

Advocating for your Child: 25 Tips for Parents

-David Fassler, M.D.

According to the Surgeon General, 1 child in 5 experiences significant problems due to a psychiatric disorder. The good news is that we can help many, if not most, of these youngsters. The real tragedy is that so few, less than 1 in 3, are receiving the comprehensive treatment they really need.

Children and adolescents with emotional and behavioral problems deserve access to the best possible mental health care. Unfortunately, such services are often difficult to obtain. Parents can help by being informed, involved and persistent advocates on behalf of their children.

The following outline offers specific tips and suggestions which parents may find useful in such advocacy efforts.

Individual advocacy for your own child:

1. **Get a comprehensive evaluation.** Child psychiatric disorders are complex and at times confusing. A full assessment often involves several visits. Effective treatment depends on a careful and accurate diagnosis.
2. **Insist on the best.** Talk to physicians, therapists, guidance counselors and other parents. Find out who in your community has the most experience and expertise in evaluating and treating your child's particular condition. Check the clinician's credentials carefully. Are they appropriately licensed or certified in your state? If he or she is a physician, are they "Board Certified"? Push schools, insurance companies and state agencies to provide the most appropriate and best possible services, not merely services that are deemed sufficient or adequate.
3. **Ask lots of questions about any diagnosis or proposed treatment.** Encourage your child to ask any questions he or she may have, as well. Remember that no one has all the answers, and that there are few simple solutions for complex child psychiatric disorders. In addition, all treatments have both risks and benefits. Make sure you and your child understand the full range of treatment options available so you can make a truly informed decision.
4. **Insist on care that is "family centered" and which builds on your child's strengths.** Ask about specific goals and objectives. How will you know if treatment is helping? If your child's problems persist or worsen, what options and alternatives are available?
5. **Ask about comprehensive "wrap around" or individualized services, geared specifically to the needs of your child and family.** Are such services available in your state or community? If not, why not?

6. **Be prepared.** One of the most important things you can do to help your child is to keep all information, including past consultation and treatment reports, in an organized place. Insist on receiving your own copies of all evaluations. Records can easily be misplaced, delayed or even destroyed. Maintaining your own file with all relevant information can help avoid unnecessary duplication of previous treatment efforts.
7. **Feel free to seek a second opinion.** Any responsible mental health professional will be glad to help with referrals or by sharing information. If you have questions about your child's diagnosis or the proposed course of treatment, by all means, arrange an independent consultation with another clinician.
8. **Help your child learn about their condition.** Use books, pamphlets and the Internet. Make sure the information is age-appropriate. Answer questions with honest, accurate and consistent information, but don't overload children with more detail than they want or need.
9. **Know the details of your insurance policy, and learn about the laws governing insurance in your state.** For example, in some states, insurance companies must provide access to a specialist, such as a child and adolescent psychiatrist, within a certain distance from your home. If no such specialist is available as part of the company's "network", you may be able to receive treatment from a provider of your choice, with the insurance company responsible for full payment.
10. **Work with the schools.** Insist on access to appropriate mental health consultation services. You can also suggest inservice training programs to enhance awareness about child psychiatric disorders. Request copies of your child's educational records, including the results of any formal testing or other evaluations. Ask to be included in any and all school meetings held to discuss your child.
11. **Learn about the reimbursement and funding systems in your state.** The more you know, the better you can advocate on behalf of your child. How does Medicaid work? Which services are covered and which are excluded? Is there a Medicaid "waiver program" which allows increased flexibility based on the specific needs of children and families? Is your child eligible? If not, why not? What other sources of funding are potentially available?
12. **If necessary, use a lawyer.** Learn about the local legal resources. Find out which lawyers in your community are familiar with educational and mental health issues. Talk to your local Protection and Advocacy agency or American Civil Liberties Union for suggestions. Call the State Bar Association. Talk to other parents who are lawyers or who have used lawyers. Consider a legal consultation to make sure you are pursuing all appropriate avenues and options regarding services for your child.

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Statewide advocacy for all children, including your own:

13. **Become politically active.** Meet with state senators and representatives. Question candidates about their positions on access to necessary and appropriate mental health services for children and families. Testify at hearings on state legislation and budgets. Legislators are more likely to be influenced and persuaded by personal stories than by data, statistics or the opinions of professionals.
14. **Get to know the state insurance commissioner and healthcare “ombudsperson” or consumer representative.** Ask them to attend regular meetings with parent groups. Let them know about your experiences.
15. **Build coalitions and work with local advocacy and parent organizations.** Some of these organizations could include the National Alliance on Mental Illness (NAMI), the National Mental Health Association (NMHA) and the Federation of Families for Children’s Mental Health. Develop and publicize a common “Agenda for Children’s Mental Health”.
16. **Teach children about advocacy.** Invite them to become involved in advocacy activities, where appropriate, but don’t force them to participate.
17. **Develop a legislative strategy.** If your state does not yet have parity legislation, put this at the top of the agenda. Other “family protection” initiatives include:
 - access to an independent panel to review and potentially reverse insurance company denials
 - consumer representation on community mental health center boards
 - adequate network provisions, which mandate timely and appropriate access to specialists
 - adequate funding for school and community based mental health services
 - interagency collaboration for children who are involved with more than one system (i.e., child welfare, mental health, education and juvenile justice).
18. **Seek bipartisan support.** Mental illness affects families of all political persuasions. Building a broad base of support has been a key to successful legislative initiatives, both at the State and Federal levels.
19. **Fight stigma.** Develop an ongoing local education campaign that reiterates the key messages:
 - child psychiatric disorders are very real illnesses
 - they affect lots of kids and adolescents
 - fortunately, they are also quite treatable, especially if treatment begins early and is individualized to the needs of each child and family.
20. **Become involved with medical education.** Meet with local medical students and residents. Sensitize them to the issues and challenges families face when caring for a child with emotional and behavioral problems.

21. **Use the media.** Write letters to the editor and/or op-ed pieces on child mental health issues. Meet with local reporters covering health care topics. Suggest story ideas to local TV stations.
22. **Work with local professional organizations.** Psychiatrists, psychologists, social workers, psychiatric nurses, and mental health counselors are natural allies with a common advocacy agenda. Coordinate efforts on issues such as parity, funding for mental health services, managed care oversight, etc. Professional organizations may also have access to resources, including funds for lobbying and/or public education initiatives, from their national associations.
23. **Talk to other parents.** Seek out and join local parent support groups. If none exist, consider starting one. Develop an email “listserv” to facilitate communication. Circulate articles, information and suggestions about local resources.
24. **Attend regional and national conferences of parent and advocacy organizations.** Such meetings provide information, ideas, camaraderie and support. Sharing experiences with other parents is both helpful and empowering.
25. **Don’t give up.** Aim for and celebrate incremental victories and accomplishments. Remember, advocacy is an ongoing process!

There’s no right or wrong way to be an advocate for your child. Advocacy efforts and initiatives should be individualized to your state, community and the particular issues, circumstances and needs within your family. Advocacy is also hard work. Even when people want to help, and are willing to listen, it takes lots of time and energy to change the system. But when it works, and it often does, the outcome is clearly worthwhile. You really can make a difference, both for your own child, and ultimately for all children who need and deserve access to appropriate and effective mental health treatment services.

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Resources

The following organizations are excellent resources regarding advocacy on behalf of children's mental health:

American Academy of Child and Adolescent Psychiatry
3615 Wisconsin Avenue, NW
Washington, DC 20016
(202) 966-7300
www.aacap.org

American Psychiatric Association
Division of Public Affairs
1400 K Street, NW
Washington, DC 20005
(202) 682-6140
www.psych.org

Federation of Families for Children's Mental Health
1101 King Street, Suite 420
Alexandria, VA 22314
(703) 684-7710
www.ffcmh.org

National Alliance for the Mentally Ill
Colonial Place Three
2107 Wilson Blvd., Suite 300
Arlington, VA 22201-3042
(703) 524-7600
www.nami.org

National Mental Health Association
1021 Prince Street
Alexandria, VA 22314-2971
1-800-969-6642
www.nmha.org

The Children's Defense Fund
25 E Street NW
Washington, DC 20001
(202) 628-8787
www.childrensdefense.org

Bazon Center for Mental Health Law
1101 15th Street NW, Suite 1212
Washington, DC 20005-5002
(202) 467-5730
www.bazon.org

Childhood and Adolescent Bipolar Foundation
1187 Wilmette Avenue
P.M.B. #331
Wilmette, IL 60091
(847) 256-8525
www.bpkids.org

Children and Adults with Attention-Deficit/Hyperactivity Disorder (CHADD)
8181 Professional Place, Suite 201,
Landover, MD 20785 CHADD
1-800-233-4050
(301) 306-7070
www.chadd.org

Juvenile Bipolar Research Foundation
49 S. Quaker Road
Pawling, NY 12564
(203) 226-2216
www.bpchildresearch.org

Depression and Bipolar Support Alliance (DBSA)
730 N. Franklin Street, Suite 501
Chicago, IL 60610
1-800-826-3632
(312) 642-0049
www.ndmda.org

Depression and Related Affective Disorders Association (DRADA)
Meyer 3-181, 600 North Wolfe Street
Baltimore, MD 21287-7381
(410) 955-4647
www.drada.org