

Advocate for Your Child's Mental Health Needs



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Connecticut families seeking mental health services for troubled children in the community today face a daunting challenge. Budgets are tight, resources are hard to access, and demand exceeds supply. In this climate, parents do well to become forceful advocates.

Scarce benefits go to those who know how to claim them. By stating your case, you can help your child while building public awareness of common problems and putting pressure on the system to improve.

Understand the System

The health insurance industry, which makes coverage unaffordable for many people and only partially affordable for some, also fails to compensate providers adequately. Parents whose children have mental health issues find that many outpatient providers have abandoned poor insurance reimbursement rates in favor of fee-for-service care (self-pay).

The picture worsens at the institutional level, where low reimbursement makes it difficult for hospitals to keep psychiatric beds available. Nowadays children often languish in emergency rooms for days or weeks.

Most children entering treatment start with individual and family treatment from an outpatient therapist, who can help locate a psychiatrist if a medication evaluation seems called for. Psychiatrists are generally harder to find when the therapist is in private practice than when he or she is part of a clinic. Clinics, however, may have months-long waiting lists. Also, because staff turnover is high, you may need to tell your child's story many times as new clinicians come on board.

The next medical step after outpatient therapy is a partial hospital or extended day treatment program lasting a few hours a day, in which groups focus on teaching patients how to regulate their behavior. Acute or hospital care, usually accessed

through the emergency room, is available only when children threaten to harm themselves or others.

Managed care authorizes payment for services on the basis of “medical necessity,” about which providers may differ. Hospital stays are often so brief that the full effects of the medications prescribed are not apparent at discharge.

Children who cannot be stabilized quickly may be referred for subacute care—basically a short-term residential setting for assessment purposes. It is assumed that children will return home soon, whether or not the system can provide the community-based supports they need, but not all children do so.

Know Your Rights

If your family’s policy includes mental health benefits, your medical insurance company is responsible for directing you to an in-network outpatient therapist and psychiatrist. If you are unable to find one or the other by calling the phone numbers supplied, the state’s managed care ombudsman may be able to help.

The ombudsman may also be able to help if you suspect that your child is being discharged prematurely from an inpatient setting because insurance threatens to deny reimbursement even though your benefit has not been exhausted.

If you need other resources—a therapeutic mentor for your child, in-home help with behavior management, respite care (usually a few hours) to relieve you, or special recreational benefits with mental health dividends (tae kwon do, music or dance lessons, or horseback riding, for instance)—you may, depending on your financial situation, be able to get them by asking the Department of Children and Families to open a voluntary services case. (To do so you will need to have a therapist for your child and a diagnosis.) Physicians can sometimes prescribe in-home services from visiting nurses.

No matter how many mental health providers are involved, you, as your child’s parent, are properly the captain of the treatment team, empowered to hire and fire other members. Demand respect, cooperation, and timely answers from everyone. Watch to make sure we are all doing our jobs.

If periodic crises send your child to the emergency room, ask the outpatient therapist to request all previous records of treatment. Next, with the therapist's help, write a detailed clinical summary, complete with institutions, dates, psychiatric diagnoses, and medication trials as well as medical, developmental, family, educational, social, and recreational histories.

Notify past providers of any errors that appear in the records they supplied. Use the clinical summary to inform the evaluating physician in the hospital on your next visit, and keep it up to date.

Ask clinicians in temporary settings to confer at intake with long-term outpatient providers. Keep a log on medication and other interventions tried with your child. Also document the apparent results.

If providers seem to be blaming the problems on your parenting rather than on the disorder itself, consider bringing in a homemade videotape that makes your point. If the child enters a hospital or subacute facility, tell the new institution what behavioral changes and support services you will need when he or she comes home to stay.

Locate Resources and Other Advocates

Much information about medical diagnoses, medications and side effects, and treatments for different conditions is available on the Internet. The computer at the University of Connecticut Health Center's medical library can guide you to relevant books and articles in the collection. The Connecticut state statutes (available at the public library or online) can help you learn, for example, about our bullying law and the legal mandate of the Department of Children and Families.

If you skim the *Diagnostic and Statistical Manual of Mental Disorders*, fourth edition (*DSM-IV-TR*), of the American Psychiatric Association, you'll see that its definitions are both symptom based and largely subjective, with a gradually increasing scientific foundation that lends support to some diagnoses but not all. (You can find the *DSM-IV-TR* also at the public library.)

Nonprofit institutions working on behalf of children may be able to direct you to other resources. People who have traveled the same path can save you lots of time by telling you what has worked for them. It can also be heartening to discover that you are not alone.

Surf the Web for disorder-specific sites. These frequently offer information, links, list serves, and chat rooms where people can share questions and practical advice across great distances. Several local mental health organizations sponsor support groups for individuals and families with different mental health issues.

Systemic problems have public policy implications. Consider joining one of the many parent advocacy groups. Working with others, you can help improve available resources and create new and better laws.

Make Your Voice Heard

Institutional bureaucracies grind their gears slowly. If you feel disserved by the mental health service delivery system, consider telling your story publicly. Write a letter to the editor about something apropos that you read in the newspaper. If your problem affects a number of people and is urgent, you may be able to place an op-ed piece.

If you don't want to take pen in hand yourself, call a newspaper reporter or columnist, and explain why your situation merits public attention. You are especially likely to succeed when a public entity has let you down bigtime.

Your advocacy efforts can direct your energies into many productive channels. Furthermore, when you assert yourself, you set a powerful example. Remember that your child is watching you to learn how to live in this world.

Society needs to hear from everyone, including children, if its changes are to be for the better. When we insist on receiving fair and equitable treatment, we honor ourselves while also serving our community, our state, and our nation.

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