Parent advocates usually are family members who have raised a child with a behavioral or emotional problem and have worked with the *system of care* and many of the agencies and providers in your community.

Respite care: This is a service that gives your family a short break—relief—when someone else temporarily takes care of your child for a few hours or a few days. Respite care can be provided in your home, at the respite care provider’s home, or at a special respite care facility.

Service coordinator or Case manager: This is an individual who keeps track of the services and supports your child and family are receiving, and makes sure that they are working together in a manner that is easy for your child and family to use.

Service plan: This is a written document that lists and describes all the services and supports your child and family will receive. Typically, service plans also include information about your child’s and family’s *strengths*, problems, and needs. Good service plans spell out what the services and supports are designed to accomplish, as well as how and when progress will be assessed. If your child is receiving special education, the service plan is called an individualized education program or IEP. A Federal law, the Individuals With Disabilities Education Act (usually called IDEA), describes who is eligible for special education and exactly what must be in an IEP. Another legal document, called a 504 Plan,

provides accommodations for students who are not in special education classes but may have special physical or mental health needs.

Service planning team: This is the group of individuals you select to help develop your child's *service plan*. You choose the family members, professionals, friends, experts, and support people who will be team members. The team meets when it is convenient for you and as often as necessary to make sure your child and family are getting the help you want and need.

Strengths: These are the positive characteristics of your child and family. No matter how challenging children's mental health needs are, they have things they do well, people they like, and activities they enjoy.

System of care: This is a coordinated network of agencies and providers that make a full range of mental health and other necessary services available as needed by children with mental health problems and their families. The values and principles of systems of care are printed in this guide.

Where to Get More Information

A wealth of information is available on the Internet. You can connect to Web sites, free of charge, at many libraries and public schools. These national resources can put you in touch with experts in your State or community.

Federal Government Information Sources

SAMHSA's National Mental Health Information Center

P.O. Box 42490

Washington, DC 20015

1.800.789.CMHS (1.800.789.2647)

TDD: 1.866.889.2647

www.mentalhealth.samhsa.gov

Child Adolescent and Family Branch

Center for Mental Health Services

Substance Abuse and Mental Health Services

Administration

One Choke Cherry Road

Room 6-1045

Rockville, MD 20850

240.276.1921

www.mentalhealth.org/child

Additional Information Sources*

Federation of Families for Children’s Mental Health

1101 King Street, Suite 420

Alexandria, VA 22314

703.684.7710

www.ffcmh.org

National Evaluation Program

ORC Macro

3 Corporate Square NE, Suite 370

Atlanta, GA 30329

404.321.3211

www.macoint.com

National Indian Child Welfare Association

5100 SW Macadam Avenue, Suite 300

Portland, OR 97239

503.222.4044

www.nicwa.org

National Technical Assistance Center for Children’s Mental Health

Georgetown University Center for Child and Human Development

3307 M Street, NW, Suite 401

Washington, DC 20007

202.687.5000

http://gucchd.georgetown.edu/programs/ta_center/index.html

Research and Training Center for Children's Mental Health

**Florida Mental Health Institute
University of South Florida**

13301 Bruce B. Downs Boulevard

Tampa, FL 33612

813.974.4661

<http://rtckids.fmhi.usf.edu>

Research and Training Center on Family Support and Children's Mental Health

Portland State University

P.O. Box 751

Portland, OR 97207

503.725.4040

www.rtc.pdx.edu

Statewide Family Networks Technical Assistance Center

1401 El Camino Ave., Suite 340

Sacramento, CA 95815

866.807.7687

www.tacenter.net

Technical Assistance Partnership for Child and Family Mental Health

1000 Thomas Jefferson Street, NW, Suite 400

Washington, DC 20007

202.403.6827

www.tapartnership.org

**** This is not an all-inclusive listing of organizations and programs on this topic. Nothing is implied by an organization or program not being referenced. The listing of an organization or program does not necessarily signify endorsement by the Substance Abuse and Mental Health Services Administration or the U.S. Department of Health and Human Services.***

Notes

Use this space to write down the names and telephone numbers of your child's *system of care service planning team* and service providers.

Name: _____

Phone: _____

Name: _____

Phone: _____

Name: _____

Phone: _____

Name: _____

Phone: _____

Name: _____

Phone: _____

Name: _____

Phone: _____

Name: _____

Phone: _____

Name: _____

Phone: _____

Notes
