THE MEDICATED CHILD
A GUIDE FOR PARENTS

Information for parents, teachers and professionals involved in helping children with behavioral and emotional issues.

THE MEDICATED CHILD
January 8, 2008 on PBS (check local listings)
Watch it online: pbs.org/frontline/medicatedchild
About the Film
In recent years, there’s been a dramatic increase in the number of children being diagnosed with serious psychiatric disorders and prescribed medications that are just beginning to be tested in children. The drugs can cause serious side effects, and virtually nothing is known about their long-term impact. “It’s really to some extent an experiment, trying medications in these children of this age,” child psychiatrist Dr. Patrick Bacon tells FRONTLINE. “It’s a gamble. And I tell parents there’s no way to know what’s going to work.” In FRONTLINE’s report, The Medicated Child, producer Marcela Gaviria confronts psychiatrists, researchers and government regulators about the risks and benefits of prescription drugs for troubled children.

Watch the Full Program Online
http://www.pbs.org/frontline/medicatedchild/

About the Parents’ Guide
This resource, written by child psychiatrist Joshua Sparrow, has been developed to support FRONTLINE’s documentary The Medicated Child. It provides background on the issues associated with treating a child with psychiatric medications. The information provided can be a resource for parents, school guidance counselors and psychologists, pediatricians, social workers, special education professionals, classroom teachers and others involved in diagnosing and treating children with behavioral and emotional problems.

Topics Covered in this Guide
When to Worry: Signs Your Child May Be in Need of Help
Observing, Describing and Understanding Your Child’s “Out-of-Control” Behavior
Parents, Children, Doctors and Teachers — The Team Approach
What to Expect from the Doctor Prescribing Psychiatric Medication
How Parents Can Partner with Schools
What Parents Can Ask School Personnel to Do
Resources and Web sites

OVERVIEW
Psychiatric medications can rescue a child from a desperate future, and sometimes even save a child’s life. But their effects on children’s developing minds and bodies are largely unknown. Most aren’t approved by the FDA for use in children. Diagnosis is challenging since “normal” behavior varies widely. Developmental crises add to the confusion. Few objective tests exist to clarify parent, teacher and child reports. Reported symptoms like impulsivity or hyperactivity may suggest a host of possible diagnoses. Parents are bound to wonder when medications will really help, and when they’re more trouble than they’re worth.

Many parents also wonder whether psychiatric medication is used to control developmentally “normal” but “unacceptable” behavior. For example, hyperactivity in a child can interfere with learning and maturing, but sometimes it simply means that a developmentally unrealistic amount of time sitting still is being demanded of the child. Even when a psychiatric diagnosis is appropriate, parents worry about the price the child will pay. Identity and self-esteem take form in the vulnerable childhood years, but last a lifetime. Taking psychiatric medication can be the most tangible symbol of a diagnosis that children often misunderstand to mean they are defective. However, when treatment helps children function more effectively at home and at school, it can bolster fragile self-esteem. In some instances, cognitive, behavioral and other therapies may replace medication or reduce the amount needed. Adjustments of the school and home environment to the child’s needs may also help.

Research and insurance coverage for non-medication treatments are underfunded. (If Big Pharma won’t fund research, who will?) Yet given medication risks, such treatments deserve further investigation, and — when indicated — should be pursued. Research to identify preventable causes might stop many children from ever needing medication. Is the fortyfold increase in the number of children and adolescents diagnosed
with bipolar disorder over the past 10 years due to increased recognition or overdiagnosis? Or might there be some preventable cause for this and other disorders reaching epidemic proportions? Environmental toxins, excessive television and modern agricultural effects on food nutrient contents are among the possible preventable causes currently under consideration.

WHEN TO WORRY
Parents usually know when to worry and often report some of the following signs when there is trouble that warrants psychiatric attention. (None of these, however, indicates a specific psychiatric condition, nor that medication will necessarily help.)

- You seem to be spending more time angry or upset with your child, or more time trying to control her behavior than you do having fun together.
- You realize that you are not enjoying your child, often worrying that you have fallen “out of love.”
- You feel constantly worn out or worried by your child’s behavior.
- People in the family are constantly arguing about the child.
- You feel like you don’t know or understand your child anymore.
- Your child doesn’t seem to be the same child you’ve always known.
- There is a sudden persistent change in your child’s behavior -- for example, activity level or choice of friends.
- Your child spends prolonged periods with drawn or in isolation.
- Rarely smiling or happy, her range of emotions seem limited mostly to anger or irritability.
- Your child’s reactions are repeatedly out of proportion to the situation.
- Other children don’t like your child, keep their distance, think she’s odd or are afraid of her.

If you’re worried about your child, you deserve honest answers to your questions. Start with your pediatrician, who should be able to refer you to a mental health professional if your child needs this kind of help.

OBSERVING, DESCRIBING AND UNDERSTANDING YOUR CHILD’S “OUT-OF-CONTROL” BEHAVIOR
All too often, terms such as “out of control,” “escalating behavior,” “aggressive behavior,” “angry outburst,” “temper tantrum” or “meltdown” take the place of detailed descriptions of the child’s behavior. Try keeping a journal to record your descriptions, noting the following:

- **Warning signs** — Can you tell that your child is on the verge of an “episode” before it starts? What are the signs you watch for? Can he tell? Can he ask for help before it’s “too late”? Is there a pattern of increased vulnerability when he is tired, hungry, anxious or stressed? Can you predict the kinds of events, settings or interactions that are likely to set him off?

- **Triggers** — What seems to set the behavior off? Sometimes there is no apparent trigger, but often there is one that goes unnoticed. A truly unprovoked episode is important to distinguish. It is also important to note whether the child’s reaction was out of proportion to the severity of the trigger. Ask your child if he thought something happened that made him upset, and get a sense from him of his perception of its seriousness relative to his reaction.

- **Contexts, settings** — Is there a pattern to when and where the troublesome behaviors occur? Always before leaving for school? When there is a transition? Separations? Only with certain friends? Only in private?

- **Symptoms** — What does your child do and say during an episode of problematic behavior? How would you describe his mood? If he’s angry, is there some basis in reality for his concerns? Can he continue to converse? Can he be reasoned with? Does he remain responsive to things he cares about, for example, settling down quickly if
Although families may feel disempowered when they turn to professionals for help, this needn’t be the case. Parents remain children’s most important caregivers and advocates. To play this role as effectively as possible, there are several steps that parents can take.

Pay attention to your questions and doubts about your child, and to the fears, feelings and memories that these may stir up in you. Parents may be haunted by their own pasts or their worst fears for the future, and not dare to speak them.

Talk about your concerns with the mental health professional caring for your child, or, if it is more comfortable, with friends and family members. Many parents find relief and renewed strength when they meet other parents experiencing similar ordeals in parent support groups.

Find supportive allies who can help, even if just with some of the routines of daily life. The symptoms of a psychiatric disorder in a child can overwhelm a family’s ability to cope, and may derail its usual ways.

Become an expert on your child’s condition. Expect that doctors and counselors will answer your questions, but that they acknowledge when and what they don’t know. Talk with other parents, teachers and school counselors; read; and use — with caution — the Internet. Trust your instincts: You know your child better than anyone.

PARENTS, CHILDREN, DOCTORS AND TEACHERS — THE TEAM APPROACH

One of the unfortunate but avoidable consequences of diagnostic labels and medication treatment is that parents may feel that as they place their child’s psychiatric care into a professional’s hands, they themselves can do little to help. Children, too, may erroneously believe that their future is no longer in their control. But they can be helped to understand that even though their struggles are not their fault, their actions remain their responsibility. This should not be presented to the child as more pressure, but as a form of respect and to help them fight for their own role in their recovery.

• Aftermath — Does he go right back to “normal” after one of these episodes? Or does he seem tired or moody for a prolonged period afterward? Can he remember what happened? Can he talk about it? How does he feel about it? Ashamed? Remorseful? Indifferent? Does he want help? Or has he given up? Can you plan together to watch out for the warning signs and to work together to prevent other episodes or to settle them sooner?

• Effect on overall functioning — What is the impact of your child’s symptoms on him and on the family? Have you had to make changes in the way you and other family members live your lives? Do you all feel that you are “held hostage” by the child’s behavior? Have the child’s performance at school or relationships with friends been affected? Does he feel that he can no longer understand or like himself?

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A friend visits or calls, or taking care not to break his favorite things when he is trashing his room? How long does the episode usually last? How often does it occur? What kinds of things have you tried that help him settle down? What makes it worse?

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Involv the child in the process. Far too many children are assessed, tested and interviewed but never told why or what the findings are. And far too often they are not respected as partners in working to understand their challenges and learning to manage them. Ask your child how he understands his struggles and what he thinks will help. Help him find ways to describe the problem that preserve his self-image and give him hope for the future: “Sometimes your feelings just get too strong for you to handle, but we can work on this together so that you’re back in control.”
WHAT TO EXPECT FROM THE DOCTOR PRESCRIBING PSYCHIATRIC MEDICATION

You may be referred to a child psychiatrist by your child’s pediatrician, a guidance counselor or therapist. Prepare for your visit by gathering together any medical information, reports you have about your child’s behavior, and notes about your own observations and questions. When you see the psychiatrist, you can expect that he or she will do the following:

**Take a thorough history.** Including allergies, other medications, past medical and psychiatric history, and family history of medical and/or psychiatric conditions.

**Conduct a careful search for possible medical and neurological causes** of the child’s symptoms before settling on a psychiatric diagnosis.

**Plan for regular monitoring and follow-up.** Children should be seen at regular intervals by the prescribing physician to monitor medication response, check for side effects and assess whether the drug is still needed.

**Take a conservative approach.** The physician should help you weigh the risks and benefits of medication, and also of not using medication. All appropriate non-medication treatments should also be considered. The lowest effective dose possible should be used, and, whenever possible, the use of more than one drug at a time should be avoided to decrease the risk of side effects.

**Provide information about side effects.** Before your child starts on medication, the doctor should explain the benefits you and your child can expect from the medication, and what to look for to know that it is working. He or she should also explain what side effects to watch for and what to do about them, and when to call the doctor or go to the emergency room.

**Offer contact information.** Before your child starts on medication, your doctor should let you know how often the child should be seen in follow-up, how he or she can be reached in an emergency, and how to reach a covering physician, if necessary.

**Provide holistic treatment.** The psychiatrist should collaborate with your child’s pediatrician and other professionals such as teachers, psychologists or social workers providing counseling or psychotherapy, speech and language therapists, and physical and occupational therapists.

**Be compassionate.** The physician should demonstrate compassion and be ready to respond to the most pressing question that many parents ask: “What would you do if this was your child?”

**Treat your child with respect.** The physician should include the child in the process of understanding his struggles and relate to the child as a person, not a label. He or she should demonstrate great care to show your family that the child’s strengths and potential are appreciated, and that his psychiatric disorder does not define him.

HOW PARENTS CAN PARTNER WITH SCHOOLS

Your child’s school ought to offer plenty of opportunities for him to learn about himself, to discover his strengths, and, to compensate for his vulnerabilities, to experience success as the reward for his efforts. It can also be a useful resource to help you assess, observe and monitor your child’s behavior. Often, a teacher might be the first person to alert you to potentially troubling behaviors. This may be painful to hear, but your relationship with teachers and other school personnel will be even more important to preserve and strengthen.

- Hold off on your initial reactions and response to disagreements or school crises until you’ve had a chance to gather your thoughts.
- Start with positive, appreciative comments about some aspect of teachers’ efforts, even if you disagree with others.
 Invite teachers to provide specific descriptions of the child’s behavior, and show them that you are listening carefully, even when you disagree. Then offer your observations so that consensus on a more complete picture of the child’s behavior can emerge.

 Avoid accusations, or responding to them, and instead ask questions: What do you think is causing this behavior? What do you think will help? Be ready with your own answers and exhibit humility by admitting when you don’t have any.

 Show your understanding of the need for classroom rules and expectations so that the child’s teacher will be more inclined to balance these with your child’s individual needs.

 Keep consensus about a plan of action for your child as your shared goal. It is easier for children to relax and understand what is expected of them when parents and teachers can show that they know how to work together as a team.

 WHAT PARENTS CAN ASK SCHOOL PERSONNEL TO DO

 • Describe their understanding of the child’s problems and of the behaviors they observe that lead them to their concerns.

 • Agree to put aside terminology that labels a child and instead provide carefully articulated and nonjudgmental descriptions of their observations.

 • Acknowledge what they don’t know and when they need help.

 • Respect your decisions, even if they may disagree with them.

 • Try to understand the situation from your perspective.

 • Show compassion to you and care about your child.

 RESOURCES

 Books, chapters, articles

 The brief sampling of reading material below includes a wide range of perspectives. Parents may find it helpful to refer to texts that offer a broad view of child behavior and development, and of specific childhood psychiatric conditions and treatments, in addition to those that focus primarily on medication in order to learn about non-medication interventions that may in some instances suffice or that may be complementary to medication treatments.

 Child Development and “Normal” Developmental Crises
 Carey, William; Understanding Your Child’s Temperament. MacMillan 1997

 Drug Problems, Drug Company Problems
 Angell, Marcia; The Truth About the Drug Companies: How They Deceive Us and What to Do About It. Random House 2005

 Non-Medication Treatment Approaches (often also compatible with medication when needed)
 DeGangi, Georgia; Kendall, Anne; Effective Parenting for the Hard-to-Manage Child: A Skills-Based Book. Routledge 2007
 Greenspan, Stanley; Glovinsky, Ira; Glovinsky, Cindy; Children and Babies with Mood Swings. Interdisciplinary Council on Developmental and Learning Disorders
 Kranowitz, Carol; Miller, Lucy; The Out-of-Sync Child: Recognizing and Coping with Sensory Processing Disorder. Revised edition. Perigree 2006
WEB SITES

American Academy of Child and Adolescent Psychiatry (AACAP)
www.aacap.org
This site is very easy to navigate and includes “Resources for Families,” where parents can view definitions of psychological terms and facts, read a glossary of symptoms, find a child psychiatrist, read statistics, and learn about clinical trials and legislative action. There is also up-to-date information related to child psychiatry and medication.

Brazelton Touchpoints Center
www.touchpoints.org
This site is a comprehensive resource on parenting and development, and also offers newsletters covering a variety of topics related to child development.

National Alliance on Mental Illness (NAMI)
www.nami.org
This easy-to-navigate Web site includes “Find Support,” a section (in both English and Spanish) with information on research, treatment and services, and articles on medications and mental health topics.

National Center for Learning Disabilities
www.ncld.org/content/view/900/456084/
This site offers a comprehensive guide for parents that explains the IDEA (Individuals with Disabilities Education Act). The guide, available to view online or as a PDF file, includes information about the federal law that requires schools to serve the educational needs of all children, along with eligibility requirements, details about an IEP (individual education plan) and a variety of resources for parents.

National Information Center for Children and Youth with Disabilities
http://www.nichcy.org/pubs/parent/pa12txt.htm
This publication “Developing Your Child’s IEP” explains the IEP process and is a useful resource for parents who need to develop an individual education plan for a child with a special need.

National Institute of Mental Health (NIMH)
www.nimh.nih.gov
This comprehensive Web site includes research about mental disorders and mental health. The home page includes some excellent articles on different issues related to child psychiatry. There are more research studies and links in the “Health & Outreach” section, as well as definitions of disorders affecting youth and treatment information.

Parent Training and Information Centers and Community Parent Resource Centers
www.taalliance.org/centers/index.htm
Click on a map to find a local organization that supports parents whose children have special needs. There is at least one parent center in every state. “Parent centers serve families of children and young adults from birth to age 22 with all disabilities: physical, cognitive, emotional and learning. They help families obtain appropriate education and services for their children with disabilities; work to improve education results for all children; train and inform parents and professionals on a variety of topics; resolve problems between families and schools or other agencies; and connect children with disabilities to community resources that address their needs.”

The Interdisciplinary Council on Developmental and Learning Disorders (ICDL)
www.idcl.org
This Web site is an excellent resource if you are creating a special program for your child. From the Getting Started/Overview area, parents can scroll down to “A Parent’s Roadmap,” which provides parents with information about disorders, treatment, intervention and evaluation.

About the Author
Joshua Sparrow, M.D., is a child psychiatrist at Children’s Hospital, Boston, and assistant professor at Harvard Medical School. He is co-author of the weekly New York Times Syndicate column “Families Today;” eight books on child development and parenting with T.B. Brazelton, M.D.; and has recently revised the 15-year anniversary edition of Brazelton’s Touchpoints Birth to Three: Your Child’s Emotional and Behavioral Development.

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