

3/20 HRC asked Chris about  
Dylan

? epilepsy?

meeting  
in time planned  
preliminary discussion -  
- roles of new players in the debate

4 pharmaceuticals

Kaiser Perm - MC

ins. co. providing only  
mental health care

insurers don't do mental health

mental health  
providers  
- represent

process  
of benefit to  
plenty of  
four sectors

insurers - action

pharmacists -

MC. Community pharmacists

MC  
represent  
pharmaceutical  
pharmacists

Teavine Ireland

disparity in  
mentioned ↑  
usage of pitaki -

Judy Hummer -

224-2831

SG's contact

4/17

Diane LaVoy -  
Child + Adolescent Bipolar  
Foundation

hasn't yet heard from Beverly  
Malone

wants to be invited to Youth  
Café  
(301) 773-6887

---

spoke w/ her - ok not to include  
her w/ conference

- she's more interested in  
Ritalin conference  
told her it had happened ya



**Bernard Arons <BArons@samhsa.gov>**

03/28/2000 05:59:36 PM

Record Type: Record

To: Heather H. Howard/OPD/EOP

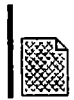
cc:

Subject: Children's Mental Health Services Grants

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As indicated in our phone conversation, I wanted to share some information about some of our activities. I'll be happy to provide more if desired.

Bernie Arons



- Nychild.wpd

## **Center for Mental Health Services (CMHS) Programs for Children in New York**

*The Center for Mental Health Services, Substance Abuse and Mental Health Services Administration, DHHS, provides national leadership in the application of mental health services research. CMHS activities are designed to improve access and reduce barriers to high-quality services for people with, or at risk for, serious mental illness, as well as their families and communities. An important priority at CMHS is to improve services for children with serious emotional disturbance, to help these children recover or manage their illnesses and build healthy and productive lives. Another priority is to engage schools and communities in the effort to reach children with best practices for fostering resilience and preventing violence. The three major CMHS programs designed to enhance services for children are listed below. Following these descriptions are program sites funded in New York.*

**Comprehensive Community Mental Health Services for Children & their Families Program** was designed to expand community service capacity for children with serious emotional disturbance and their families. Through individualized case planning and coordination, the Program enables communities to integrate child and family-serving agencies (such as health, mental health, substance abuse treatment, child welfare, education, and juvenile justice) into a community-based system of care, while at the same time involving families in developing and supporting care for their children.

**School and Community Action Grant Program** was initiated in response to President Clinton's Call to Action at the 1998 White House Conference on School Safety. This Program engages community-based organizations in promoting healthy development, enhancing resilience, and preventing violence, substance abuse, and suicide. The target population includes preschool and school-aged children and adolescents, and their families who are at risk of becoming perpetrators, victims, or witnesses of violence. Grant activities are designed to adopt and adapt evidence-based exemplary practices for use within and outside schools.

**Safe Schools/Healthy Students Initiative** is an interDepartmental initiative to address the problem of youth violence. CMHS is collaborating with the Safe and Drug-free Schools Program in the Department of Education and the Department of Justice to develop and implement a large grant program, the Safe Schools/Healthy Students Initiative. Grants have been awarded to 54 local education authorities with formal partnerships with local mental health and law enforcement agencies. These partnerships have developed and are implementing comprehensive plans to promote healthy development, fostering resilience in the face of adversity, and preventing violence. The plans cover six areas: school safety; alcohol and other drugs and violence prevention/early intervention programs; school and community mental health promotion and treatment services; early childhood psychosocial and emotional development programs; educational reform; and safe school policies.

## Programs for Children in New York

### Comprehensive Community Mental Health Services for Children & their Families Program

- \* Westchester County Department of Community Mental Health: The Westchester Community Network

The five-year Westchester Community Network initiative began in October 1999 with a goal of developing, implementing and evaluating a family-driven system of care for children with serious social, emotional, and behavioral difficulties. The Westchester Community Network will integrate every major service sector in developing a range of service delivery options, including family resource centers, addition of a mobile clinical case management team, new and expanded respite opportunities, in-home family preservation services, wraparound services for juvenile sex offenders and fire setters, as well as peer and vocational support for youth. Westchester County will unite in efforts to reduce duplication, streamline county processes, promote coordinated planning, and develop local community assets. The county also will establish a partnership with the state in order to sustain the activities under the grant through the development of a blended funding model through the Children's Special Needs Plan. The evaluation plan is a longitudinal assessment of the experience of youth and their families, supplemented by information from program directors and service providers, as well as from service contact data for children served by the Initiative.

- \* Mott Haven, New York: Families Reaching in Ever New Directions (FRIENDS)

Mott Haven's Families Reaching in Ever New Directions (FRIENDS) received funding from CMHS from November 1994 - October 1999. The project has been extended through a one-year, no-cost extension, ending October 31, 2000. The goal is to implement a family-driven, integrated system of care to meet the mental health needs of children with serious emotional disorders and their families. The New York City Department of Mental Health, the New York City Department of Probation, the New York City Board of Education, and the New York City Administration for Children Services have participated in the project. FRIENDS also has involved families in assisting in everything from developing interagency structure to helping collect data for national and local evaluation efforts.

## **School and Community Action Grant Program**

### \* Buffalo, New York: Catholic Charities

Catholic Charities, in collaboration with Niagara County Department of Social Services, Juvenile Probation, and Niagara County schools have engaged in building community collaboration and consensus to pilot Multisystemic Therapy. The target population is 50 high-risk youth ages 7-11 with the following breakdown: 50% Caucasian, 40% African American, and 10% Native American. The stakeholders group include the school superintendent, several service providers from child serving agencies, housing authority, probation department, police department, health center, department of social services, special education, and a foster parent. They plan to implement Multisystemic Therapy starting October 2000 and are actively looking for ways to sustain it.

### \* Cheektowaga, New York: Community Action Partnership

The Community Action Partnership is the lead agency and is actively building community collaboration with several other local agencies, including the Cheektowaga-Sloan School District and various community based organizations known as the Family Services Network. They plan to implement Functional Family, a short term, easily trainable, well-document program which has been applied successfully to a wide range of high-risk youth and their families in various contexts, rural, urban, multicultural, international. Functional Family Therapy involves specific phases and techniques designed to engage and motivate youth and families, and especially deal with the intense negative affect (hopelessness, anger) that prevents change.

### \* Mastic Beach, New York: William Floyd School District

The William Floyd School District, locates 70 miles east of New York City, and partnering agencies has been building community support for the implementation of FAST - Families and Schools Together with elementary children and their families. Of note, the school district have helped to form a community council of parents and plans to hire a parent to work on this project. This project has the personal support of the school superintendent among others.

### \* New York, New York: Inwood Community Services, Inc.

Inwood Community Services has been working with IS 52, a middle school next door, that they have had a relationship with for 16 years to identify 8<sup>th</sup> graders who are high-risk for services. The proposed evidence-based practice is Quantum Opportunities Program. The target population is largely Spanish speaking and originally from the Dominican Republic. Quantum Opportunities directly address the problem of dropping out of high school by providing life and academic skills training. High school participants will receive financial incentives to work in day camps or at innovative programs of the applicant's local partner agencies.

### \* New York, New York: Isaacs Neighborhood Center

The Isaccs Neighborhood Center is actively engaged in a community collaboration process to gather support for the implementation of Quit It, a bullying prevention program. Quit It is a school-wide model directed towards all adults that have an impact on children in a school setting such as administrators, teachers, guidance counselors, paraprofessionals, school aides, family workers, and parents. The implementation of Quit It includes a needs assessment, teacher development, training for paraprofessionals, family workers, and school aides, parent workshops, pro-social curriculum implementation, ongoing teacher and parent discussion groups, and consistent school wide policy on teasing and bullying. The target population are children ages 5-14.

\* Poughkeepsie, New York: Mental Health Association, Dutchess County

County Executive William Steinhaus and Congresswoman Sue Kelly jointly announced that the Mental Health Association in Dutchess County had received a grant from SAMHSA to pilot FAST, a program promoting violence prevention and resilience enhancement among elementary school aged children. Mr. Steinhaus stated that the pilot program will eventually be replicated throughout Dutchess County, in urban, suburban, and rural settings. A total of 40-60 families will be enrolled in the project to bridge the gap between family, school, and children through better communication and bonding.

\* Rochester, New York: Primary Mental Health Project Inc.

The Primary Mental Health Project Inc., has been engaged in an intensive community-wide collaboration. They will pilot the Primary Mental Health Project, a school-based prevention program, to serve 1st-3rd grade children in two urban elementary schools, Rochester City School District No. 9 and No. 34. They have conducted a needs assessment and the support of key stakeholders in the two schools (parents, administrators, teachers, school mental health professionals) has been attained. Their implementation and evaluation plan, which includes randomizing children to the intervention and the wait-control is quite impressive. The Project Director, Dr. Peter Wyman, is a nationally recognized figure in the field of youth violence prevention.

## **Safe Schools/Healthy Students Initiative**

\* Auburn, New York:

This upstate Cayuga County suburban and rural area of the Finger Lakes is a partnership between the Auburn Enlarged School District, the Cayuga County Health and Human Services Department and the Auburn (includes county Mental Health Center) and Port Byron Police Department. The first year grant for \$1.8 million will provide: prenatal and post-partum home visits by nurses and clinical social workers to 75 high-risk families; for school-aged children training on the relationship between mental health, substance abuse, and violence in families; expanded after-school and weekend programs; and other appropriate interventions.

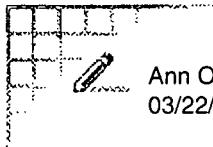
\* Westbury, New York:

This is a partnership between the Board of Cooperative Educational Services of Nassau County, the South Shore Child Guidance Center and North Shore Child and Family Guidance Center, and, the Freeport and Westbury Police Departments. Annual funds of over \$500,000 will support comprehensive programs and integrated community linkages to promote psychosocial and emotional development through an early childhood program; early intervention and prevention programs and workshops; and a comprehensive review of safe school policies.

\* Yonkers, New York:

Over \$1.8 million will support partnership activities by the Yonkers City Public Schools, the County and City Mental Health Department and the Yonkers Police Department. A comprehensive network, maintained by a multi disciplinary advisory council. Will provide a continuum of integrated services to meet the developmental needs of, and enhance resiliency factors in, children through young adulthood. Among many thrusts the project will replicate a pilot mental health program in at least one high school.

New SS/HS grants are expected to be announced soon for Dobbs Ferry (\$900,000) and Ozone Park (\$2.7 million). These grants will provide an impressive array of initiative services in similar partnerships between the school district, the local public mental health agency and the local law enforcement agency.



Ann O'Leary  
03/22/2000 04:35:35 PM

Record Type: Record

To: Christopher C. Jennings/OPD/EOP@EOP, Devorah R. Adler/OPD/EOP@EOP, Trooper Sanders/OVP@OVP

cc: Heather H. Howard/OPD/EOP@EOP

Subject: Conference on kids' psych meds

Diane La Voy is an old friend of HRC. She is one of the founders of a new organization, the Child and Adolescent Bipolar Foundation. If we have follow-up meetings, we should include her. I have also asked her to contact the SGs office to get involved in the conference.

----- Forwarded by Ann O'Leary/OPD/EOP on 03/22/2000 04:33 PM -----



**Diane La Voy <dlavoy@erols.com>**  
03/20/2000 10:59:48 PM

Record Type: Record

To: Ann O'Leary/OPD/EOP

cc:

Subject: Conference on kids' psych meds

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Ann,

Following up our conversation, here's a little background on the Child and Adolescent Bipolar Foundation, whose website is [www.bpkids.org](http://www.bpkids.org). (I'll try to attach home page below.)

CABF is a new web-based membership organization that informs and supports families and the professionals treating kids with bipolar disorder, and advocates for better diagnosis and treatment. We bring together some of the top people in the field of researching and treating bipolar disorder in kids, and over 500 families of kids with this disorder who regularly support each other through electronic lists. Our Board of Directors, a working board, which actually leads our program activities, includes leading researchers such as Demetri Papolos and Barbara Geller, and our Professional Advisory Board, which also actively supports our program, includes 14 leaders in the field, including Dr. Kay Redfield Jamison. Our website, which is only two months old, has already served about two million pages of authoritative information and support, and has attracted nearly 2000 subscribers to our on-line newsletter.

I was very glad to learn from you that the NYT article overstated the conference organizers' concern about "curbing" the use of medications, and that the concern is centrally on the need for proper diagnosis. We are especially concerned that sloppy diagnosis is causing many kids with bpd to be treated as ADHD, and Ritalin is harmful to children with bipolar disorder. A recent study by Dr. Joseph Biederman of Harvard found that 20% of kids who are diagnosed as ADHD have the necessary symptoms for bipolar. Unfortunately, many of them are not given a proper diagnosis. Those who have bipolar are likely to get much worse, even psychotic, when taking Ritalin.

We know that those kids who are bipolar must receive mood stabilizers such as lithium or depakote, and the earlier the better, as well as other therapy that may be needed. We're very concerned when the topic is discussed in terms of "curbing" the use of drugs, rather than in terms of proper diagnosis. Most families of children with serious brain disorders such as bpd find it very hard to obtain affordable health services as it is.

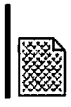
We agree that there's a huge need for more research, and as parents we're painfully aware that none of the drugs we're giving our kids have been specifically tested for psychiatric use in children. But we disagree with a statement in today's NYT article in which Dr. Joseph Coyle of Harvard is quoted as saying, in an AMA journal editorial, that there's "no empirical evidence" to support the use of psychotropic drug treatment in very young children. With regard to bipolar disorder, there is a vast amount of anecdotal evidence coming from doctors and families around the country showing that the use of mood stabilizers can be effective in the treatment of very young children with bipolar disorders.

Thank you for offering to put me in touch with the right person(s) in the Surgeon General's Office, which will be organizing the conference this fall on the diagnosis and treatment of mental illness in young children.

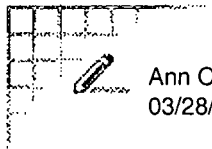
We would like to assist as appropriate in its planning. As I mentioned, Dr. Steven Hyman has asked us to participate in a symposium that NIMH is holding next month (April 25, Chicago) on research needs to address children with neurobiological disorders. We believe that we can bring both scientific expertise and the vast experience of our members to the policy process that Mrs. Clinton has announced.

Thanks again.

Diane La Voy  
CABF Teams Coordinator  
and Washington Liaison  
(301) 773-6887



- [www.bpkids.org](http://www.bpkids.org)



Ann O'Leary  
03/28/2000 02:34:36 PM

Record Type: Record

To: Heather H. Howard/OPD/EOP@EOP  
cc:  
Subject: Children's Meds. Follow-up

could you please follow-up? thanks.

----- Forwarded by Ann O'Leary/OPD/EOP on 03/28/2000 02:34 PM -----



Trooper Sanders@OVP

03/21/2000 11:07

Record Type: Record

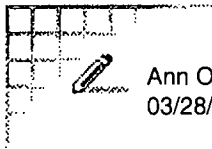
To: Ann O'Leary/OPD/EOP@EOP  
cc:  
Subject: Children's Meds. Follow-up

When you get a chance, would you mind calling Dr. Bernie Arons, director of the Center for Mental Health Services at HHS? He says CMHS is working on a number of children's mental health programs in the field that are relevant to the children's med. issue. He'd like to make sure you and your office are aware of it.

Mrs. Gore relies heavily on Bernie and he is a really great guy to bring into any follow-up work.


His number is 301/443-0001.

Thank you!



Ann O'Leary  
03/28/2000 02:35:36 PM

Record Type: Record

To: Trooper Sanders/OVP@OVP  
cc: Heather H. Howard/OPD/EOP@EOP  
bcc:  
Subject: Re: Bernie Arons 

My apologies - I have not. Heather Howard from our staff is going to take the lead on follow-up to Ritalin. I've asked her to give him a buzz.

Trooper Sanders@OVP



Trooper Sanders@OVP

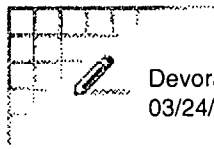


03/27/2000 10:41

Record Type: Record


To: Ann O'Leary/OPD/EOP@EOP  
cc:  
Subject: Bernie Arons

Have you had a chance to talk to Bernie Arons at the Center for Mental Health Services re: children's psych. meds? Thanks.

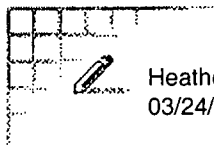


Devorah R. Adler  
03/24/2000 11:51:23 AM

Record Type: Record

To: Heather H. Howard/OPD/EOP@EOP  
cc:  
bcc:  
Subject: Re: SG's Fall Conference on Children with Behavioral . . . 

Beverly Malone. 690-7694  
Heather H. Howard



Heather H. Howard  
03/24/2000 11:50:09 AM

Record Type: Record

To: Devorah R. Adler/OPD/EOP@EOP  
cc:  
Subject: SG's Fall Conference on Children with Behavioral . . .

do you know if there is a contact in the SG's office to whom we can refer people who want to be involved with the conference?

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## First Lady urges Ritalin caution

BY ANJETTA MCQUEEN  
ASSOCIATED PRESS

March 20, 2000 | WASHINGTON -- Hillary Rodham Clinton was launching a White House effort Monday to caution parents about giving their preschool children Ritalin and other mind-altering drugs meant to treat attention deficit disorders.

The plan -- which reportedly includes new government warning labels for the drugs, a national study of their use and a fall conference on children's mental health -- was to be sketched Monday by a working group at the White House, said Jennifer Smith, a spokeswoman for Clinton.

Recent studies show a doubling to tripling of the number of children under age 4 taking Ritalin, a common brand name for the stimulant methylphenidate, which is believed to increase a child's alertness by stimulating the central nervous system.

Attention deficit disorder, or ADD, usually is diagnosed in school-age children based on interviews and observed behavior.

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Symptoms of ADD include the restless inability to sit still to read, study or even watch television. Often a child cannot play in group games, and a common symptom is the inability to control impulses. Some mild forms of these symptoms are common in many children, leading experts to worry that ADD is diagnosed too often.

Some authorities worry that the drugs supplant behavior therapy, which in many cases might be more helpful.

In addition to Ritalin, more young children are also taking clonidine, a blood pressure drug used to treat sleep problems stemming from attention disorders, and antidepressants such as Prozac. In the federal Medicaid program, prescriptions for antidepressants have doubled.

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Barry Scheck and Jim Dwyer talk about the Innocence Project, which has helped overturn eight wrongful convictions of death-row inmates.

By Alicia Montgomery

The National Institute of Mental Health is about to start a nationwide study of Ritalin use in children under the age of 6, said Clarissa Wittenberg, communication director of the mental health arm of the National Institutes of Health.


Children at selected sites around the nation will be observed. Previous study, Wittenberg said, shows that drugs alone are not the answer to treating children with such disorders.

"While behavioral therapy can be very effective and medication was most effective, probably the wisest course to go for treating children is both," she said.


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# DRAFT FOR PARENTS

## Questions and Answers: Treatment of Children with Mental Disorders

### A Note to Parents

There has been recent public concern over reports that very young children are being prescribed psychotropic medications. Some parents are criticized for giving their children these medications, while others are criticized for not doing so. The studies to date are incomplete, and much more needs to be learned about young children who are treated with medications for all kinds of illnesses. In the field of mental health, new studies are needed to tell us what the best treatments are for children with emotional and behavioral disturbances. For medications, we must also make sure that there are no negative consequences for the developing brain.

While there has been progress made in diagnosing the mental illnesses that begin in childhood, children are in a state of rapid change and growth, and diagnosis and treatment of mental disorders must be viewed with this in mind. While some problems are short lived, others are persistent and very serious, and parents should seek ways to help their children.

Not long ago, it was thought that many brain disorders such as anxiety disorders, depression, and bipolar disorder began only later in life. We now know they can begin in childhood. An estimated 6 to 9 million children and adolescents in the United States suffer from a serious

behavioral or emotional disturbance. Perhaps the most studied, diagnosed, and treated childhood-onset mental disorder is attention deficit hyperactivity disorder (ADHD), but even with this disorder there is a need for further research in very young children. Every decision about treatment should be weighed for risk and benefit, and each child should be viewed individually.

### Questions and Answers

*Q: What should I do if I am concerned about mental, behavioral, or emotional symptoms in my young child?*

A: Talk to your child's doctor. Ask questions and find out everything you can about the behavior or symptoms that worry you. Every child is different and even normal development varies from child to child. Sensory processing, language, and motor skills are developing during early childhood, as well as the ability to relate to parents and to socialize with caregivers and other children. If your child is in daycare or preschool, ask the caretaker or teacher if your child has been showing any worrisome changes in behavior, and discuss this with the doctor. Always bring extreme symptoms, such as self-injury, impulsive or aggressive behavior, persistent sadness,

hyperactivity, or social withdrawal, to the attention of the doctor.

*Q: How do I know if my child's problems are serious?*

*For example*  
A: Many everyday stresses cause changes in behavior. The birth of a sibling may cause a child to temporarily act much younger. It is important to recognize such behavior changes, but also to differentiate them from signs of more serious problems. Problems deserve attention when they are severe, persistent, and impact on daily activities. Seek help for your child if you observe persistent problems such as sleep disturbances, changes in appetite, social withdrawal, or fearfulness; behavior that slips back to an earlier phase such as bed wetting; signs of distress such as sadness or tearfulness; self-destructive behavior such as head banging; or a tendency to have frequent injuries. In addition, it is essential to review the development of your child, any important medical problem he/she might have had, family history of mental disorders, physical and psychological traumas or situations that may cause stress.

*Q: Whom should I consult to help my child?*

A: First, consult your child's pediatrician. Ask for a complete health examination of



# DRAFT FOR PARENTS

attention deficit and disruptive behavior disorders; autism and other pervasive developmental disorders; eating disorders (e.g., anorexia nervosa); mood disorders (e.g. major depression, bipolar disorder); schizophrenia; and tic disorders. Enuresis and encopresis may be symptoms of a mental disorder.

*Q: Can family events such as a death in the family, illness in a parent, onset of poverty, or divorce cause symptoms?*

A: Yes. When a tragedy occurs or some extreme stress hits, every member of a family is affected, even the youngest ones. This should also be considered when evaluating mental, emotional, or behavioral symptoms in a child.

*Q: What difference does it make if a medication is specifically approved for use in children or not?*

A: The approval of a medication by the U.S. Food and Drug Administration (FDA) allows for doctors to prescribe the medication as they feel appropriate. In some cases there is extensive clinical experience in using medications for children or adolescents. However, everyone agrees that studies in children would be valuable for finding appropriate dosages and learning the effects of medications.

*Q: What does "off-label" use of a medication mean?*

A: Based on clinical experience and medication knowledge, a physician may prescribe to children a medication that has been FDA-approved for use only in adults. This use of the medication is called "off

label." Most medications prescribed for child mental disorders, including many of the newer medications that are proving helpful, are prescribed off label, because only a few of them have been systematically studied for safety and efficacy in children. Medications that have not undergone such testing are dispensed with the statement that "safety and efficacy have not been established in children."

*Q: Why haven't many medications been tested in children?*

A: In the past, medications were not studied in children because of ethical concerns about involving children in clinical trials. However, this created a new ethical problem: lack of knowledge about the best treatments for children. But in clinical settings, medications are being prescribed for children at increasingly early ages. The NIH and the FDA have begun examining the issue of research on medications in young children. New research approaches are being considered, and progress is being made to require such studies when a medication is undergoing FDA approval.

*Q: Does the FDA approve medications for different age groups among children?*

A: Yes. For example, Ritalin® is approved for children age 6 and older, whereas Dexedrine® is approved for children as young as 3. The lowest age for which the FDA approves a given medication is a function of the policies in effect at the time of initial approval and the specific requests of the drug manufacturer. Dexedrine® is an older medication than Ritalin®. When Ritalin®

was tested for efficacy by the pharmaceutical company that developed it, only children age 6 and above were involved; therefore, age 6 was established as the lower age limit for Ritalin®. There is no reason to believe that one medication is safer than the other based on differences in FDA approval.

*Q: What medications are used for which kinds of childhood mental disorders?*

A: There are several major categories of psychotropic medications: stimulants, antidepressants, anti-anxiety agents, antipsychotics, and mood stabilizers. For medications approved by the FDA for use in children, dosages depend on body weight and age.

■ *Stimulant Medications:* There are four stimulant medications that are approved for use in the treatment of attention deficit hyperactivity disorder (ADHD), the most common behavioral disorder of childhood. These medications have all been extensively studied and are specifically labeled for pediatric use. Children with ADHD exhibit such symptoms as short attention span, excessive activity, and impulsivity that cause substantial impairment in functioning. Stimulant medication should be prescribed only after a careful evaluation to establish the diagnosis of ADHD and to rule out other disorders or conditions. Medication treatment should be administered and monitored in the context of the overall needs of the child and family, and consideration should be given to combining it with behavioral therapy. If the child is of school age, collaboration with teachers is essential.

# DRAFT FOR PARENTS

## Stimulant Medications

Brand Name	Generic Name	Approved Age (children)
Adderal	amphetamines	3 and older
Cylert	pemoline	6 and older
Dexedrine	dextro-amphetamine	3 and older
Ritalin	methylphenidate	6 and older

▪ *Antidepressant and Antianxiety Medications:* These medications follow the stimulant medications in prevalence among children and adolescents. They are used for depression, a disorder recognized only in the last twenty years as a problem for children, and for the anxiety disorders, including obsessive-compulsive disorder (OCD). The

medications most widely prescribed for these disorders are the selective serotonin reuptake inhibitors (the SSRIs).

In the human brain, there are many "neurotransmitters" that affect the way we think, feel, and act. Three of these neurotransmitters that antidepressants influence are serotonin, dopamine, and

norepinephrine. SSRIs affect mainly serotonin and have been found to be effective in treating depression and anxiety without as many side effects as some older antidepressants. The following are the most commonly prescribed medications for children with depression or anxiety disorders (including OCD).

## Antidepressant and Antianxiety Medications

Brand Name	Generic Name	Approved Age (children)
Anafranil	clomipramine	10 and older (for OCD)
Effexor	venlafaxine	
Luvox (SSRI)	fluvoxamine	8 and older (for OCD)
Paxil (SSRI)	paroxetine	
Prozac (SSRI)	fluoxetine	
Serzone (SSRI)	nefazodone	
Sinequan	doxepin	12 and older
Tofranil	imipramine	6 and older (for bedwetting)
Wellbutrin	bupropion	
Zoloft (SSRI)	sertraline	6 and older (for OCD)

# DRAFT FOR PARENTS

■ *Antipsychotic Medications:* These medications are used to treat children with schizophrenia, bipolar disorder, autism, Tourette's syndrome, and severe

conduct disorders. Some of the older antipsychotic medications have specific indications and dose guidelines for children. Some of the newer "atypical"

antipsychotics, which have fewer side effects, are also being used for children. Such use requires close monitoring for side effects.

## Antipsychotic Medications

Brand Name	Generic Name	Approved Age (children)
Clozaril (atypical)	clozapine	
Haldol	haloperidol	3 and older
Risperdal (atypical)	risperidone	
Seroquel (atypical)	quetiapine	
(generic only)	thioridazine	2 and older
Zyprexa (atypical)	olanzapine	
Orap	pimozide	12 and older (for Tourette's syndrome). Data for age 2 and older Indicate similar safety profile.

■ *Mood Stabilizing Medications:* These medications are used to treat bipolar disorder (manic depressive illness). However, because there is very limited data on the safety and efficacy of most mood stabilizers in youth, treatment of children and adolescents is based mainly on experience with adults. The most typically used mood stabilizers are lithium and valproate (Depakote®), which are often very effective for controlling mania and preventing recurrences of manic and depressive episodes in adults. Research on the effectiveness of these and other medications in children and adolescents

with bipolar disorder is ongoing. In addition, studies are investigating various forms of psychotherapy, including cognitive-behavioral therapy, to complement medication treatment for this illness in young people.

Effective treatment depends on appropriate diagnosis of bipolar disorder in children and adolescents. There is some evidence that using antidepressant medication to treat depression in a person who has bipolar disorder may induce manic symptoms if it is taken without a mood stabilizer. In addition, using

stimulant medications to treat co-occurring ADHD or ADHD-like symptoms in a child with bipolar disorder may worsen manic symptoms. While it can be hard to determine which young patients will become manic, there is a greater likelihood among children and adolescents who have a family history of bipolar disorder. If manic symptoms develop or markedly worsen during antidepressant or stimulant use, a physician should be consulted immediately, and diagnosis and treatment for bipolar disorder should be considered.

# DRAFT FOR PARENTS

## Mood Stabilizing Medications

Brand Name	Generic Name	Approved Age (children)
Cibalith-S	lithium citrate	12 and older
Depakote	divalproex sodium	2 and older (for seizures)
Eskalith	lithium carbonate	12 and older
Lamictal*	lamotrigine	16 and older (for seizures)
Lithobid	lithium carbonate	12 and older
Neurontin*	gabapentin	12 and older (for seizures)
Tegretol	carbamazepine	any age (for seizures)

\* Putative mood stabilizers

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Zito JM, et al., 2000. Trends in the prescribing of psychotropic medications to preschoolers. *Journal of the American Medical Association*, 283: 1025-1030.

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NIMH home page address:  
[www.nimh.nih.gov](http://www.nimh.nih.gov)

1. How can I be sure that my child is accurately diagnosed? Isn't it difficult to diagnose a mental disorder in very young children?
2. What criteria or methodology are used to make these diagnoses in very young children?
3. What types of providers should I take my child to?
4. Won't my child just grow out of this?
5. Are there types of normal behavior in children under the age of 7 that are sometimes misinterpreted to be abnormal? Is this different for girls? For boys?
6. What are the consequences of not treating my child for their disorder?

### **QUESTIONS ON MEDICATIONS**

1. How do I know if my child needs medication?
2. What happens if my child is overmedicated?
3. What happens if my child is undermedicated?
4. When appropriately prescribed, what are the common dosage levels by age groups?
5. Should my child take medication only when she is in school? Or should she take it for all waking hours?
6. Is it a good idea to give my child a break from their medication every once in a while?
7. Even when appropriately prescribed, are there any health risks associated with the use of psychotropic drugs in children?
8. Does it make a difference if a medication is specifically approved for use in children? Does that increase the risks associated with the use of the drug?
9. Is there anything my child shouldn't do while he is on this type of medication?

### **QUESTIONS ON TREATMENT**

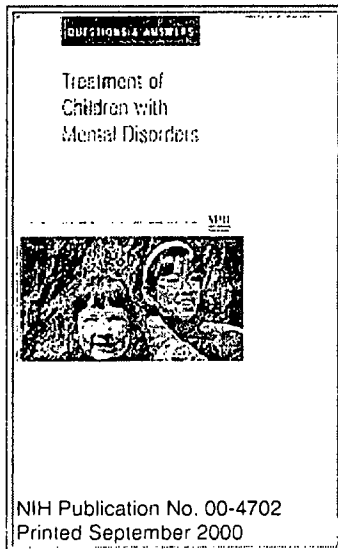
1. What are examples of non-medical interventions that help children?
2. Do therapies or other types of treatments work? How effective are they as compared to medications?
3. Are these therapies ever used by themselves? Do they always have to be used together

with medications?

4. What types of providers specialize in these therapies and treatments?
5. What does a behavioral therapist do?
6. What does a family counselor do?
7. What does a social worker do?



## Treatment of Children with Mental Disorders



### A Note to Parents

There has been public concern over reports that very young children are being prescribed psychotropic medications. The studies to date are incomplete, and much more needs to be learned about young children who are treated with medications for all kinds of illnesses. In the field of mental health, new studies are needed to tell us what the best treatments are for children with emotional and behavioral disturbances.

Children are in a state of rapid change and growth during their developmental years. Diagnosis and treatment of mental disorders must be viewed with these changes in mind. While some problems are short-lived and don't need treatment, others are persistent and very serious, and parents should seek professional help for their children.

Not long ago, it was thought that many brain disorders such as anxiety disorders, depression, and bipolar disorder began only after childhood. We now know they can begin in early childhood. An estimated 1 in 10 children and adolescents in the United

States suffers from mental illness severe enough to cause some level of impairment. Fewer than 1 in 5 of these ill children receives treatment. Perhaps the most studied, diagnosed, and treated childhood-onset mental disorder is attention deficit hyperactivity disorder (ADHD), but even with this disorder there is a need for further research in very young children.

This booklet contains answers to frequently asked questions regarding treatment of children with mental disorders.

### Questions and Answers

***Q: What should I do if I am concerned about mental, behavioral, or emotional symptoms in my young child?***

**A:** Talk to your child's doctor. Ask questions and find out everything you can about the behavior or symptoms that worry you. Every child is different and even normal development varies from child to child. Sensory processing, language, and motor skills are developing during early childhood, as well as the ability to relate to parents and to socialize with caregivers and other children. If your child is in daycare or preschool, ask the caretaker or teacher if your child has been showing any worrisome changes in behavior, and discuss this with your child's doctor.

***Q: How do I know if my child's problems are serious?***

**A:** Many everyday stresses cause changes in behavior. The birth of a sibling may cause a child to temporarily act much younger. It is important to recognize such behavior changes, but also to differentiate them from signs of more serious problems. Problems deserve attention when they are severe, persistent, and impact on daily activities. Seek help for your child if you observe problems such as changes in appetite or sleep, social withdrawal, or fearfulness; behavior that seems to slip back to an earlier phase such as bedwetting; signs of distress such as sadness or tearfulness; self-destructive behavior such as head banging; or a tendency to have frequent injuries. In addition, it is essential to review the development of your child, any important medical problem he/she might have had, family history of mental disorders, and physical and psychological traumas or situations that may cause stress.

***Q: Whom should I consult to help my child?***

**A:** First, consult your child's doctor. Ask for a complete health examination of your child. Describe the behaviors that worry you. Ask whether your child needs further evaluation by a specialist in child behavioral problems. Such specialists may include psychiatrists, psychologists, social workers, and behavioral therapists. Educators may also be needed to help your child.

***Q: How are mental disorders diagnosed in young children?***

A: Similar to adults, disorders are diagnosed by observing signs and symptoms. A skilled professional will consider these signs and symptoms in the context of the child's developmental level, social and physical environment, and reports from parents and other caretakers or teachers, and an assessment will be made according to criteria established by experts. Very young children often cannot express their thoughts and feelings, which makes diagnosis a challenging task. The signs of a mental disorder in a young child may be quite different from those of an older child or an adult.

***Q: Won't my child get better with time?***

A: Sometimes yes, but in other cases children need professional help. Problems that are severe, persistent, and impact on daily activities should be brought to the attention of the child's doctor. Great care should be taken to help a child who is suffering, because mental, behavioral, or emotional disorders can affect the way the child grows up.

***Q: Which mental disorders are seen in children?***

A: Mental disorders with possible onset in childhood include: anxiety disorders; attention deficit and disruptive behavior disorders; autism and other pervasive developmental disorders; eating disorders (e.g., anorexia nervosa), mood disorders (e.g., major depression, bipolar disorder); schizophrenia; and tic disorders. Under some circumstances, bedwetting and soiling may be symptoms of a mental disorder.

***Q: Are there situations in which it is advisable to use psychotropic medications in young children?***

A: Psychotropic medications may be prescribed for young children with mental, behavioral, or emotional symptoms when the potential benefits of treatment outweigh the risks. Some problems are so severe and persistent that they would have serious negative consequences for the child if untreated, and psychosocial interventions may not always be effective by themselves. The safety and efficacy of most psychotropic medications have not yet been studied in young children. As a parent, you will want to ask many questions and evaluate with your doctor the risks of starting and continuing your child on these medications. Learn everything you can about the medications prescribed for your child, including potential side effects. Learn which side effects are tolerable and which ones are threatening. In addition, learn and keep in mind the goals of a particular treatment (e.g., change in specific behaviors). Combining multiple psychotropic medications should be avoided in very young children unless absolutely necessary.

***Q: Does medication affect young children differently from older children or adults?***

A: Yes. Young children's bodies handle medications differently than older individuals and this has implications for dosage. The brains of young children are in a state of very rapid development, and animal studies have shown that the developing neurotransmitter systems can be very sensitive to medications. A great deal of research is still needed to determine the effects and benefits of medications in children of all ages. Yet it is important to remember that serious untreated mental disorders themselves negatively impact brain development.

***Q: If my preschool child receives a diagnosis of a mental disorder, does this mean that medications have to be used?***

A: No. Psychotropic medications are not generally the first option for a preschool child with a mental disorder. The first goal is to understand the factors that may be contributing to the condition. The child's own physical and emotional state is key, but many other factors such as parental stress or a changing family environment may influence the child's symptoms. Certain psychosocial treatments may be as effective as medication.

***Q: How should medication be included in an overall treatment plan?***

A: When medication is used, it should not be the only strategy. There are other services that you may want to investigate for your child. Family support services, educational classes, behavior management techniques, as well as family therapy and other approaches should be considered. If medication is prescribed, it should be monitored and evaluated regularly.

***Q: What medications are used for which kinds of childhood mental disorders?***

A: There are several major categories of psychotropic medications: stimulants, antidepressants, anti-anxiety

agents, antipsychotics, and mood stabilizers. For medications approved by the U.S. Food and Drug Administration (FDA) for use in children, dosages depend on body weight and age. The medications chart in this booklet shows the most commonly prescribed medications for children with mood or anxiety disorders.

**Stimulant Medications:** There are four stimulant medications that are approved for use in the treatment of attention deficit hyperactivity disorder (ADHD), the most common behavioral disorder of childhood. These medications have all been extensively studied and are specifically labeled for pediatric use. Children with ADHD exhibit such symptoms as short attention span, excessive activity, and impulsivity that cause substantial impairment in functioning. Stimulant medication should be prescribed only after a careful evaluation to establish the diagnosis of ADHD and to rule out other disorders or conditions. Medication treatment should be administered and monitored in the context of the overall needs of the child and family, and consideration should be given to combining it with behavioral therapy. If the child is of school age, collaboration with teachers is essential.

**Antidepressant and Antianxiety Medications:** These medications follow the stimulant medications in prevalence among children and adolescents. They are used for depression, a disorder recognized only in the last twenty years as a problem for children, and for anxiety disorders, including obsessive-compulsive disorder (OCD). The medications most widely prescribed for these disorders are the selective serotonin reuptake inhibitors (the SSRIs).

In the human brain, there are many "neurotransmitters" that affect the way we think, feel, and act. Three of these neurotransmitters that antidepressants influence are serotonin, dopamine, and norepinephrine. SSRIs affect mainly serotonin and have been found to be effective in treating depression and anxiety without as many side effects as some older antidepressants.

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**Mood Stabilizing Medications:** These medications are used to treat bipolar disorder (manic-depressive illness). However, because there is very limited data on the safety and efficacy of most mood stabilizers in youth, treatment of children and adolescents is based mainly on experience with adults. The most typically used mood stabilizers are lithium and valproate (Depakote®), which are often very effective for controlling mania and preventing recurrences of manic and depressive episodes in adults. Research on the effectiveness of these and other medications in children and adolescents with bipolar disorder is ongoing. In addition, studies are investigating various forms of psychotherapy, including cognitive-behavioral therapy, to complement medication treatment for this illness in young people.

Effective treatment depends on appropriate diagnosis of bipolar disorder in children and adolescents. There is some evidence that using antidepressant medication to treat depression in a person who has bipolar disorder may induce manic symptoms if it is taken without a mood stabilizer. In addition, using stimulant medications to treat co-occurring ADHD or ADHD-like symptoms in a child with bipolar disorder may worsen manic symptoms. While it can be hard to determine which young patients will become manic, there is a greater likelihood among children and adolescents who have a family history of bipolar disorder. If manic symptoms develop or markedly worsen during antidepressant or stimulant use, a physician should be consulted immediately, and diagnosis and treatment for bipolar disorder should be considered.

**Q: What difference does it make if a medication is specifically approved for use in children or not?**

A: Approval of a medication by the U.S. Food and Drug Administration (FDA) means that adequate data have been provided to the FDA by the drug manufacturer to show safety and efficacy for a particular therapy in a particular population. Based on the data, a label indication for the drug is established that includes proper dosage, potential side effects, and approved age. Doctors prescribe medications as they feel appropriate even if those uses are not included in the labeling. Although in some cases there is extensive clinical experience in using medications for children or adolescents, in many cases there is not. Everyone agrees that more studies in children are needed if we are to know the appropriate dosages, how a drug works in children, and what effects there are on learning and development.

**Q: What does "off-label" use of a medication mean?**

A: Many medications that are on the market have not been officially approved by the FDA for use in children. Treatment of children with these medications is called "off-label" use. For some medications, the off-label use is supported by data from well-conducted studies in children. For instance, some antidepressant medications have

been shown to be effective in children and adolescents with depression. For other medications, there are no controlled studies in children, but only isolated clinical reports. In particular, the use of psychotropic medications in preschoolers has not been adequately studied and must be considered very carefully by balancing severity of symptoms, degree of impairment, and potential benefits and risks of treatment.

**Q: Why haven't many medications been tested in children?**

A: In the past, medications were not studied in children because of ethical concerns about involving children in clinical trials. However, this created a new problem: lack of knowledge about the best treatments for children. In clinical settings where children are suffering from mental or behavioral disorders, medications are being prescribed at increasingly early ages. The FDA has been urging that products be appropriately studied in children and has offered incentives to drug manufacturers to carry out such testing. The NIH and the FDA are examining the issue of medication research in children and are developing new research approaches.

**Q: Does the FDA approve medications for different age groups among children?**

A: Yes. However, this is based on the data provided to the FDA by the drug manufacturer and the policies in effect at the time of approval. For example, Ritalin® is approved for children age 6 and older, whereas Dexedrine® is approved for children as young as 3. When Ritalin® was tested for efficacy by its manufacturer, only children age 6 and above were involved; therefore, age 6 was approved as the lower age limit for Ritalin®.

**Q: Can events such as a death in the family, illness in a parent, onset of poverty, or divorce cause symptoms?**

A: Yes. When a tragedy occurs or some extreme stress hits, every member of a family is affected, even the youngest ones. This should also be considered when evaluating mental, emotional, or behavioral symptoms in a child.

## Stimulant Medications

Brand Name	Generic Name	Approved Age
Adderall	amphetamines	3 and older
Concerta	methylphenidate	6 and older
Cylert*	pemoline	6 and older
Dexedrine	dextroamphetamine	3 and older
Dextrostat	dextroamphetamine	3 and older
Ritalin	methylphenidate	6 and older

\* Due to its potential for serious side effects affecting the liver, Cylert should not ordinarily be considered as first line drug therapy for ADHD.

## Antidepressant and Antianxiety Medications

<b>Brand Name</b>	<b>Generic Name</b>	<b>Approved Age</b>
Anafranil	clomipramine	10 and older (for OCD)
BuSpar	bupirone	18 and older
Effexor	venlafaxine	18 and older
Luvox (SSRI)	fluvoxamine	8 and older (for OCD)
Paxil (SSRI)	paroxetine	18 and older
Prozac (SSRI)	fluoxetine	18 and older
Serzone (SSRI)	nefazodone	18 and older
Sinequan	doxepin	12 and older
Tofranil	imipramine	6 and older (for bedwetting)
Wellbutrin	bupropion	18 and older
Zoloft (SSRI)	sertraline	6 and older (for OCD)

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### **Antipsychotic Medications**

<b>Brand Name</b>	<b>Generic Name</b>	<b>Approved Age</b>
Clozaril (atypical)	clozapine	18 and older
Haldol	haloperidol	3 and older
Risperdal (atypical)	risperidone	18 and older
Seroquel (atypical)	quetiapine	18 and older
(generic only)	thioridazine	2 and older
Zyprexa (atypical)	olanzapine	18 and older
Orap	pimozide	12 and older (for Tourette's syndrome). Data for age 2 and older indicate similar safety profile.

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### **Mood Stabilizing Medications**

Brand Name	Generic Name	Approved Age
Cibalith-S	lithium citrate	12 and older
Depakote	divalproex sodium	2 and older (for seizures)
Eskalith	lithium carbonate	12 and older
Lithobid	lithium carbonate	12 and older
Tegretol	carbamazepine	any age (for seizures)

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# **TREATMENT OF YOUNG CHILDREN WITH MENTAL CONDITIONS**

## **When to Get Help • People to Talk To • Learning About Medications**

### **A NOTE TO PARENTS**

There has been recent public concern over reports that increasing numbers of very young children are being prescribed psychotropic medications. Some parents are criticized for giving their children these medications, while others are criticized for not doing so. New studies are needed to tell us what the best treatments are for children with emotional and behavioral disturbances.

Although progress has been made in diagnosing the mental illnesses that begin in childhood, children's brains are in a state of rapid change and growth, and diagnosis and treatment of mental disorders must be viewed with this in mind. While some problems are short lived, others are persistent and very serious, and parents should seek help for their children. Treatment decisions should be weighed for risks and benefits, and each child should be viewed individually.

### **WHEN TO GET HELP**

Changes in behavior can be of real concern to parents. It's important to recognize behavior changes, but also to differentiate them from signs of more serious problems. All children act out at times as part of typical development. Some children, however, experience significant changes that may indicate a more serious problem. But in some cases, children need help. Problems deserve attention when they are severe, persistent, and impact daily activities. Seek help for your child if you observe persistent problems such as sleep disturbances, changes in appetite, social withdrawal, or fearfulness; behavior that slips back to an earlier phase such as bedwetting; signs of depression; erratic and aggressive behavior, a tendency to be easily distracted or forgetful, or an inability to sustain attention; self-destructive behavior such as head banging; or a tendency to have frequent injuries. It's important to address concerns early – mental, behavioral, or emotional disorders affect the way your child grows up.

### **PEOPLE TO TALK TO IF YOU ARE CONCERNED ABOUT YOUR CHILD**

Remember that every child is different, and even normal development varies from child to child. If your child is in daycare or preschool, ask the teacher if your child has shown any troubling changes in behavior, and discuss this with your doctor. Ask your doctor questions and find out everything you can about the behavior or symptoms that worry you. Be sure to tell your doctor about extreme symptoms, such as self-injury, impulsive or aggressive behavior, hyperactivity, or social withdrawal.

Ask your doctor whether your child needs further evaluation by a specialist in child behavioral problems. A variety of specialists, including psychiatrists, neurologists, psychologists, behavioral therapists, social workers and educators may be needed to help your child. Consistent follow-up is critical to successful treatment.

### **LEARNING ABOUT MEDICATIONS**

The use of medication is not generally the first option for a preschool child with a psychiatric disorder. When medication is used, it should not be the only strategy. Family support services, educational classes on parenting strategies, behavior management techniques, and other approaches should be considered. If medication is prescribed, it should be monitored and evaluated closely and regularly. There are several categories of medications used for emotional and behavioral disorders: stimulants, anti-depressants, anti-anxiety agents, anti-psychotics, and mood stabilizers.

### Stimulants

There are four stimulant medications that are approved for use in the treatment of attention deficit hyperactivity disorder (ADHD), the most common behavioral disorder of childhood. Children with ADHD exhibit symptoms such as short attention span, excessive activity, and impulsivity that cause substantial impairment in functioning. If the child attends school, collaboration with teachers is essential. These medications are labeled for pediatric use.

<u>Brand Name</u>	<u>Generic Name</u>	<u>Approved Age</u>
Adderal	amphetamines	3 and older
Cyclert	pemoline	6 and older
Dexedrine	dextro-amphetamine	3 and older
Ritalin	methylphenidate	6 and older

### Anti-Depressant and Anti-Anxiety Medications

These medications are used for depression and for anxiety disorders, including obsessive compulsive disorder.

<u>Brand Name</u>	clomipramine	8 and older (OCD)
Anafranil	fluvoxamine	12 and older
Luvox	doxepin	6 and older (bedwetting)
Sinequan	imipramine	6 and older (OCD)
Tofranil	sertranline	
Zoloft	<u>Approved Age</u>	
<u>Generic Name</u>	10 and older (OCD)	

Other medications that are used to treat these disorders in children include Effexor (venlafaxine), Paxil (paroxetine), Prozac (fluoxetine), Serzone (nefazodone), and Wellbutrin (bupropion). They are not labeled for pediatric use.

### Anti Psychotics

These medications are used to treat schizophrenia, bipolar disorder, autism, Tourette's syndrome, and conduct disorders.

<u>Brand Name</u>	<u>Generic Name</u>	<u>Approved Age</u>
Haldol	Haloperidol	3 and older
generic only	Thioridazine	2 and older
Orap	Pimozide	12 and older

There are other medications used to treat these disorders in children, including clozaril (clozapine), Risperidal (risperidone), seroquel (quetiapine), Zyprexa (olanzapine). These drugs are newer (atypical) antipsychotics, and have fewer side effects. These medications are not labeled for pediatric use.

### Mood Stabilizers

These medications are used to treat bipolar disorder (manic depressive illness).

<u>Brand Name</u>		<u>Generic Name</u>
Cibalith-S	Lamictal	lithium citrate
Depakote	Lithobid	divalproex sodium
Eskalith	Neurontin	lithium carbonate
	Tegretol	

lamotrigine	<u>Approved Age</u>	16 and older (for seizures)
lithium carbonate	12 and older	12 and older
gabapentin	2 and older (for seizures)	12 and older (for seizures)
carbamazepine	12 and older	any age (for seizures)

Research on the effectiveness of these and other medications in children and adolescents with bipolar disorder are ongoing. In addition, studies are investigating various forms of psychotherapy, including cognitive-behavioral therapy, to complement medication treatment for this illness in young people.

**FOR MORE INFORMATION ON MENTAL DISORDERS IN CHILDREN  
CONTACT THE NATIONAL INSTITUTES OF MENTAL HEALTH 301 443 4513 / [www.nimh.nih.gov](http://www.nimh.nih.gov)**

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# **TREATMENT OF YOUNG CHILDREN WITH MENTAL DISORDERS**

## **When to Get Help • People to Talk To • Learning About Medications**

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There has been recent public concern over reports that very young children are being prescribed psychotropic medications. Some parents are criticized for giving their children these medications, while others are criticized for not doing so. New studies are needed to tell us what the best treatments are for children with emotional and behavioral disturbances.

Although progress has been made in diagnosing the mental illnesses that begin in childhood, children are in a state of rapid change and growth, and diagnosis and treatment of mental disorders must be viewed with this in mind. While some problems are short lived, others are persistent and very serious, and parents should seek ways to help their children. Treatment decisions should be weighed for risks and benefits, and each child should be viewed individually.

### **WHEN TO GET HELP**

It's important to recognize behavior changes, but also to differentiate them from signs of more serious problems. Sometimes, changes in behavior that you find worrisome may be a normal part of your child's development, and do not need medical attention. But in some cases, children need help. Problems deserve attention when they are severe, persistent, and impact daily activities. Seek help for your child if you observe persistent problems such as sleep disturbances, changes in appetite, social withdrawal, or fearfulness; behavior that slips back to an earlier phase such as bedwetting; signs of depression; erratic and aggressive behavior, a tendency to be easily distracted or forgetful, or an inability to sustain attention; self-destructive behavior such as head banging; or a tendency to have frequent injuries. It's important to address concerns early – mental, behavioral, or emotional disorders affect the way your child grows up.

### **PEOPLE TO TALK TO IF YOU ARE CONCERNED ABOUT YOUR CHILD**

If you are concerned about your child's behavior, talk to your doctor. Ask questions and find out everything you can about the behavior or symptoms that worry you. Remember that every child is different, and even normal development varies from child to child. If your child is in daycare or preschool, ask the teacher if your child has shown any troubling changes in behavior, and discuss this with your doctor. Be sure to tell your doctor about extreme symptoms, such as self-injury, impulsive or aggressive behavior, persistent sadness, hyperactivity, or social withdrawal.

Ask your doctor whether your child needs further evaluation by a specialist in child behavioral problems. A variety of specialists, including psychiatrists, neurologists, psychologists, and behavioral therapists, and educators may be needed to help your child. Consistent follow-up is critical to successful treatment.

### **LEARNING ABOUT MEDICATIONS**

The use of medication is not generally the first option for a preschool child with a psychiatric disorder. When medication is used, it should not be the only strategy. Family support services, educational classes on parenting strategies, behavior management techniques, and other approaches should be considered. If medication is prescribed, it should be monitored and evaluated closely and

regularly. There are several categories of medications used for emotional and behavioral disorders: stimulants, anti-depressants, anti-anxiety agents, anti-psychotics, and mood stabilizers.

### Stimulants

There are four stimulant medications that are approved for use in the treatment of attention deficit hyperactivity disorder (ADHD), the most common behavioral disorder of childhood. Children with ADHD exhibit symptoms such as short attention span, excessive activity, and impulsivity that cause substantial impairment in functioning. If the child attends school, collaboration with teachers is essential. These medications are labeled for pediatric use.

<u>Brand Name</u>	<u>Generic Name</u>	<u>Approved Age</u>
Adderal	amphetamines	3 and older
Cyclert	pemoline	6 and older
Dexedrine	dextro-amphetamine	3 and older
Ritalin	methylphenidate	6 and older

### Anti-Depressant and Anti-Anxiety Medications

These medications are used for depression and for anxiety disorders, including obsessive compulsive disorder.

<u>Brand Name</u>	clomipramine	8 and older (OCD)
Anafranil	fluvoxamine	12 and older
Luvox	doxepin	6 and older (bedwetting)
Sinequan	imipramine	6 and older (OCD)
Tofranil	sertranline	
Zoloft	<u>Approved Age</u>	
<u>Generic Name</u>	10 and older (OCD)	

Other medications that are used to treat these disorders in children include Effexor (venlafaxine), Paxil (paroxetine), Prozac (fluoxetine), Serzone (nefazodone), and Wellbutrin (bupropion). They are not labeled for pediatric use.

### Anti Psychotics

These medications are used to treat children with schizophrenia, bipolar disorder, autism, Tourette's syndrome, and severe conduct disorders.

<u>Brand Name</u>	<u>Generic Name</u>	<u>Approved Age</u>
Haldol	Haloperidol	3 and older
generic only	Thioridazine	2 and older
Orap	Pimozide	12 and older

There are other medications used to treat these disorders in children, including clozaril (clozapine), Risperidal (risperidone), seroquel (quetiapine), Zyprexa (olanzapine). These drugs are newer (atypical) antipsychotics, and have fewer side effects. These medications are not labeled for pediatric use.

### Mood Stabilizers

These medications are used to treat bipolar disorder (manic depressive illness).

<u>Brand Name</u>	Depakote	Lamictal
Cibalith-S	Eskalith	Lithobid

Neurontin	lamotrigine	2 and older (for seizures)
Tegretol	lithium carbonate	12 and older
<u>Generic Name</u>	gabapentin	16 and older (for seizures)
lithium citrate	carbamazepine	12 and older
divalproex sodium	<u>Approved Age</u>	12 and older (for seizures)
lithium carbonate	12 and older	any age (for seizures)

Research on the effectiveness of these <sup>and other</sup> medications in children and adolescents with bipolar disorder are ongoing. In addition, studies are investigating various forms of psychotherapy, including cognitive-behavioral therapy, to complement medication treatment for this illness in young people.

**FOR MORE INFORMATION ON MENTAL DISORDERS IN CHILDREN  
CONTACT THE NATIONAL INSTITUTES OF MENTAL HEALTH 301 443 4513 / [www.nimh.nih.gov](http://www.nimh.nih.gov)**

Planning

3/19

# Conference Call

of groups  
Sunday night  
prior to event

Chris Jenkins  
Barbara Woolley

logistics - event starts 9:30

Claire Holland -  
Pediatricians  
Kevin Dwyer -  
School Psychol.

- groups arrive 9-9:15

Elizabeth Burns

9:30 meeting - of Secretary, Shalela chairing

R.P.

of Satchel Hyman + Henney + Huenemann

~~ANAT~~ ANA

HRC comes during meeting -

Ch + abol. Psych.

opts to meet each group

A Psychiatrist A.

each group gets 10 minutes - quick intro  
what  
on group does

School Nurses

more to announcement: - Roosevelt Room

NMH Assoc

- picture of HRC - Staff meets up  
of principals

So. Soc. Work Assoc.

Amer. Psychol. A.

Shalela ~~announces~~ introduces HRC

COF

HRC makes announcement

AFT

State out

Chris - announcements:

focus on substance

children are properly diagnosed, tested, managed, <sup>handled</sup>  
collaboration b/w health professionals, parents, educators

① pediatric labeling - FDA

Through Pediatric Advisory Council

② multi-million \$ - NIMH research commitment

3/19

②

what we know, don't know

③ releasing NIMH fact sheet

not just medication - treatment behavioral, etc

④ Natl. Conference hosted by S.C. in Fall  
collaborate w/ groups as members to conference.

⑤ highlight # of issues in private sector

① pediatrician's commitment to release  
now diagnostic + treatment guidelines  
this month      this Fall

not just focus on ADHD - all behavioral  
+ emotional issues

give the issue much-needed further attention

3/15

# Ritalin ~~Conference~~ Event - conference call

- Chris Jennings
- Liz Summy
- Beverly McLoe
- Dr. Satcher
- Bill Hall
- Daron
- Jane
- Steve Hynar
- Bill Hubbard
- Ken Wirtick - Educ.

10 am Monday

Roosevelt / Run Shobela open up - introduce PR HTRC

Cabinet / Run private strategy meeting stake out later

- how does, etc at strategy meeting?

Tipper Gore - interested - not sure if she can participate

Steve Hynar - NIMH

- don't focus on good or bad - not reputation or medication  
 focus on what's being offered - kids needs -  
 empower parents  
 proper evaluation  
 teacher training - how to handle this issue; kids behavior, PCP's, psychiatrists  
 how to evaluate their needs, how to serve, how to evaluate success

Education - updating packet for schools + parents  
w. ADHD

Steve NIMH handout - goal to get out Monday

Satcher - emphasize team wgt approach - partnership parents - teachers

if it gets cleared - put on web, cross-link updates of info for - WH Conference on ADHD

how do we get out otherwise? how do we out to PCP's

②

Ritalin

incorporate educat. references - kids eligible through IDEA, § 504

NIMH - Ritalin research - still going through ethics procedures  
Cort announce it

announce it's intention of NIMH to fund research on effects of Ritalin for kids under 6. - will get Chris about tomorrow

FDA + NIMH

Conference on treatment of children of mental + behavioral disorders

pediatric

FDA research - labeling - we can require mfr. to conduct pediatric research

announce -

use of ritalin + other medications for toddlers - concerning work of industry

psychotropic drugs - focus not just on ritalin

be careful b/c of ethical issues re: testing on kids

Steve -

Safety + efficacy - toddlers  
mis match - over + under medicating  
diagnosing - careful diagnosis + careful follow-up  
- careful contemplation + management

~~Handwritten scribble~~

Chris - FDA needs more info esp. for toddlers

FDA - work of NIMH - don't know enough to know <sup>whether</sup> here

should be more research before going into labeling & forcing

③

Can't require drug industries to do more research

FDA

announce work of NIMH

Pediatric Advisory Bd research agenda atg  
to make appropriate recomm. on those

Studies are appropriately done

if need to get more info - will then put  
into labeling

Real world application of treatment - effectiveness

Monday - release timetable & agenda list  
for conference  
summer?

contacts

NIMH - Ben Vitello - pediatric psychopharmac pers -

St - Beverly

FDA - Diane Murphy

Edue - Lois Danielson 205-9864

Monday attendees:

Pediatrics, Family Physicians

school nurses, ANA

Am. Assoc. School Psychologists

Am. Academy of Child & Adolescent Psychiatry

Shalala will be there - tentatively she will run mtg after HRC chair

Web  
Ch 3  
HW

4/15

# Partners Conference Call - w/ groups

Chris Jennings -  
Dartmouth

Peter Jensen -  
Columbia -  
ADHD research

Elaine Hilland -  
Am. Acad. Pediatrics

ANA  
Social workers

A Psych. A

AAAP

School Psych. etc.

A Psychology Assoc.  
Natl. Mental Health Assoc.

A.A. Family Physicians

Chris Jennings - PE is moving force  
concerned about over + under medicalization  
very concerned about under 6 population

Ok of misformation, PE interested in constructive dialogue,  
educating the public

meeting - Monday w/ PE  
w/ Steve Hyman, Shalala, Jane Heffley, Satler  
announce # of initiatives

focus on what we know  
begin stronger collaboration b/w health + educ partners

general info  
commitment to dedicating more research \$ - esp. younger kids  
has best to get info to parents + physicians  
research issues

don't just focus on ~~medication~~ vitalen  
also - focus on all behavioral issues - not just medication -  
focus on management, teamwork

teacher representation - special ed teachers  
NEA (has special ed rep who works w/ behavior)

Chris no? APT

Chris - not anti-drug - trying to find appropriate PE mgmt  
more appropriate utilization - combine w/ behavioral  
interventions

②

Ritalin - groups

we will get back to groups re: program

Pediatrics - legit. to get more drug studies for kids is working very well  
- up for reauthorization soon (pediatric labeling)  
Academy coming up w/ guidelines for diagnosing ADHD

regarding labeling - ethical issue so go carefully

get groups copies of NIMH brochure - if they're comfortable w/ it <sup>maybe</sup> they can make comments about distributing

AA-CAP - will send info to Chris + OPL

PL urging all groups to work together cross-professionally

commitment to broader conference - 1 - Fall  
will start a process

~~Barbara~~ get weekend phone + fax <sup>fr</sup> groups so we can get them press papers

maybe do conference call Sunday night -

same phone #  
9:30 pm  
757-2104  
code 26775

- 1. Nat. President - stop for Cabinet mtg
- 1. Staff person Center in Roosevelt Room

pediatric labeling - been a success - 200 studies - big jump <sup>(between 11 studies)</sup> - have they done labeling?  
15 drugs received exclusivity (?)

off label use - no hook to get studies done, no hook to get labeling done. Need new reward system.

③

~~the~~ process to set up appropriate study models - w/ NIMH

Agency for Health Care Quality (ARC ?)

- Pediatric Pharmacology

balanced approach

→ logistics mtg? where to go

# Ritalin-logistics

PL scheduling  
press

10 am - HRC arrival

45 minutes from HRC  
Proskult-Shalala introduces HRC - [validate HRC, highlight her leadership] ~~press reception HRC~~  
7 min - HRC frames the issue  
makes the announcement, Success in pediatric labeling

Bill Shalala - 2 minutes

HRC - 5 minutes

Roosevelt - podium - HRC + Shalala  
behind - Satcher, Henney, Hyman

~~meeting~~ - white house photo - HRC goes = for beginning of mtg.  
after - stake out

deliverables - ① more info to parents - NIMH QIA  
② HHS announce - by conference a children + health board  
③ FDA recognize lack of info - going to study

title: talk ~~to~~ to Chris about how to frame.

Barbara - 12 groups - Red, FP, APA, APA, Soc. U, AANA, Schol. Assoc, NBA, AFT

12 people for Wait Room + 6 others (Shalala, Satcher, Educ(?)  
Ayna, Henney, Judy, Hyman)

standing up - + 4

Shalala intro

press parent group - CHAD (ADD)

HRC speak

concurrent group -

proceed to room TBD

Roosevelt room

Shelala introduce

HRC - top 7 issue  
debatable

move into strategy sess. 2

press - leak on Sunday to get a story on Monday  
to push it along

statement - Shelala cont. -

press - don't invite science reporters -

mtg - agenda - each group gets ~~12 minutes~~ 1 minute (30 second?)  
give HRC + Shelala questions to get conversation going

Turn 10 am

logistics - Ritchie

Donna introduce Shelala

HRC

private meeting

~~private~~

mtg - 20 around noon - engine introduced

HRC - thank engine

met public-private partnership

begins today but disrupted

want to work w/ you through

? - Men Admin. people talk >

HRC - I'm going to ask Donna to report back

we want to work w/ you

we look forward to collaboration

I've gotten preliminary reports on what you've  
been doing + I'm very excited

Start of mtg -

~~Shelala~~  
Shelala's hand

get photos  
to key enter  
the room

Shelala - underscore + affirm HRC's interest in this

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Original Contribution

## Trends in the Prescribing of Psychotropic Medications to Preschoolers

*Julie Magno Zito, PhD; Daniel J. Safer, MD; Susan dosReis, PhD; James F. Gardner, ScM; Myde Boles, PhD; Frances Lynch, PhD*

**Context** Recent reports on the use of psychotropic medications for preschool-aged children with behavioral and emotional disorders warrant further examination of trends in the type and extent of drug therapy and sociodemographic correlates.

**Objectives** To determine the prevalence of psychotropic medication use in preschool-aged youths and to show utilization trends across a 5-year span.

**Design** Ambulatory care prescription records from 2 state Medicaid programs and a salaried group-model health maintenance organization (HMO) were used to perform a population-based analysis of three 1-year cross-sectional data sets (for the years 1991, 1993, and 1995).

**Setting and Participants** From 1991 to 1995, the number of enrollees aged 2 through 4 years in a Midwestern state Medicaid (MWM) program ranged from 146,369 to 158,060; in a mid-Atlantic state Medicaid (MAM) program, from 34,842 to 54,237; and in an HMO setting in the Northwest, from 19,107 to 19,322.

**Main Outcome Measures** Total, age-specific, and gender-specific utilization prevalences per 1000 enrollees for 3 major psychotropic drug classes (stimulants, antidepressants, and neuroleptics) and 2 leading psychotherapeutic medications (methylphenidate and clonidine); rates of increased use of these drugs from 1991 to 1995, compared across the 3 sites.

**Results** The 1995 rank order of total prevalence in preschoolers (per 1000) in the MWM program was: stimulants (12.3), 90% of which represents methylphenidate (11.1); antidepressants (3.2); clonidine (2.3); and neuroleptics (0.9). A similar rank order was observed for the MAM program, while the HMO had nearly 3 times more clonidine than antidepressant use (1.9 vs 0.7). Sizable increases in prevalence were noted between 1991 and 1995 across the 3 sites for clonidine, stimulants, and antidepressants, while neuroleptic use increased only slightly. Methylphenidate prevalence in 2 through 4-year-olds increased at each site: MWM, 3-fold; MAM, 1.7-fold; and HMO, 3.1-fold. Decreases occurred in the relative proportions of previously dominant psychotherapeutic agents in the stimulant and antidepressant classes, while increases occurred for newer, less established agents.

**Conclusions** In all 3 data sources, psychotropic medications prescribed for preschoolers increased dramatically between 1991 and 1995. The predominance of medications with off-label

(unlabeled) indications calls for prospective community-based, multidimensional outcome studies.

*JAMA. 2000;283:1025-1030*

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<b>JAMA</b>   	
<b>Original Contribution</b>	
<b>Trends in the Prescribing of Psychotropic Medications to Preschoolers</b>	
<i>Julie Magno Zito, PhD; Daniel J. Safer, MD; Susan dosReis, PhD; James F. Gardner, ScM; Myde Boles, PhD; Frances Lynch, PhD</i>	
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INTRODUCTION

(unlabeled) indications calls for prospective community-based, multidimensional outcome studies.

*JAMA. 2000;283:1025-1030*

The prevalence of psychotropic medication treatment for children and adolescents with emotional and behavioral disorders has significantly increased in the United States during the last few decades, particularly in the last 15 years. Specifically, the 5 through 14-year-old age group has experienced a great increase in stimulant treatment for attention-deficit/hyperactivity disorder (ADHD), and the 15 through 19-year-old age group has had sizable increases in the use of antidepressant medications.<sup>1, 2</sup>

Approved and unapproved indications for psychotropic medications in young children are not extensive. These include: short-term use of analgesics and sedatives/hypnotics for pain relief; hydroxyzine for situational anxiety associated with medical, presurgical, and dental procedures; tricyclic antidepressants for nocturnal enuresis (6-year-olds and older); and amphetamines for ADHD in those 3 years old and older.<sup>3</sup> Accordingly, the prevalence of psychotropic medication treatment for children younger than 5 years old has not received much professional attention until recently.<sup>4-6</sup>

Concern about this age group relates to off-label (unlabeled) use, ie, for treatment indications with little or no proven efficacy and lacking product package insert labeling information approved by the US Food and Drug Administration (FDA).<sup>7</sup> One psychiatric newsletter, citing FDA-compiled marketing data, reported that 3000 prescriptions for fluoxetine hydrochloride were written for children aged younger than 1 year in 1994.<sup>8</sup> In a 1998 professional meeting report,<sup>5</sup> pediatric researchers noted that 57% of 223 Michigan Medicaid enrollees aged younger than 4 years with a diagnosis of ADHD received at least 1 psychotropic medication to treat this condition during a 15-month period in 1995-1996. Of the treatments, methylphenidate and clonidine were prescribed most often.

Although the use of psychotropic medication in preschool-aged children compared with older youths is relatively small, the reports cited argue for additional assessment to more systematically estimate its use. Consequently, 3 large, computerized data sources were used to estimate total, age-specific, and gender-specific psychotropic medication prevalence for 2 through 4-year-olds; to compare prevalence in the youngest age group with that in older children and adolescents; and to show utilization trends in the 5-year span from 1991-1995.

## METHODS

### Data Sources

Three large data sets were assembled from 2 types of health care systems. The first 2 are outpatient data sets from 2 geographically distinct Medicaid populations, 1 in a Midwestern state and 1 in a mid-Atlantic state. The third set of data comes from a group-model health maintenance organization (HMO) serving a predominantly employed population in the northwest region of the United States

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employed population in the northwest region of the United States. The total enrollments for those younger than age 20 years in 1991 and 1995, respectively, are as follows: Midwestern Medicaid (MWM), 669,164 and 687,722; mid-Atlantic Medicaid (MAM), 165,502 and 248,466; and group-model HMO (HMO), 131,038 and 131,860. These populations included both continuous and noncontinuous enrollees for each study year. The Medicaid youth populations were almost entirely eligible under Aid to Families with Dependent Children, and a small proportion qualified because of disability status (Supplemental Security Income) or foster care status. Nonwhites were overrepresented in the Medicaid populations and were underrepresented among HMO enrollees according to general statistical profiles of the settings.<sup>9</sup>

### Study Measures

Psychotropic medication prevalence was defined for each study year as the frequency of persons with 1 or more HMO pharmacy records or Medicaid prescription claims for a psychotropic medication class, subclass, or specific medication per 1000 enrolled youths. Time trends were assessed across the 5-year span with data from 3 cross-sectional annual analyses (1991, 1993, and 1995).

For age-specific prevalence, children were grouped into 4 age strata (aged 2-4, 5-9, 10-14, and 15-19 years) according to US census categories. Data analyses focused on children aged 2 through 4 years. We were unable to investigate psychotropic medication use in infants 1 year old or younger in the 2 Medicaid populations because year of birth is recorded in a 2-digit field. Thus, "95" could refer to someone born in 1895 or 1995. We were unable, therefore, to distinguish those 1 year old and younger from 100- and 101-year-olds. We do present data on methylphenidate use in infants 1 year old or younger from the HMO program, as 4-digit years of birth were available. From 1991-1995, the number of enrollees aged 2 through 4 years ranged from 146,369 to 158,060 in the MWM program; from 34,842 to 54,237 in the MAM program, and from 19,107 to 19,322 in the HMO.

A separate analysis was performed to examine medication use among preschool-aged children by year of age. Gender-specific prevalence provided separate prevalence rates for boys and for girls.

### Psychotropic Medications

Three psychotropic medication classes were examined: stimulants (methylphenidate, other stimulants), antidepressants (selective serotonin reuptake inhibitors [SSRIs], tricyclic antidepressants [TCAs], and other antidepressants), and neuroleptics. Selection was based on the frequent use of stimulants and antidepressants and the public health significance of the use of neuroleptics in the very young. In addition, 2 specific medications (methylphenidate and clonidine) were examined because their use alone or as a combined treatment has increased substantially since the early 1990s. All the drugs were identified using a data dictionary encompassing the national drug codes for each of the 3 study years. The study was given an exempt classification by the institutional review board—expedited review.

## RESULTS

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### Total Psychotropic Medication Prevalence

The rank order of psychotropic medication prevalence in 1995 for the MWM program shows that, per 1000 enrollees, stimulants (12.3) were the leading treatment among those 2 through 4 years old, followed by antidepressants (3.2), clonidine (2.3), and neuroleptics (0.9) (Table 1). Within classes, methylphenidate prevalence (11.1 per 1000 enrollees) represented 90% of the stimulant treatment, while TCA prevalence (2.4 per 1000 enrollees) led the antidepressant class. A similar ranking of medication prevalence in 1995 was observed for the MAM program, while preschool-aged children in the HMO had nearly 3 times more clonidine use than antidepressant use (Table 1).

Pronounced differences in psychotropic prevalence across the 3 sites are apparent from Table 1. Stimulant and antidepressant use in 1995 was considerably less among preschoolers in the MAM program and HMO than among those in the MWM program. Enrollees in the MWM program and in the HMO led in the use of clonidine, whereas its use in the MAM program was one-half to two-thirds that of the other sites. Neuroleptic use per 1000 enrollees in either Medicaid program (0.9 in the MWM program, and 0.5 in the MAM program) was more common than in the HMO (0.2).

### Time Trends in Psychotropic Medication Prevalence Across a 5-Year Span

The rate of psychotropic medication prescribed for preschoolers in the MWM program increased substantially from 1991-1995. The increase was greatest for clonidine (28.2-fold), stimulants (3.0-fold), and antidepressants (2.2-fold). By contrast, neuroleptic use did not increase substantially during this time. Comparisons of psychotropic medication between sites showed that trends were similar in all 3 sites, with minor deviations for neuroleptics and antidepressants in the population enrolled in the HMO (Table 1). Specifically, the methylphenidate prevalence increase by site was: MWM, 3-fold; MAM, 1.7-fold; and HMO, 3.1-fold. Increases were more dramatic when the base prevalence was low. For example, methylphenidate use in the HMO was the lowest of the 3 sites, but its rise from 1.3 per 1000 enrollees in 1991 to 4.0 per 1000 in 1995 represented the largest methylphenidate increase (3.1-fold) across the 3 sites (Table 1).

### Age-Specific Methylphenidate Medication Prevalence

Methylphenidate use according to age group in children and adolescents in the MWM program was most prominent for those aged 5 through 14 years (Figure 1). By comparison, children 2 through 4 years old were treated at approximately one tenth the rate of their 5 through 14-year-old counterparts. The time trend analysis revealed that those in all 4 age groups experienced increases in the use of methylphenidate during the 5-year period. The largest methylphenidate increase (311%) was among 15 through 19-year-olds, whereas the 2 through 4-year-olds, like the 5- through 14-year-olds, had a smaller but still substantial increase (169% to 176%). The increase in prevalence within the preschool-aged group was greater for older children in the MWM program (from 6.9 to 20.8 per 1000 4-year-olds vs 1.1 to 3.5 per 1000 2-year-olds). The age-specific trends by year of age for those in the MAM program and HMO were consistent with those in the MWM program (Figure

1). There was no methylphenidate use in infants 1 year old or younger in the HMO population.

### Gender-Specific Methylphenidate Medication Prevalence

There was a greater proportional increase in preschool-aged girls receiving methylphenidate from 1991 through 1995; in the HMO, the male-to-female ratio decreased from 7:1 to 4:1 during this time. A similar but less dramatic trend was evident in the MAM program (4:1 in 1991 to 3:1 in 1995). By contrast, the gender ratio for methylphenidate treatment in the MWM program was stable over these years (3:1 in 1991 and in 1995).

### Changes in Drug Utilization and Off-Label Use

Changes in the use of older agents with a well-established efficacy profile were observed. For example, despite a general increase in total stimulant use, methylphenidate use in the MAM program decreased proportionally by 7% from 1991 to 1995, while the use of other stimulant medications rose from 15% to 27% of total stimulant use among preschoolers. In all 3 sites, TCAs were the mainstay of the antidepressant category in 1991, and their prevalence remained relatively stable through 1995. By contrast, the use of SSRI antidepressants increased dramatically at the Medicaid sites, although by 1995 these drugs comprised only a small proportion of antidepressants used in the HMO (Figure 2). Thus, antidepressant use increased, particularly through off-label use, in the preschool-aged group.

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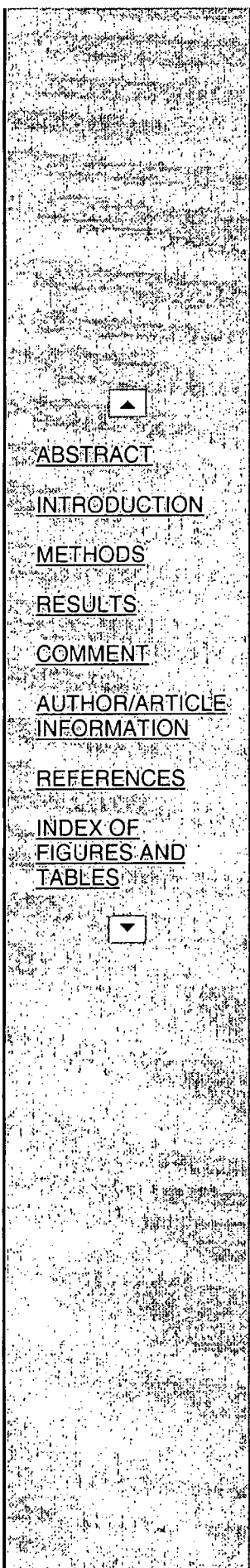
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## COMMENT

Several prominent trends characterized the use of psychotropic medications in preschoolers during the early to mid 1990s. Overall, there were large increases for all study medications (except the neuroleptics) and considerable variation according to gender, age, geographic region, and health care system. These findings are remarkable in light of the limited knowledge base that underlies psychotropic medication use in very young children.<sup>10</sup> Controlled clinical studies to evaluate the efficacy and safety of psychotropic medications for preschoolers are rare.<sup>3</sup> Efficacy data are essentially lacking for clonidine and the SSRIs and methylphenidate's adverse effects for preschool children are more pronounced than for older youths.<sup>11</sup> Consequently, the vast majority of psychotropic medications prescribed for preschoolers are being used off-label.<sup>7</sup> Specific study findings are discussed below according to 3 major outcomes: prevalence findings for specific medications; age- and gender-specific data; and geographic and health care system variations.

### Prevalence Findings

Stimulant treatment in preschoolers increased approximately 3-fold during the early 1990s. The prominence of stimulant and clonidine use is consistent with Michigan Medicaid use patterns for children younger than 4 years with an ADHD diagnosis.<sup>5</sup> The data show greater US methylphenidate prevalence for children younger than age 5 years than was reported in a prevalence study in Western



Australia (0.26% to 0.64% vs approximately 0.1%).<sup>14</sup> Hypothesized reasons for the overall increased stimulant use include: (1) a larger pool of eligible youths because of expanded diagnostic criteria for ADHD since 1980<sup>13</sup>; (2) more girls being treated for ADHD as evidenced by the narrowing of the gender ratio even among preschoolers; (3) greater acceptance of biological treatments for a behavioral disorder; and (4) the expanded role of school and preschool health personnel in identifying medical needs.<sup>14</sup>

Methylphenidate accounted for the vast majority of stimulant use (eg, 90% of the 1995 stimulant use in the MWM program). There was a modest but consistent decrease in the proportion of methylphenidate use relative to other stimulants across the 3 time periods. Generalizing from the efficacy and adverse effect experience of stimulants in older youths to preschoolers is often not valid,<sup>11</sup> at least partly because of preschoolers' developmental immaturity.

Clonidine had the most dramatic increases, although its use in 1995 was only 15% to 35% of the prevalence rate of stimulants. Clonidine use is particularly notable because its increased prescribing is occurring without the benefit of rigorous data to support it as a safe and effective treatment for attentional disorders. Cardiovascular adverse effects including bradycardia, atrioventricular block, and syncope with exercise have been reported in children treated with clonidine in combination with other medications for the treatment of ADHD and its comorbidities.<sup>15, 16</sup> Problems with abrupt withdrawal producing noradrenergic overdrive have been reported. Its use to combat the insomnia associated either with ADHD itself or secondary to the stimulant treatment of ADHD is new and largely uncharted,<sup>17, 18</sup> and its increased use for ADHD since 1991 helps explain the increased clonidine poisonings in children taking either their own medications or that of siblings.<sup>19, 20</sup>

The combined use of clonidine and methylphenidate has been associated with questions of safety<sup>16, 21</sup> and has been debated.<sup>22</sup> Unfortunately, the present data do not distinguish single vs concomitant medication use, information vital to understanding how these agents are being used in children. Such an analysis is better undertaken in a continuously enrolled cohort so that censored data do not create artifactual findings. We are currently conducting a continuously enrolled retrospective cohort study.

Antidepressants were the second most commonly prescribed psychotropic class of drugs for preschoolers, and their use increased substantially from 1991-1995. Tricyclic antidepressants still represent the bulk of early childhood antidepressant use, although the growth in use of SSRIs was strong in those enrolled in both Medicaid programs but very modest in those in the HMO. The proportional decrease in use of TCAs was largely explained by the recent increase in use of SSRIs, a trend we have previously shown for older youths<sup>2</sup> and one that has been documented in adults.<sup>23</sup> The use of TCAs for enuresis is common among 5 through 13-year-olds,<sup>24</sup> but its use in the preschool group is puzzling. It is also likely that some use of imipramine and desipramine was related to the treatment of ADHD in preschoolers.<sup>25</sup>

Neuroleptic use was infrequent and relatively stable across the study period. The neuroleptic prevalence rate in this preschool data showed rates one-tenth to one-half the annual prevalence among 5 through 19-year-olds in Rome from 1986 through 1991.<sup>26</sup> Both the neuroleptic and antidepressant findings bring new information on

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population-based prevalence and provide some benchmarks to chart the use of these agents in ambulatory settings. Additional clinical interpretation, however, awaits prospective outcome studies.

### Age- and Gender-Specific Prevalence Findings

Preschoolers' use of methylphenidate showed increases similar to those of 5 through 14-year-olds, suggesting that the expanded use of this medication for attentional disorders in US youths extends even to the very young. It is notable that the largest gains in use occurred among high school-aged students (15 through 19-year-olds), a trend that has been documented from county school survey data.<sup>13</sup>

### Geographic and Health Care System Variations

Disparities in psychotropic medication prevalence data between the 2 state Medicaid program populations are provocative and suggest numerous hypotheses. These include differences between the states in (1) policies for eligibility or access to continuing care; (2) the proportion of individuals with emotional or mental disorders that may be related to the proportion of youths receiving Supplemental Security Income and foster care in each state; (3) preschool health assessment and referral programs; (4) physician specialty training, particularly among psychiatrists and primary care providers, with resultant referral or practice differences; (5) the cultural values that underlie families' decisions to accept or reject medication for behavioral or mental disorders; and (6) racial/ethnic population differences that may affect cultural orientations and beliefs. Also notable is the finding that the HMO prevalence rates, collectively, were substantially lower than those of the Medicaid programs. In this instance, geography and clinical population factors confound the prevalence findings related to HMO vs Medicaid systems. The presence of less severely disabled youths in the HMO population is likely to explain a large part of the differences, but geographic and patient cultural factors need to be considered as well. Also, the rapid expansion of Supplemental Security Income benefits since 1990 resulted in more youths with ADHD being eligible for Medicaid coverage than in previous years.<sup>27</sup>

### Limitations

The study is limited in several ways. First, the findings may be generalizable to comparable Medicaid programs and to group-model HMO enrollees, but the extent to which they may apply to other treatment settings is unknown. Second, the cross-sectional nature of the data from the 3 study years do not permit a follow-up of the natural course of treatment. Until a continuously enrolled cohort is assembled, descriptive data on the natural course of treatment and prescription changes over time cannot be adequately assessed. However, noncontinuously enrolled individuals make up the bulk of the Medicaid membership. Thus, capturing these annual data snapshots of both noncontinuous and continuous enrollees is useful for clinical description. Third, no diagnostic codes were linked to the medications in this analysis, thus limiting information about why certain medications were selected. Fourth, computerized data sources use a limited number of variables to describe the clinical patterns in the usual practice settings. However, they have the advantage of describing the usual practice setting without the artificiality and the interference that prospective studies impose on physicians' decisions about medication and patients' decisions about treatment. Compared with data from specialty clinic samples, data from community treatment settings provide a far more accurate

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non community treatment settings provide a far more accurate assessment of medication practices, therapy variations, and treatment. Adding outcome assessments would allow the effectiveness of the treatments to be evaluated.

### Clinical Research Recommendations

Because children's responses to medications are not necessarily similar to those of adults, systematic and careful outcome research specifically needs to be done for them.<sup>7</sup> Two types of studies would help provide more systematic information on psychotropic drug therapy in children. First, epidemiologic (naturalistic) studies could describe youth treatment in major medical settings (eg, traditional preferred provider organizations, Medicaid, salaried medical group-model HMOs, and other managed care organizations) to document types of treatments, diagnosis, severity, and time in treatment and to evaluate clinical outcomes. Outcome measures could include symptom control; social, day care, and preschool functioning; parent satisfaction; reasons for initiation and discontinuation; and adverse drug events.<sup>28</sup> Second, randomized, double-blind, controlled clinical trials are needed for off-label indications to evaluate dosages, efficacy, and safety of single and multiple agents shown to be commonly used or widely recommended. For disorders that occur very infrequently or questionable combinations of drug therapy with unknown risks, a case registry approach may be useful.

Future studies using large databases for clinical descriptive information should require that the year of birth be stored as a 4-digit number to avoid misclassification of elders as youths. Finally, youths in Medicaid programs should be subdivided by type of eligibility (eg, low income [formerly Aid to Families with Dependent Children, now called Temporary Assistance for Needy Families], Supplemental Security Income, or foster care) so that the total treatment prevalence, which includes children with known disabilities and major social stressors, will not be unfairly compared with that of less impaired youths in non-Medicaid populations.<sup>27</sup>

Unresolved questions involve the long-term safety of psychotropic medications, particularly in light of earlier ages of initiation and longer durations of treatment. While it is reassuring that anecdotal reports have rarely documented these problems, the possibility of adverse effects on the developing brain cannot be ruled out.<sup>29</sup> Active surveillance mechanisms for ascertaining subtle changes that the developing personality may undergo as a result of a psychotropic drug's impact on brain neurotransmitters should be developed.

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## CHAPTER 3

# CHILDREN AND MENTAL HEALTH

Spanning roughly 20 years, childhood and adolescence are marked by dramatic changes in physical, cognitive, and social-emotional skills and capacities. Mental health in childhood and adolescence is defined by the achievement of expected developmental cognitive, social, and emotional milestones and by secure attachments, satisfying social relationships, and effective coping skills. Mentally healthy children and adolescents enjoy a positive quality of life; function well at home, in school, and in their communities; and are free of disabling symptoms of psychopathology (Hoagwood et al., 1996).

The basic principles for understanding health and illness discussed in the previous chapter apply to children and adolescents, but it is important to underscore the often heard admonition that “children are not little adults.” Even more than is true for adults, children must be seen in the context of their social environments, that is, family, peer group, and their larger physical and cultural surroundings. Childhood mental health is expressed in this context, as children proceed through development.

Development, characterized by periods of transition and reorganization, is the focus of much research on children and adolescents. Studies focus on normal and abnormal development, trying to understand and predict the forces that will keep children and adolescents mentally healthy and maintain them on course to become mentally healthy adults. These studies ask what places some at risk for mental illness and what protects some but not others, despite exposure to the same risk factors.

In addition to studies of normal development and of risk factors, much additional research focuses on mental illness in childhood and adolescence and what can be done to prevent or treat it. The science is

challenging because of the ongoing process of development. The normally developing child hardly stays the same long enough to make stable measurements. Adult criteria for illness can be difficult to apply to children and adolescents, when the signs and symptoms of mental disorders are often also the characteristics of normal development. For example, a temper tantrum could be an expected behavior in a young child but not in an adult. At some point, however, it becomes clearer that certain symptoms and behaviors cause great distress and may lead to dysfunction of children, their family, and others in their social environment. At these points, it is helpful to consider serious deviations from expected cognitive, social, and emotional development as “mental disorders.” Specific treatments and services are available for children and adolescents with such mental disorders, but one cannot forget that these disorders emerge in the context of an ongoing developmental process and shifting relationships within the family and community. These developmental factors must be carefully addressed, if one is to maximize the healthy development of children with mental disorders, promote remediation of associated impairments, and enhance their adult outcomes.

The developmental perspective helps us understand how estimated prevalence rates for mental disorders in children and adolescents vary as a function of the degree of impairment that the child experiences in association with specific symptom patterns. For example, the MECA Study (Methodology for Epidemiology of Mental Disorders in Children and Adolescents) estimated that almost 21 percent of U.S. children ages 9 to 17 had a diagnosable mental or addictive disorder associated with at least minimum impairment (see Table 3-1). When diagnostic criteria

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**Table 3-1. Children and adolescents age 9–17 with mental or addictive disorders, combined MECA sample, 6-month (current) prevalence\***

	(%)
Anxiety Disorders	13.0
Mood Disorders	6.2
Disruptive Disorders	10.3
Substance Use Disorders	2.0
Any Disorder	20.9

\* Disorders include diagnosis-specific impairment and Child Global Assessment Scale  $\leq 70$  (mild global impairment)

Source: Shaffer et al., 1996a

required the presence of *significant* functional impairment, estimates dropped to 11 percent. This estimate translates into a total of 4 million youth who suffer from a major mental illness that results in significant impairments at home, at school, and with peers. Finally, when *extreme* functional impairment is the criterion, the estimates dropped to 5 percent.

Given the process of development, it is not surprising that these disorders in some youth are known to wax and wane, such that some afflicted children improve as development unfolds, perhaps as a result of healthy influences impinging on them. Similarly, other youth, formerly only “at risk,” may develop full-blown forms of disorder, as severe and devastating in their impact on the youth and his or her family as are the analogous conditions that affect adults. Characterizing such disorders as relatively unchangeable underestimates the potential beneficial influences that can redirect a child whose development has gone awry. Likewise, characterizing children with mental disorders as “only” the victims of negative environmental influences that might be fixed if societal factors were just changed runs the risk of underestimating the severity of these conditions and the need for focused, intensive clinical interventions for suffering children and adolescents. Thus, the science of mental health in childhood and adolescence is a complex mix of the study of development and the study of discrete

conditions or disorders. Both perspectives are useful. Each alone has its limitations, but together they constitute a more fully informed approach that spans mental health and illness *and* allows one to design developmentally informed strategies for prevention and treatment.

### Normal Development

Development is the lifelong process of growth, maturation, and change that unfolds at the fastest pace during childhood and adolescence. An appreciation of normal development is crucial to understanding mental health in children and adolescents and the risks they face in maintaining mental health. Distortions in the process of development may lead to mental disorders. This section deals with the normal development of understanding (cognitive development) in young children and the development of social relationships and temperament.

### Theories of Development

Historically, the changes that take place in a child’s psyche between birth and adulthood were largely ignored. Child development first became a subject of serious inquiry at the beginning of this century but was mostly viewed from the perspective of mental disorders and from the cultural mainstream of Europe and white America. Some of the “grand theories” of child development, such as that propounded by Sigmund Freud, grew out of this focus, and they unquestionably drew attention to the importance of child development in laying the foundation for adult mental health. Even those theories that resulted from the observation of healthy children, such as Piaget’s theory of cognitive development, paid little attention to the relationship between the development of the “inner self” and the environment into which the individual was placed. In contrast, the interaction of an individual with the environment was central to the school of thought known as behaviorism.

Theories of normal development, introduced in Chapter 2, are presented briefly below, because they form the basis of many current approaches to understanding and treating mental illness and mental health problems in children and adults. These theories

have not achieved the broader objective of explaining how children grow into healthy adults. More study and perhaps new theories will be needed to improve our ability to guide healthy child-rearing with scientific evidence.

### ***Development Viewed as a Series of Stages***

Freud and the psychoanalyst Erik Erikson proposed a series of stages of development reflecting the attainment of biological objectives. The stages are expressed in terms of functioning as an individual and with others—within the family and the broader social environment (particularly in Erikson's theories) (see Chapter 2). Although criticized as unscientific and relevant primarily to the era and culture in which they were conceived, these theories introduced the importance of thinking developmentally, that is, of considering the ever-changing physical and psychological capacities and tasks faced by people as they age. They emphasized the concept of “maturation” and moving through the stages of life, adapting to changing physical capacities and new psychological and social challenges. And they described mental health problems associated with failure to achieve milestones and objectives in their developmental schemes.

These theories have guided generations of psychodynamic therapists and child development experts. They are important to understand as the underpinnings of many therapeutic approaches, such as interpersonal therapy, some of which have been evaluated and found to be efficacious for some conditions. By and large, however, these theories have rarely been tested empirically.

### ***Intellectual Development***

The Swiss psychologist Jean Piaget also developed a stage-constructed theory of children's intellectual development. Piaget's theory, based on several decades' observations of children (Inhelder & Piaget, 1958), was about how children gradually acquire the ability to understand the world around them through active engagement with it. He was the first to recognize that infants take an active role in getting to know their

world and that children have a different understanding of the world than do adults. The principal limitations of Piaget's theories are that they are descriptive rather than explanatory. Furthermore, he neglected variability in development and temperament and did not consider the crucial interplay between a child's intellectual development and his or her social experiences (Bidell & Fischer, 1992).

### ***Behavioral Development***

Other approaches to understanding development are less focused on the stages of development. Behavioral psychology focused on observation and measurement, explaining development in terms of responses to stimuli, such as rewards. Not only did the theories of the early pioneers (e.g., Pavlov, Watson, and Skinner) generate a number of valuable treatments, but their focus on precise description set the stage for current programs of research based on direct observation. Social learning theory (Bandura, 1977) emphasized role models and their impact on children and adolescents as they develop. Several important clinical tools came out of behaviorism (e.g., reinforcement and behavior modification) and social learning theory (cognitive-behavioral therapy). Both treatment approaches are used effectively with children and adolescents.

## **Social and Language Development**

### ***Parent-Child Relationships***

It is common knowledge that infants and, for the most part, their principal caretakers typically develop a close bond during the first year of life, and that in the second year of life children become distressed when they are forcibly separated from their mothers. However, the clinical importance of these bonds was not fully appreciated until John Bowlby introduced the concept of *attachment* in a report on the effects of maternal deprivation (Bowlby, 1951). Bowlby (1969) postulated that the pattern of an infant's early attachment to parents would form the basis for all later social relationships. On the basis of his experience with disturbed children, he hypothesized that, when the mother was unavailable or only partially available

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during the first months of the child's life, the attachment process would be interrupted, leaving enduring emotional scars and predisposing a child to behavioral problems.

A mother's bond with her child often starts when she feels fetal movements during pregnancy. Immediately after birth, most, but by no means all, mothers experience a surge of affection that is followed by a feeling that the baby belongs to them. This experience may not occur at all or be delayed under conditions of addiction or postnatal depression (Robson & Kumar, 1980; Kumar, 1997). Yet, like all enduring relationships, it seems that the relationship between mother and child develops gradually and strengthens over time. Some infants who experience severe neglect in early life may develop mentally and emotionally without lasting consequences, for example, if they are adopted and their adoptive parents provide sensitive, stable, and enriching care, or if depressed or substance-abusing mothers recover fully (Koluchova, 1972; Dennis, 1973; Downey & Coyne, 1990). Unfortunately, however, early neglect is all too often the precursor of later neglect. When the child remains subject to deprivation, inadequate or insensitive care, lack of affection, low levels of stimulation, and poor education over long periods of time, later adjustment is likely to be severely compromised (Dennis, 1973; Curtiss, 1977).

In general, it appears that the particular caregiver with whom infants interact (i.e., biological mother or another) is less important for the development of good social relationships than the fact that infants interact over a period of time with someone who is familiar and sensitive (Lamb, 1975; Bowlby, 1988). One of the problems in the later development of children who experience early institutionalization or significant neglect is that there may have been no opportunities for the caretakers and the infants to establish strong and mutual attachments in a reciprocating relationship.

### *Origins of Language*

Recent research has established that successful use of language and communication is a cornerstone of childhood mental health. Not only are strong language

capabilities critical to the development of such skills as listening and speaking, but they also are fundamental to the acquisition of proficient reading and writing abilities. In turn, children with a variety of speech and language impediments are at increasing risk as their language abilities fall behind those of their peers. Caretaker and baby start to communicate with each other vocally as well as visually during the first months of life. Many, but not all, developmental psychologists believe that this early pattern of mother-infant reciprocity and interchange is the basis on which subsequent language and communication develop. Various theorists have attempted to explain the relations between language and cognitive development (Vygotsky, 1962; Chomsky, 1965, 1975, 1986; Bruner, 1971; Luria, 1971), but no single theory has achieved preeminence. While a number of theories address language development from different perspectives, all theories suggest that language development depends on both biological and socio-environmental factors. It is clear that language competence is a critical aspect of children's mental health.

### *Relationships With Other Children*

To be healthy, children must form relationships not only with their parents, but also with siblings and with peers. Peer relationships change over time. In the toddler period, children's social skills are very limited; they spend most of their time playing side by side rather than with each other in a give-and-take fashion.

As children grow, their abilities to form close relationships become highly dependent on their social skills. These include an ability to interpret and understand other children's nonverbal cues, such as body language and pitch of voice. Children whose social skills develop optimally respond to what other children say, use eye contact, often mention the other child's name, and may use touch to get attention. If they want to do something that other children oppose, they can articulate the reasons why their plan is a good one. They can suppress their own wishes and desires to reach a compromise with other children and may be willing to change—at least in the presence of another child—a stated belief or wish. When they are with a

group of children they do not know, they are quiet but observant until they have a feeling for the structure and dynamics of the group (Coie & Kuperschmidt, 1983; Dodge, 1983; Putallaz, 1983; Dodge & Feldman, 1990; Kagan et al., 1998).

In contrast, children who lack such skills tend to be rejected by other children. Commonly, they are withdrawn, do not listen well, and offer few if any reasons for their wishes; they rarely praise others and find it difficult to join in cooperative activities (Dodge, 1983). They often exhibit features of oppositional defiant or conduct disorder, such as regular fighting, dominating and pushing others around, or being spiteful (Dodge et al., 1990). Social skills improve with opportunities to mix with others (Bridgeman, 1981). In recent years, knowledge of the importance of children's acquisition of social skills has led to the development and integration of social skills training components into a number of successful therapeutic interventions.

### **Temperament**

During the past two decades, as psychologists began to view the child less as a passive recipient of environmental input but rather as an active player in the process, the importance of temperament has become better appreciated (Plomin, 1986). Temperament is defined as the repertoire of traits with which each child is born; this repertoire determines how people react to the world around them. Such variations in characteristics were first described systematically by Anna Freud from her observations of children orphaned by the ravages of World War II. She noticed that some children were affectionate, some wanted to be close but were too shy to approach adults, and some were difficult because they were easily angered and frustrated (A. Freud, 1965).

The first major longitudinal observations on temperament were begun in the 1950s by Thomas and Chess (1977). They distinguished 10 aspects of temperament, but there appear to be many different ways to describe temperamental differences (Goldsmith et al., 1987). Although there is some continuity in temperamental qualities throughout the life span (Chess

& Thomas, 1984; Mitchell, 1993), temperament is often modified during development, particularly by the interaction with the caregiver. For example, a timid child can become bolder with the help of parental encouragement (Kagan, 1984, 1989). Some traits of temperament, such as attention span, goal orientation, lack of distractibility, and curiosity, can affect cognitive functioning because the more pronounced these traits are, the better a child will learn (Campos et al., 1983). Of note, it is not always clear whether extremes of temperament should be considered within the spectrum of mental disorder (for example, shyness or anxiety) or whether certain forms of temperament might predispose a child to the development of certain mental disorders.

### **Developmental Psychopathology**

#### *Current Developmental Theory Applied to Child Mental Health and Illness*

A number of central concepts and guiding assumptions underpin our current understanding of children's mental health and illness. These have been variously defined by different investigators (Sroufe & Rutter, 1984; Cicchetti & Cohen, 1995; Jensen, 1998), but by and large these tenets are based on the premise that psychopathology in childhood arises from the complex, multilayered interactions of specific characteristics of the child (including biological, psychological, and genetic factors), his or her environment (including parent, sibling, and family relations, peer and neighborhood factors, school and community factors, and the larger social-cultural context), and the specific manner in which these factors interact with and shape each other over the course of development. Thus, an understanding of a child's particular history and past experiences (including biologic events affecting brain development) is essential to unravel the why's and wherefore's of a child's particular behaviors, both normal and abnormal.

While this principle assumes developmental continuities, to the extent that early experiences are "brought forward" into the current behavior, it is also

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important to consider developmental discontinuities, where qualitative shifts in the child's biological, psychological, and social capacities may occur. These may not be easily discerned or predicted ahead of time and may reflect the emergence of new capacities (or incapacities) as the child's psychological self, brain, and social environment undergo significant reorganization.

A second precept underlying an adequate understanding of children's mental health and illness concerns the innate tendencies of the child to adapt to his or her environment. This principle of adaptation incorporates and acknowledges children's "self-righting" and "self-organizing" tendencies; namely, that a child within a given context naturally adapts (as much as possible) to a particular ecological niche, or when necessary, modifies that niche to get needs met. When environments themselves are highly disordered or pathological, children's adaptations to such settings may also be pathologic, especially when compared with children's behaviors within more healthy settings. This principle underscores the likelihood that some (but not all) "pathologic" behavioral syndromes might be best characterized as adaptive responses when the child or adolescent encounters difficult or adverse circumstances. Notably, this ability to adapt behaviorally is reflected at multiple levels, including the level of brain and nervous system structures (sometimes called neuroplasticity).

A third consideration that guides both research-based and clinical approaches to understanding child mental health and illness concerns the importance of age and timing factors. For example, a behavior that may be quite normal at one age (e.g., young children's distress when separated from their primary caretaking figure) can be an important symptom or indicator of mental illness at another age. Similarly, stressors or risk factors may have no, little, or profound impact, depending on the age at which they occur and whether they occur alone or with other accumulated risk factors.

A fourth premise underpinning an adequate understanding of children's mental health and illness concerns the importance of the child's context. Perhaps

the most important context for developing children is their caretaking environment. Research with both humans and animals has demonstrated that gross disruptions in this critical parameter have immediate and long-term effects, not just on the young organism's later social-emotional development but also on physical health, long-term morbidity and mortality, later parenting practices, and even behavioral outcomes of its offspring. Moreover, context may play a role in the definition of what actually constitutes psychopathology or health. The same behavior in one setting or culture might be acceptable and even "normative," whereas it may be seen as pathological in another.

Yet another principle central to understanding child mental health and illness is that normal and abnormal developmental processes are often separated only by differences of degree. Thus, supposed differences between normal and abnormal behavior may be better understood by taking into account the differences in the amount or degree of the particular behavior, or the degree of exposure to a particular risk factor. Frequently, no sharp distinctions can be made.

The virtue of these developmental considerations when applied to children is that (a) they enable a broader, more informed search for factors related to the onset of, maintenance of, and recovery from abnormal forms of child behavior; (b) they help move beyond static diagnostic terms that tend to reduce the behaviors of a complex, developing, adapting, and feeling child to an oversimplified diagnostic term; (c) they offer a new perspective on potential targets for intervention, whether child-focused or directed toward environmental or contextual factors; and (d) they highlight the possibility of important timing considerations: windows of opportunity during a child's development when preventive or treatment interventions may be especially effective.

In the sections that follow, these considerations will help the reader understand the important differences from chapters focusing principally on adults, as well as the unique opportunities for intervention that occur because of these differences.

## Overview of Risk Factors and Prevention

Current approaches to understanding the etiology of mental disorders in childhood are driven by empirical advances in neuroscience and behavioral research rather than by theories. Epidemiological research on the factors that make children vulnerable to mental illness is important for several reasons: delineating the range of risk factors for particular mental disorders helps to understand their etiology; the populations most at risk can be identified; understanding the relative strength of different risk factors allows for the design of appropriate prevention programs for children in different contexts; and resources can be better allocated to intervene so as to maximize their effectiveness.

### Risk Factors

There is now good evidence that *both* biological factors and adverse psychosocial experiences during childhood influence—but not necessarily “cause”—the mental disorders of childhood. Adverse experiences may occur at home, at school, or in the community. A stressor or risk factor may have no, little, or a profound impact, depending on individual differences among children and the age at which the child is exposed to it, as well as whether it occurs alone or in association with other risk factors. Although children are influenced by their psychosocial environment, most are inherently resilient and can deal with some degree of adversity. However, some children, possibly those with an inherent biological vulnerability (e.g., genes that convey susceptibility to an illness), are more likely to be harmed by an adverse environment, and there are some environmental adversities, especially those that are long-standing or repeated, that seem likely to induce a mental disorder in all but the hardiest of children. A recent analysis of risk factors by Kraemer and colleagues (1997) has provided a useful framework for differentiating among categories of risk and may help point this work in a more productive direction.

Risk factors for developing a mental disorder or experiencing problems in social-emotional development include prenatal damage from exposure to alcohol, illegal drugs, and tobacco; low birth weight;

difficult temperament or an inherited predisposition to a mental disorder; external risk factors such as poverty, deprivation, abuse and neglect; unsatisfactory relationships; parental mental health disorder; or exposure to traumatic events.

### *Biological Influences on Mental Disorders*

It seems likely that the roots of most mental disorders lie in some combination of genetic and environmental factors—the latter may be biological or psychosocial (Rutter et al., 1999). However, increasing consensus has emerged that biologic factors exert especially pronounced influences on several disorders in particular, including pervasive developmental disorder (Piven & O’Leary, 1997), autism (Piven & O’Leary, 1997), and early-onset schizophrenia (McClellan & Werry, in press). It is also likely that biological factors play a large part in the etiology of social phobia (Pine, 1997), obsessive-compulsive disorder (Leonard et al., 1997), and other disorders such as Tourette’s disorder (Leckman et al., 1997).

Two important points about biological factors should be borne in mind. The first is that biological influences are not necessarily synonymous with those of genetics or inheritance. Biological abnormalities of the central nervous system that influence behavior, thinking, or feeling can be caused by injury, infection, poor nutrition, or exposure to toxins, such as lead in the environment. These abnormalities are not inherited. Mental disorders that are most likely to have genetic components include autism, bipolar disorder, schizophrenia, and attention-deficit/hyperactivity disorder (ADHD) (National Institute of Mental Health [NIMH], 1998). Second, it is erroneous to assume that biological and environmental factors are independent of each other, when in fact they interact. For example, traumatic experiences may induce biological changes that persist. Conversely, children with a biologically based behavior may modify their environment. For example, low-birth-weight infants who have sustained brain damage, and thereby become excessively irritable, may change the behavior of caretakers in a way that adversely affects the caretaker’s ability to provide good care. Thus, it is now well documented

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that a number of biologic risk factors exert important effects on brain structure and function and increase the likelihood of subsequently developing mental disorders. These well-established factors include intra-uterine exposure to alcohol or cigarette smoke (Nichols & Chen, 1981), perinatal trauma (Whitaker et al., 1997), environmental exposure to lead (Needleman et al., 1990), malnutrition of pregnancy, traumatic brain injury, nonspecific forms of mental retardation, and specific chromosomal syndromes.

### *Psychosocial Risk Factors*

A landmark study on risks from the environment (Rutter & Quinton, 1977) showed that several factors can endanger a child's mental health. Dysfunctional aspects of family life such as severe parental discord, a parent's psychopathology or criminality, overcrowding, or large family size can predispose to conduct disorders and antisocial personality disorders, especially if the child does not have a loving relationship with at least one of the parents (Rutter, 1979). Economic hardship can indirectly increase a child's risk of developing a behavioral disorder because it may cause behavioral problems in the parents or increase the risk of child abuse (Dutton, 1986; Link et al., 1986; Wilson, 1987; Schorr, 1988). Exposure to acts of violence also is identified as a possible cause of stress-related mental health problems (Jenkins & Bell, 1997). Studies point to poor caregiving practices as being a risk factor for children of depressed parents (Zahn-Waxler et al., 1990).

The quality of the relationship between infants or children and their primary caregiver, as manifested by the security of attachment, has long been felt to be of paramount importance to mental health across the life span. In this regard, the relationship between maternal problems and those factors in children that predispose them to form insecure attachments, particularly young infants' and toddlers' security of attachment and temperament style and their impact on the development of mood and conduct disorders, is of great interest to researchers. Many investigators have taken the view that the nature and the outcome of the attachment process are related to later depression, especially when

the child is raised in an abusive environment (Toth & Cicchetti, 1996), and to later conduct disorder (Sampson & Laub, 1993). The relationship of attachment to mental disorders has been the subject of several important review articles (Rutter, 1995; van IJzendoorn et al., 1995).

There is controversy as to whether the key determinant of "insecure" responses to strange situations stems from maternal behavior or from an inborn predisposition to respond to an unfamiliar stranger with avoidant behaviors, such as is found in socially phobic children (Belsky & Rovine, 1987; Kagan et al., 1988; Thompson et al., 1988; Kagan, 1994, 1995). Kagan demonstrated that infants who were more prone to being active, agitated, and tearful at 4 months of age were less spontaneous and sociable and more likely to show anxiety symptoms at age 4 (Snidman et al., 1995; Kagan et al., 1998). These findings are of considerable significance, because long-term study of such highly reactive, behaviorally inhibited infants and toddlers has shown that they are excessively shy and avoidant in early childhood and that this behavior persists and predisposes to later anxiety (Biederman et al., 1993). There is also some controversy as to whether "difficult" temperament in an infant is an early manifestation of a behavior problem, particularly in children who go on to demonstrate such problems as conduct disorder (Olds et al., 1999). One analysis of the attachment literature suggests that abnormal or insecure forms of attachment are largely the *product* of maternal problems, such as depression and substance abuse, rather than of individual differences in the child (van IJzendoorn et al., 1992).

The relationship between a child's temperament and parenting style is complex (Thomas et al., 1968); it may be either protective if it is good or a risk factor if it is poor. Thus, a difficult child's chances of developing mental health problems are much reduced if he or she grows up in a family in which there are clear rules and consistent enforcement (Maziade et al., 1985), while a child exposed to inconsistent discipline is at greater risk for later behavior problems (Werner & Smith, 1992).

### ***Family and Genetic Risk Factors***

As noted above in the relationships between temperament and attachment, in some instances the relative contributions of biologic influences and environmental influences are difficult to tease apart, a problem that particularly affects studies investigating the impact of family and genetic influences on risk for childhood mental disorder. For example, research has shown that between 20 and 50 percent of depressed children and adolescents have a family history of depression (Puig-Antich et al., 1989; Todd et al., 1993; Williamson et al., 1995; Kovacs, 1997b). The exact reasons for this increased risk have not been fully clarified, but experts tend to agree that both factors interact to result in this increased risk (Weissman et al., 1997). Family research has found that children of depressed parents are more than three times as likely as children of nondepressed parents to experience a depressive disorder (see Birmaher et al., 1996a and 1996b for review). Parental depression also increases the risk of anxiety disorders, conduct disorder, and alcohol dependence (Downey & Coyne, 1990; Weissman et al., 1997; Wickramaratne & Weissman, 1998). The risk is greater if both parents have had a depressive illness, if the parents were depressed when they were young, or if a parent had several episodes of depression (Merikangas et al., 1988; Downey & Coyne, 1990; McCracken, 1992a, 1992b; Mufson et al., 1992; Warner et al., 1995; Wickramaratne & Weissman, 1998).

### ***Effects of Parental Depression***

Depressed parents may be withdrawn and lack energy and consequently pay little attention to, or provide inadequate supervision of, their children. Alternatively, such parents may be excessively irritable and overcritical, thereby upsetting children, demoralizing them, and distancing them (Cohn et al., 1986; Field et al., 1990). At a more subtle level, parents' distress—being pessimistic, tearful, or threatening suicide—is sometimes seen or heard by the child, thereby inducing anxiety. Depressed parents may not model effective coping strategies for stress; instead of “moving on,” some provide an example of “giving up” (Garber &

Hilsman, 1992). Depression is also often associated with marital discord, which may have its own adverse effect on children and adolescents. Conversely, the behavior of the depressed child or teenager may contribute to family stress as much as being a product of it. The poor academic performance, withdrawal from normal peer activities, and lack of energy or motivation of a depressed teenager may lead to intrusive or reprimanding reactions from parents that may further reduce the youngster's self-esteem and optimism.

The consequences of maternal depression vary with the state of development of the child, and some of the effects are quite subtle (Cicchetti & Toth, 1998). For example, in infancy, a withdrawn or unresponsive depressed mother may increase an infant's distress, and an intrusive or hostile depressed mother may lead the infant to avoid looking at and communicating with her (Cohn et al., 1986). Other studies have shown that if infants' smiles are met with a somber or gloomy face, they respond by showing a similarly somber expression and then by averting their eyes (Murray et al., 1993).

During the toddler stage of development, research shows that the playful interactions of a toddler with a depressed mother are often briefer and more likely to be interrupted (by either the mother or the child) than those with a nondepressed parent (Jameson et al., 1997). Research has shown that some depressed mothers are less able to provide structure or to modify the behavior of excited toddlers, increasing the risk of out-of-control behavior, the development of a later conduct disorder, or later aggressive dealings with peers (Zahn-Waxler et al., 1990; Hay et al., 1992). A depressed mother's inability to control a young child's behavior may result in the child failing to learn appropriate skills for settling disputes without reliance on aggression.

### ***Stressful Life Events***

The relationship between stressful life events and risk for child mental disorders is well established (e.g., Garmezy, 1983; Hammen, 1988; Jensen et al., 1991; Garber & Hilsman, 1992), although this relationship in children and adolescents is complicated, perhaps reflecting the impact of individual differences and

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developmental changes. For example, there is a relationship between stressful life events, such as parental death or divorce, and the onset of major depression in young children, especially if they occur in early childhood and lead to a permanent and negative change in the child's circumstances. Yet findings are mixed as to whether the same relationship is true for depression in midchildhood or in adolescence (Birmaher et al., 1996a and 1996b; Garrison et al., 1997).

### ***Childhood Maltreatment***

Child abuse is a very widespread problem; it is estimated that over 3 million children are maltreated every year in the United States (National Committee to Prevent Child Abuse, 1995). Physical abuse is associated with insecure attachment (Main & Solomon, 1990), psychiatric disorders such as post-traumatic stress disorder, conduct disorder, ADHD (Famularo et al., 1992), depression (Kaufman, 1991), and impaired social functioning with peers (Salzinger et al., 1993). Psychological maltreatment is believed to occur more frequently than physical maltreatment (Cicchetti & Carlson, 1989); it is associated with depression, conduct disorder, and delinquency (Kazdin et al., 1985) and can impair social and cognitive functioning in children (Smetana & Kelly, 1989).

### ***Peer and Sibling Influences***

The influence of maladaptive peers can be very damaging to a child and greatly increases the likelihood of adverse outcomes such as delinquency, particularly if the child comes from a family beset by many stressors (Friday & Hage, 1976; Loeber & Farrington, 1998). One way to reduce antisocial behavior in adolescents is to encourage such youths to interact with better adapted youths under the supervision of a mental health worker (Feldman et al., 1983). Sibling rivalry is a common component of family life and, especially in the presence of other risk factors, may contribute to family stresses (Patterson & Dishion, 1988). Although almost universal, in the presence of other risk factors it may be the origin of aggressive behavior that eventually extends beyond the family (Patterson &

Dishion, 1988). In stressed or large families, parents have many demands placed on their time and find it difficult to oversee, or place limits on, their young children's behavior. When parental attention is in short supply, young siblings squabbling with each other attract available attention. In such situations, parents rarely comment on good or neutral behavior but do pay attention, even if in a highly critical and negative way, when their children start to fight; as a result, the act of fighting may be inadvertently rewarded. Thus, any attention, whether it be praise or physical punishment, increases the likelihood that the behavior is repeated.

### ***Correlations and Interactions Among Risk Factors***

Recent evidence suggests that social/environmental risk factors may combine with physical risk factors of the child, such as neurological damage caused by birth complications or low birth-weight, fearlessness and stimulation-seeking behavior, learning impairments, autonomic underarousal, and insensitivity to physical pain and punishment (Raine et al., 1996, 1997, 1998). However, testing models of the impact of risk factor interactions for the development of mental disorders is difficult, because some of the risk factors are difficult to measure. Thus, the trend these days is to move away from the consideration of *individual* risk factors toward identifying *measurable* risk factors and their *combinations* and incorporating all of them into a single model that can be tested (Patterson, 1996).

The next section describes a series of preventive interventions directed against the environmental risk factors described above.

### **Prevention**

Childhood is an important time to prevent mental disorders and to promote healthy development, because many adult mental disorders have related antecedent problems in childhood. Thus, it is logical to try to intervene early in children's lives before problems are established and become more refractory. The field of prevention has now developed to the point that reduction of risk, prevention of onset, and early intervention are realistic possibilities. Scientific

methodologies in prevention are increasingly sophisticated, and the results from high-quality research trials are as credible as those in other areas of biomedical and psychosocial science. There is a growing recognition that prevention does work; for example, improving parenting skills through training can substantially reduce antisocial behavior in children (Patterson et al., 1993).

The wider human services and law enforcement communities, not just the mental health community, have made prevention a priority. Policymakers and service providers in health, education, social services, and juvenile justice have become invested in intervening early in children's lives: they have come to appreciate that mental health is inexorably linked with general health, child care, and success in the classroom and inversely related to involvement in the juvenile justice system. It is also perceived that investment in prevention may be cost-effective. Although much research still needs to be done, communities and managed health care organizations eager to develop, maintain, and measure empirically supported preventive interventions are encouraged to use a risk and evidence-based framework developed by the National Mental Health Association (Mrazek, 1998).

Some forms of primary prevention are so familiar that they are no longer thought of as mental health prevention activities, when, in fact, they are. For example, vaccination against measles prevents its neurobehavioral complications; safe sex practices and maternal screening prevent newborn infections such as syphilis and HIV, which also have neurobehavioral manifestations. Efforts to control alcohol use during pregnancy help prevent fetal alcohol syndrome (Stratton et al., 1996). All these conditions may produce mental disorders in children.

This section describes several exemplary interventions that focus on enhancing mental health and primary prevention of behavior problems and mental health disorders. Prevention of a disorder or its recurrence or exacerbation is discussed together with that disorder in other sections of this chapter. Prevention strategies usually target high-risk infants,

young children, adolescents, and/or their caregivers, addressing the risk factors described above.

### ***Project Head Start***

Project Head Start, though generally conceived of as an early childhood intervention program, is probably this country's best known prevention program. In 1965, when it was designed and first implemented in 2,500 communities, Head Start's target population was economically disadvantaged preschool children. Its goal was to improve the social competence of these children through an 8-week comprehensive intervention that included a center-based component and a home visit by community aides, focusing on social, health, and education services (Karloly et al., 1998). A number of psychologists, most notably Jerome Bruner (1971), argued that children can be *trained* to think in a more logical way and that the development of logic is not entirely predetermined. Bruner's views were very influential in launching early intervention programs such as Head Start. There is now ample evidence that, by providing an appropriately stimulating environment, significant advances in knowledge and reasoning ability can be achieved.

The program has served over 15 million children and has cost \$31 billion since its inception (General Accounting Office, 1997). It has changed in many ways in the intervening years, and there now is considerable program variation across localities (Zigler & Styfco, 1993). Early evaluations of Head Start showed promising results in terms of higher IQ scores, but over the years many of the findings have met with criticism and skepticism. The reason is that there has been no national randomized controlled trial to evaluate the program as originally designed (Karloly et al., 1998).

Repeated evaluations of Head Start programs that did not employ such a rigorous design (Berrento-Clement et al., 1984; Seitz et al., 1985; Lee et al., 1990; Yoshikawa, 1995) have shown that, although focused early education can improve test scores, the advantage is short-lived. The test scores of children of comparable ability who do not receive early childhood education quickly catch up with those who have been in Head Start programs (Lee et al., 1990). Yet there appear to be

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more enduring academic outcomes. A review of 36 studies of Head Start and other early childhood programs found them to lower enrollment in special education and to enhance rates of high school graduation and promotion to the next grade level (Barnett, 1995). Head Start and other forms of early education offer arguably even more important benefits, which do not become apparent until children are older. The advantages are mainly social, rather than cognitive, and include better peer relations, less truancy, and less antisocial behavior (Berrento-Clement et al., 1984; Provence, 1985; Seitz et al., 1985; Webster-Stratton, 1998; Weikart, 1998). Although important from a societal perspective, it is not known whether these very significant benefits are due to direct effects on the child or to the parent education programs that often accompany Head Start programs (Zigler & Styfco, 1993).

### *Carolina Abecedarian Project*

The Carolina Abecedarian Project is an example of an early educational intervention for high-risk children that has been tested more rigorously than Head Start in well-designed, randomized, and controlled trials. It addresses the issue of the timing of the intervention, that is, when an intervention should begin and how long it should continue. Unlike Head Start, children were enrolled in this program at birth and remained in it for several years.

In the Carolina Abecedarian Project, children who had been identified at birth as being at high risk for school failure on the basis of social and economic variables were enrolled in a child-centered prevention-oriented intervention program delivered in a day care setting from infancy to age 5 (Campbell & Ramey, 1994<sup>1</sup>). The preschool intervention operated 8 hours a day for 50 weeks a year and included an infant curriculum to enhance development and parent activities. At elementary school age, a second intervention was provided: the children, who were then in kindergarten, received 15 home visits a year for 3 years from a teacher who prepared a home program to

supplement the school's basic curriculum. There were significant positive effects from the two-phase intervention on intellectual development and academic achievement, and these effects were maintained through age 12, which was 4 years after the intervention ended.

### *Infant Health and Development Program*

The Infant Health and Development Program (IHDP) also began at birth and continued for several years and was also designed for low-birth-weight and premature infants (McCarton et al., 1997<sup>2</sup>). The intervention was provided until the children reached 3 years of age. It included pediatric care, home visits, parent group meetings, and center-based schooling 5 days a week from 12 months of age to 3 years. At the end of the intervention, the group receiving it had significantly higher mean IQ scores than did the control group. Of note, although children's behavior problems were not targeted by the intervention, mothers of children in the intervention group reported significantly fewer behavior problems than those in the control group.

### *Elmira Prenatal/Early Infancy Project*

The Elmira Prenatal/Early Infancy Project is an excellent example of a preventive intervention that targeted an at-risk population to prevent the onset of a series of health, social, and mental health problems in children and in their mothers (Olds et al., 1998 and previous years<sup>3</sup>). This study warrants special attention because of its positive and enduring findings, randomized, controlled design, cost-benefit analysis, and unusually long-term follow up of 15 years. The study began by focusing on pregnant women bearing their first child in a small, semirural county in upstate New York. The children of these women were considered high risk because of their mother's young maternal age, single-parent status, or low socio-economic level. There were four study groups to which

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<sup>1</sup> Also see Ramey et al., 1984; Ramey & Campbell, 1984; Horacek et al., 1987; Martin et al., 1990.

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<sup>2</sup> Also see IHDP, 1990; Ramey et al., 1992; Brooks-Gunn et al., 1994a, 1994b; Casey et al., 1994.

<sup>3</sup> Also see Olds et al., 1986a, 1986b, 1988, 1993, 1994a, 1994b, 1995, and 1997.

random assignment was made. The first group received developmental screening at ages 1 and 2; the second group received screening and free transportation to health care; the third group received screening, transportation, and nurse home visits once every 2 weeks during pregnancy; and the fourth group received all of the above plus continued home visits by a nurse on a diminishing schedule until the infants were 24 months of age. The intervention focused on parent education, enhancement of the women's informal support systems, and linkage with community services.

Women in both groups receiving home visits from nurses had many positive behavioral outcomes compared with groups that received screening only or screening plus transportation. Among the women at highest risk for caregiver dysfunction, those who were visited by a nurse had fewer instances of verified child abuse and neglect during the first 2 years of their children's lives. They were observed in their homes to restrict and punish their children less frequently, and they provided more appropriate play materials. There were no differences between groups in the rates of new cases of child abuse and neglect or in the children's intellectual functioning in the period when the children were 25 to 48 months of age. However, nurse-visited children had fewer behavioral and parental coping problems (as noted in the physician record). Nurse-visited mothers were observed to be more involved with their children than were mothers in the comparison groups.

A cost-benefit analysis estimated program costs (direct costs of nurse visitation, costs of services to which nurses linked families, and costs of transportation) and benefits (cost outcomes presumed to be affected by the program through improved maternal and child functioning, such as less use of Aid to Families With Dependent Children, Medicaid, food stamps, child protective services, and greater tax revenues generated by women's working). Taking a time point of 2 years after the program ended, the net cost of the program for the sample as a whole was \$1,582 per family, but for low-income families, the cost

of the program was recovered with a dividend of \$180 per family.

Fifteen years after the birth of the index child (13 years after termination of the intervention), women who were visited by nurses during pregnancy and infancy had significantly fewer subsequent pregnancies, less use of welfare, fewer verified reports of abuse and neglect, fewer behavioral impairments due to use of alcohol and other drugs, and fewer arrests. Their children, now adolescents, reported fewer instances of running away, fewer arrests, fewer convictions and violations of probation, fewer lifetime sex partners, fewer cigarettes smoked per day, and fewer days having consumed alcohol in the last 6 months. The parents of these adolescents reported that their children had fewer behavioral problems related to use of alcohol and other drugs.

### ***Primary Mental Health Project***

The Primary Mental Health Project (PMHP) is a 42-year-old program for early detection and prevention of young children's school adjustment problems. PMHP currently operates in approximately 2,000 schools in 700 school districts nationally and internationally. Seven states in the United States are implementing the program systematically, based on authorizing legislation and state appropriations.

PMHP has four key elements: (1) a focus on primary grade children; (2) systematic use of brief objective screening measures for early identification of children in need; (3) use of carefully selected, trained, closely supervised nonprofessionals (called child associates) to establish a caring and trusting relationship with children; and (4) a changing role for the school professionals that features selection, training, and supervision of child associates, early systematic screening, and functioning as program coordinator, liaison, and consultant to parents, teachers and other school personnel.

The PMHP model has been applied flexibly to diverse ethnic and sociodemographic groups in settings where help is most needed. Over 30 program evaluation studies, including several at the state level, underscore

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the program's efficacy (Cowen et al., 1996). Significant improvements were detected in children's grades, achievement test scores, and adjustment ratings by teachers and child associates. PMHP represents a successful mental health intervention that does not require highly trained and skilled mental health professionals.

### ***Other Prevention Programs and Strategies***

These and other prevention trials demonstrate that positive adaptation and social-emotional well-being in children and youth can be enhanced, and that risk factors for behavioral and emotional disorders can be reduced, by intervening in home, school, day care, and other settings. Programs have focused not only on mental health problems but also on other problem behaviors (Botvin et al., 1995; St. Lawrence et al., 1995; Kellam & Anthony, 1998).

Other prevention trials are showing similar benefits. For example, a large-scale, four-site school- and home-based prevention trial, known as FastTrack, has shown clear benefits in reducing behavior problems among high-risk children, as well as in reducing needs for and use of special education, which has substantial cost-effectiveness implications (Conduct Problems Prevention Research Group, 1999a, 1999b). Another trial is now under way to test the efficacy of a preventive intervention provided to adolescents whose parents are currently being treated for depression within a health maintenance organization (Clark et al., 1998). Treatment of mood disorders also has potential effectiveness for the primary prevention of suicide, as explained in the later section on Depression and Suicide in Children and Adolescents.

## **Overview of Mental Disorders in Children**

A consideration of developmental principles enhances understanding of mental illness in children and adolescents by reconciling the concept of mental disorder as a stable state or condition with the ongoing

development of the child. According to these principles, a mental disorder results from the interaction of a child and his or her environment. Thus, mental illness often does not lie within the child alone. Within the conceptual framework and language of integrative neuroscience, the mental disorder is an "emergent property" of the transaction with the environment. Proper assessment of a child's mood, thought, and behaviors demands a simultaneous consideration of nature and nurture, genes and environment, and biology and psychosocial influences. These relationships are reciprocal. The brain shapes behavior, and learning shapes the brain.

Mental disorders must be considered within the context of the family and peers, school, home, and community. Taking the social-cultural environment into consideration is essential to understanding mental disorders in children and adolescents, as it is in adults. However, the changing nature of these environments, coupled with the progressively unfolding processes of brain development, makes the emphasis on context, as well as development, more complex *and* more central in child mental health (Jensen & Hoagwood, 1997).

Thus, developmental psychopathology encourages consideration of the transactions between the individual and the social and physical environment at the same time that signs and symptoms of mental disorder are considered. Moreover, focusing on diagnostic labels alone provides too limited a view of mental disorders in children and adolescents.

### **General Categories of Mental Disorders of Children**

Mental disorders with onset in childhood and adolescence are listed in Table 3-2 as they appear in DSM-IV. These disorders fall into a number of broad categories, most of which apply not just to children but across the entire life span: anxiety disorders; attention-deficit and disruptive behavior disorders; autism and other pervasive developmental disorders; eating disorders (e.g., anorexia nervosa); elimination disorders

**Table 3-2. Selected mental disorders of childhood and adolescence from the DSM-IV**

<ul style="list-style-type: none"> <li>• Anxiety Disorders</li> <li>• Attention-Deficit and Disruptive Behavior Disorders</li> <li>• Autism and Other Pervasive Developmental Disorders</li> <li>• Eating Disorders</li> <li>• Elimination Disorders</li> <li>• Learning and Communication Disorders</li> <li>• Mood Disorders (e.g., Depressive Disorders)</li> <li>• Schizophrenia</li> <li>• Tic Disorders</li> </ul>
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(e.g., enuresis, encopresis); learning and communication disorders; mood disorders (e.g., major depressive disorder, bipolar disorder); schizophrenia; and tic disorders (Tourette’s disorder). Several of the more common childhood conditions are described below.

Disorders of anxiety and mood are characterized by the repeated experience of intense internal or emotional distress over a period of months or years. Feelings associated with these conditions may be those of unreasonable fear and anxiety, lasting depression, low self-esteem, or worthlessness. Syndromes of depression and anxiety very commonly co-occur in children. The disorders in this broad group include separation anxiety disorder, generalized anxiety disorder, post-traumatic stress disorder, obsessive-compulsive disorder, major depressive disorder, dysthymia, and bipolar disorder (DSM-IV).

Children who suffer from attention-deficit disorder, disruptive disorder, and oppositional defiant disorder may be inattentive, hyperactive, aggressive, and/or defiant; they may repeatedly defy the societal rules of the child’s own cultural group or disrupt a well-ordered environment such as a school classroom.

Children with autism and other pervasive developmental disorders often suffer from disordered cognition or thinking and have difficulty understanding and using language, understanding the feelings of others, or, more generally, understanding the world around them. Such disorders are often associated with

severe learning difficulties and impaired intelligence. The disorders in this category include the pervasive developmental disorders, autism, Asperger’s disorder, and Rett’s disorder (DSM-IV).

It is not uncommon for a child to have more than one disorder or to have disorders from more than one of these groups. Thus, children with pervasive developmental disorders often suffer from ADHD. Children with a conduct disorder are often depressed, and the various anxiety disorders may co-occur with mood disorders. Learning disorders are common in all these conditions, as are alcohol and other substance use disorders (DSM-IV).

**Assessment and Diagnosis**

As with adults, assessment of the mental function of children has several important goals: to learn the unique functional characteristics of each individual (sometimes called formulation) and to diagnose signs and symptoms that suggest the presence of a mental disorder. Case formulation helps the clinician understand the child in the context of family and community. Diagnosis helps identify children who may have a mental disorder with an expected pattern of distress and limitation, course, and recovery. Both processes are useful in planning for treatment and supportive care. Both are helpful in developing a treatment plan.

Even with the aid of widely used diagnostic classification systems such as DSM-IV (see Chapter 2), diagnosis and diagnostic classification present a greater challenge with children than with adults for several reasons. Children are often unable to verbalize thoughts and feelings. Clinicians by necessity become more reliant on parents, teachers, and other professionals, who may be unable to assess these mental processes in children. Children’s normal development also presents an ever-changing backdrop that complicates clinical presentation. As previously noted, some behaviors may be quite normal at one age but suggest mental illness at another age. Finally, the criteria for diagnosing most mental disorders in children are derived from those for adults, even though relatively little research attention has been paid to the validity of these criteria in

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children. Expression, manifestation, and course of a disorder in children might be very different from those in adults. The boundaries between normal and abnormal are less distinct and those between one diagnosis and another are fluid.

Thus, the field of childhood mental health historically downplayed diagnosis. This trend began to change in the 1980s, in part as a result of developing practice guidelines and tougher reimbursement standards (Lonigan et al., 1998) and more appropriate diagnostic categories and criteria (DSM III, III-R, and IV). The body of accumulated research on treatment and services referred to throughout this chapter reflects the past emphasis on the efficacy of treatments, sometimes with and sometimes independently of diagnosis.

Most disorders are diagnosed by their manifestations, that is, by symptoms and signs, as well as functional impairment (see Chapter 2). A diagnosis is made when the combination and intensity of symptoms and signs meet the criteria for a disorder listed in DSM-IV. However, diagnosis of childhood mental disorders, as noted earlier, is rarely an easy task. Many of the symptoms, such as outbursts of aggression, difficulty in paying attention, fearfulness or shyness, difficulties in understanding language, food fads, or distress of a child when habitual behaviors are interfered with, are normal in young children and may occur sporadically throughout childhood. Well-trained clinicians overcome this problem by determining whether a given symptom is occurring with an unexpected frequency, lasting for an unexpected length of time, or is occurring at an unexpected point in development. Clinicians with less experience may either overdiagnose normal behavior as a disorder or miss a diagnosis by failing to recognize abnormal behavior. Inaccurate diagnoses are more likely in children with mild forms of a disorder.

### Evaluation Process

When conducted by a mental health professional, the evaluation process usually consists of gathering information from several sources: the child, parents,

teachers, pediatricians, and hospital records. The mental health professional also makes observations of the child's or teenager's behavior and patterns of speech. Very often, additional testing is requested to assess the child's or youth's intelligence and learning abilities. Information about symptoms can be obtained more reliably by direct questioning (Gittelman-Klein, 1978; Gittelman, 1985).

A full evaluation may take several hours. By that time, the professional should have a good understanding of how the child is functioning at home, at school, and in society and some understanding of the family's characteristics. With this information, the child or adolescent psychiatrist, clinical psychologist, or social worker can suggest further investigations and, if needed, initiate treatment of the child and provide counseling to parents and teachers on how to best assist the child or teenager to overcome problems.

There is a dearth of child psychiatrists, appropriately trained clinical child psychologists, or social workers (Thomas & Holzer, 1999). Furthermore, many barriers remain that prevent children, teenagers, and their parents from seeking help from the small number of specially trained professionals who are available. This places a burden on pediatricians, family physicians, and other gatekeepers (such as school counselors and primary child care workers) to identify children for referral and treatment decisions. These gatekeepers are unlikely to have the time and specialized training to do an evaluation requiring several hours. Their responsibility often is to "triage" cases, that is, refer children who need further evaluation to specialists. Many, however, are involved in treating children and adolescents. They may be greatly aided by various diagnostic aids such as brief questionnaires that can be completed in the waiting room of the pediatrician, the school counseling office, or some other community setting. Ideally, these screening questionnaires would be accompanied by a clear guide on interpreting results and identifying what kind of score or behavior would normally indicate a need for referral to a professional.

Some of the questionnaires that specifically address mood disorders are shown in Figure 3-1. Other questionnaires, such as the Adolescent Antisocial Self-Report Behavior Checklist (Kulik et al., 1968), the Eyberg Child Behavior Inventory (Eyberg & Robinson, 1983), and the Family Interaction Coding Pattern (Patterson, 1982), assess antisocial behavior. Adults and teachers can use instruments such as the Child Behavior Checklist (Achenbach & Edelbrock, 1983) to assess a relatively full range of behavioral and emotional symptoms and disorders from the perspective of adult informants. The Minnesota Multiphasic Personality Inventory-2 (MMPI-2; Hathaway & McKinley, 1989) and the Millon Adolescent Personal-

**Treatment Strategies**

Children and adolescents receive most of the traditional treatments described in Chapter 2, particularly psychosocial treatments, such as psychotherapies, and various medications. Specific psychosocial and pharmacological treatment approaches are described in subsequent sections on specific mental disorders. Much of the research, however, has been conducted on adults, with results extrapolated to children. Some of the treatments, such as interactive or play therapy with young children, are unique to clinical work with this group, while others, such as individual psychotherapy with adolescents, are similar to clinical work with adults. Many of the treatment interventions have been

**Figure 3-1. Questionnaires used to assess childhood mood disorders**

Title	Source
The Children's Depression Inventory (CDI)	Kovacs, 1985
Beck Depression Inventory (BDI)	Beck, Ward, Mendelson, Mock, & Erbaugh, 1961
Reynolds Adolescent Depression Scale (RADS)	Reynolds, 1986
Children's Depression Scale (CDS)	Tisher & Lang, 1983
Center for Epidemiological Studies of Depression (CES-D)	Radloff, 1977
Kandel Depression Scale (KDS)	Kandel & Davies, 1982
Zung Self-Rating Depression Scale (SDS)	Zung, 1965
Diagnostic Interview Schedule for Children (DISC)	Shaffer & Fisher, 1998

ity Inventory (MAPI) (Millon et al., 1982) questionnaires may be used with adolescents to assess normal and abnormal personality function.

The advent of highly structured, computer-driven assessment tools, such as the NIMH Diagnostic Interview Schedule for Children, which comes in a spoken version that can be given through headphones to children and/or their parents (Shaffer et al., 1996a), promises to greatly improve the ability of professionals outside of the mental health field to obtain robust diagnostic information, which can guide them in decisions about further referral or treatment.

“packaged” together in particular arrangements for delivery in specific clinical settings.

More attention is being paid to the value of multimodal therapies, that is, the combination of pharmacological and psychosocial therapies. While research is limited, multimodal studies have shown benefits for treatment of ADHD (see later section), anxiety (Kearney & Silverman, 1998), and depression. Tempering the value of psychotherapy as well as pharmacotherapy, which is discussed below, is that the efficacy of these therapies in the research setting is greater than that in the real world. The problem of the

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gap between research and clinical practice is discussed in greater depth elsewhere in this chapter and in Chapter 2.

### *Psychotherapy*

The major types of psychotherapy for children are supportive, psychodynamic, cognitive-behavioral, interpersonal, and family systemic. With the exception of the latter, these therapies originally were developed for adults and then tailored for use in children.

Most psychotherapies are deemed effective for children and adolescents because they improve more than with no treatment, as discussed later in this chapter under Treatment Interventions (Casey & Berman, 1985; Hazelrigg et al., 1987; Weisz et al., 1987; Kazdin et al., 1990; Baer & Nietzel, 1991; Grossman & Hughes, 1992; Shadish et al., 1993; Weisz & Weiss, 1993; Weisz et al., 1995). But despite this strong body of research on children comparing treatment with no treatment, far less attention has been paid to, and guidance provided about, the efficacy of a given psychotherapy for a specific diagnosis (Lonigan et al., 1998). In other words, it is not clear which therapies are best for which conditions. The American Psychological Association sought to rectify this problem by convening two task forces, the second of which exhaustively reviewed the professional literature to evaluate the strength of the evidence for treating individual disorders in children. The second task force refined two sets of criteria against which to evaluate the evidence: the first, and more rigorous, set of criteria was for *Well-Established Psychosocial Interventions*, while the other was for *Probably Efficacious Psychosocial Interventions* (Lonigan et al., 1998). The findings of the task force's comprehensive evaluation were published, disorder by disorder, in an entire issue of the *Journal of Clinical Child Psychology* in June 1998. While findings relating to individual disorders are presented in the next section of this chapter, this was the overarching conclusion: ". . . the majority of these [psychosocial] interventions do not meet criteria for the highest level of empirical support, the well-established criteria" (Lonigan et al., 1998). The problem, according to these authors, is that too few

well-controlled studies have been performed for each disorder. To meet the criteria for a *Well-Established Psychosocial Intervention*, there must be at least two well-conducted group-design studies conducted by different teams of researchers, among other criteria.<sup>4</sup> Hereafter, these criteria are referred to as the American Psychological Association Task Force Criteria.

Some other general points are warranted about the value of psychotherapies for children. Psychotherapies are especially important alternatives for those children who are unable to tolerate, or whose parents prefer them not to take, medications. They also are important for conditions for which there are no medications with well-documented efficacy. They also are pivotal for families under stress from a child's mental disorder. Therapies can serve to reduce stress in parents and siblings and teach parents strategies for managing symptoms of the mental disorder in their child (see later sections on Disruptive Disorders and Home-Based Services).

### *Psychopharmacology*

Dramatic increases have occurred over the past decade in the use of pharmacological therapies for children and adolescents with mental disorders, but research has lagged behind the surge in their use (Jensen et al., 1999). Our gaps in knowledge span three areas in particular. First, for most prescribed medications, there are no studies of safety and efficacy for children and adolescents. This is true for medications for mental disorders as well as for somatic disorders. Depending on the specific medication, evidence may be lacking for short-term, or most commonly, for long-term safety and efficacy. The problem is even more pronounced with newer medications, most of which have been introduced into the market for adults. Only in the case of psychostimulants for ADHD is there an adequate body of research on their safety and efficacy in children and adolescents, albeit short-term information only (Greenhill et al., 1998) (see later section on ADHD). Second, there is often limited information about pharmacokinetics, that is, drug concentrations in body

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<sup>4</sup> The criteria are listed in Chapter 1.

fluids and tissues over time (Clein & Riddle, 1996). Most of what is known about pharmacokinetics comes from studies of adults. But pediatric pharmacokinetic studies are crucial to identifying the appropriate dose and dose frequency for children of different ages and body sizes. Third, the combined effectiveness of pharmacological and psychosocial treatments, that is, multimodal treatments, is seldom studied. Multimodal treatments have the potential to yield dose reductions in pharmacological treatments, thereby improving the side-effect profile, parental acceptance, and patient compliance.

The dearth of research on children and adolescents has allowed for widespread “off-label” use of medications. This means that, for this population, physicians who are prescribing a given drug do not have the benefit of research and drug labeling information developed by the sponsor and approved by the Food and Drug Administration (FDA). Under U.S. food and drug law, a drug is approved by the FDA only for a defined population. Yet after its approval and market availability, physicians are at liberty to prescribe it for anyone, even though the sponsor only is allowed to *market* the drug for the approved population (which typically is adults) (FDA, 1998). Fortunately, there is a large body of clinical experience with children and adolescents to guide prescribing practices, despite few controlled studies (Green, 1996).

There are several reasons for the paucity of research on medications for children and adolescents. One is greater caution on the part of both the medical profession and parents to experiment with children or to prescribe drugs with potentially serious side effects. Another reason is the need for compliance with dosing requirements of the clinical trial protocol. When children are research subjects, enforcing compliance is generally perceived to be more difficult. Researchers must rely on parents to assess the degree of compliance. A final reason is the cost of research. Once drugs have reached the market for adults, pharmaceutical companies have fewer financial incentives to conduct expensive and methodologically demanding studies with children, to whom drugs may be given

through off-label prescribing. The problem has been significant enough to have galvanized Congress into passing legislation, the FDA Modernization Act of 1997, to create financial incentives for drug sponsors to conduct research with pediatric subjects [FDA, 1999 Title 21 USC 505A(g)]. The FDA Modernization Act may help alleviate this problem, but it is too early to tell.

Despite the relative lack of information concerning safety and efficacy of psychotropic agents in children, six scientific reviews have been completed recently; these reviews comprehensively surveyed all available published research concerning the safety and efficacy of psychotropic medication, focusing on six general classes of medication: the psychostimulants (Greenhill et al., 1998), the mood stabilizers and antimanic agents (Ryan et al., 1999), the selective serotonin reuptake inhibitors (SSRIs) (Emslie et al., 1999), antidepressants (Geller et al., 1998), antipsychotic agents (Campbell et al., 1999), and other miscellaneous agents (Riddle et al., 1998).

Review of this comprehensive body of research evidence indicates strong support for the safety and efficacy of several classes of agents for several conditions, specifically, SSRIs for childhood/adolescent obsessive-compulsive disorder, and the psychostimulants for ADHD. For many other disorders and medications, however, information from rigorously controlled trials is sparse or altogether absent (see Figure 3-2). Further, only in the area of ADHD is information now emerging on longer term safety and efficacy, as well as on the merits of combining psychopharmacologic and psychotherapeutic treatments.

Given the inadequacy of efficacy data for most nonstimulant psychotropics, studies are needed for the majority of agents. However, efficacy data appear to be most urgently needed for SSRIs, mood stabilizers, and novel antipsychotics, since the level of usage of these medications appears to be highest among the growing list of psychotropic medications used in youth (Fisher & Fisher, 1996). In contrast to adult psychopharmacology that is focusing on differential efficacy and speed of onset of these categories of psychotropics,

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Figure 3-2. Grading the Level of Evidence for Efficacy of Psychotropic Drugs in Children

Category	Indication	Level of Supporting Data				Estimated Frequency of Use Rank
		Short-Term Efficacy	Long-Term Efficacy	Short-Term Safety	Long-Term Safety	
Stimulants	ADHD	A	B	A	A	1
Selective Serotonin Reuptake Inhibitors	Major depression	B	C	A	C	2
	OCD	A	C	A	C	
	Anxiety disorders	C	C	C	C	
Central Adrenergic Agonists	Tourette syndrome	B	C	B	C	3
	ADHD	C	C	C	C	
Valproate and Carbamazepine	Bipolar disorders	C	C	A	A	4
	Aggressive conduct	C	C	A	A	
Tricyclic Antidepressants	Major depression	C	C	B	B	5
	ADHD	B	C	B	B	
Benzodiazepines	Anxiety disorders	C	C	C	C	6
Antipsychotics	Childhood schizophrenia and psychoses	B	C	C	B	7
	Tourette syndrome	A	C	B	B	
Lithium	Bipolar disorders	B	C	B	C	8
	Aggressive conduct	B	C	C	C	

Key: A =  $\geq 2$  randomized controlled trials (RCTs).  
 B = At least 1 RCT.  
 C = Clinical opinion, case reports, and uncontrolled trials.

Source: Jensen et al., 1999

pediatric psychopharmacology needs basic studies of efficacy.

Additional information on specific medication treatment is presented in the succeeding sections, providing more detailed discussion of particular disorders. In-depth information is presented on two disorders where a great deal of research has been done, namely, ADHD and major depressive disorder, followed by briefer discussions of other childhood mental disorders.

### Attention-Deficit/Hyperactivity Disorder

As its name implies, attention-deficit/hyperactivity disorder (ADHD) is characterized by two distinct sets of symptoms: inattention and hyperactivity-impulsivity

(see Table 3-3). Although these problems usually occur together, one may be present without the other to qualify for a diagnosis (DSM-IV). Inattention or attention deficit may not become apparent until a child enters the challenging environment of elementary school. Such children then have difficulty paying attention to details and are easily distracted by other events that are occurring at the same time; they find it difficult and unpleasant to finish their schoolwork; they put off anything that requires a sustained mental effort; they are prone to make careless mistakes, and are disorganized, losing their school books and assignments; they appear not to listen when spoken to and often fail to follow through on tasks (DSM-IV; Waslick & Greenhill, 1997).

**Table 3-3. DSM-IV criteria for Attention-Deficit/Hyperactivity Disorder**

<p>A. Either (1) or (2):</p> <p>(1) six (or more) of the following symptoms of <b>inattention</b> have persisted for at least 6 months to a degree that is maladaptive and inconsistent with developmental level:</p> <p><i>Inattention</i></p> <ul style="list-style-type: none"> <li>(a) often fails to give close attention to details or makes careless mistakes in schoolwork, work, or other activities</li> <li>(b) often has difficulty sustaining attention in tasks or play activities</li> <li>(c) often does not seem to listen when spoken to directly</li> <li>(d) often does not follow through on instructions and fails to finish schoolwork, chores, or duties in the workplace (not due to oppositional behavior or failure to understand instructions)</li> <li>(e) often has difficulty organizing tasks and activities</li> <li>(f) often avoids, dislikes, or is reluctant to engage in tasks that require sustained mental effort (such as schoolwork or homework)</li> <li>(g) often loses things necessary for tasks or activities (e.g., toys, school assignments, pencils, books, or tools)</li> <li>(h) is often easily distracted by extraneous stimuli</li> <li>(i) is often forgetful in daily activities</li> </ul> <p>(2) six (or more) of the following symptoms of <b>hyperactivity-impulsivity</b> have persisted for at least 6 months to a degree that is maladaptive and inconsistent with developmental level:</p> <p><i>Hyperactivity</i></p> <ul style="list-style-type: none"> <li>(a) often fidgets with hands or feet or squirms in seat</li> <li>(b) often leaves seat in classroom or in other situations in which remaining seated is expected</li> <li>(c) often runs about or climbs excessively in situations in which it is inappropriate (in adolescents or adults, may be limited to subjective feelings of restlessness)</li> <li>(d) often has difficulty playing or engaging in leisure activities quietly</li> <li>(e) is often "on the go" or often acts as if "driven by a motor"</li> <li>(f) often talks excessively</li> </ul> <p><i>Impulsivity</i></p> <ul style="list-style-type: none"> <li>(g) often blurts out answers before questions have been completed</li> <li>(h) often has difficulty awaiting turn</li> <li>(i) often interrupts or intrudes on others (e.g., butts into conversations or games)</li> </ul> <p>B. Some hyperactive-impulsive or inattentive symptoms that cause impairment were present before age 7 years.</p> <p>C. Some impairment from the symptoms is present in two or more settings (e.g., at school [or work] and at home).</p> <p>D. There must be clear evidence of clinically significant impairment in social, academic, or occupational functioning.</p> <p>E. The symptoms do not occur exclusively during the course of a pervasive developmental disorder, schizophrenia, or other psychotic disorder and are not better accounted for by another mental disorder (e.g., mood disorder, anxiety disorder, dissociative disorder, or a personality disorder).</p>
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The symptoms of hyperactivity may be apparent in very young preschoolers and are nearly always present before the age of 7 (Halperin et al., 1993; Waslick & Greenhill, 1997). Such symptoms include fidgeting, squirming around when seated, and having to get up frequently to walk or run around. Hyperactive children have difficulty playing quietly, and they may talk excessively. They often behave in an inappropriate and uninhibited way, blurting out answers in class before the teacher's question has been completed, not waiting their turn, and interrupting often or intruding on others' conversations or games (Waslick & Greenhill, 1997).

Many of these symptoms occur from time to time in normal children. However, in children with ADHD they occur very frequently and in several settings, at home and at school, or when visiting with friends, and they interfere with the child's functioning. Children suffering from ADHD may perform poorly at school; they may be unpopular with their peers, if other children perceive them as being unusual or a nuisance; and their behavior can present significant challenges for parents, leading some to be overly harsh (DSM-IV).

Inattention tends to persist through childhood and adolescence into adulthood, while the symptoms of motor hyperactivity and impulsivity tend to diminish with age. Many children with ADHD develop learning difficulties that may not improve with treatment (Mannuzza et al., 1993). Hyperactive behavior is often associated with the development of other disruptive disorders, particularly conduct and oppositional-defiant disorder (see Disruptive Disorders). The reason for the relationship is not known. Some believe that the impulsivity and heedlessness associated with ADHD interfere with social learning or with close social bonds with parents in a way that predisposes to the development of behavior disorders (Barkley, 1998).

Even though a great many children with this disorder ultimately adjust (Mannuzza et al., 1998), some—especially those with an associated conduct or oppositional-defiant disorder—are more likely to drop out of school and fare more poorly in their later careers than children without ADHD. As they grow older,

some teens who have had severe ADHD since middle childhood experience periods of anxiety or depression. This seems to be especially common in children whose predominant symptom is inattention (Morgan et al., 1996). Excellent reviews of ADHD can be found in DSM-IV and other sources.<sup>5</sup>

### *Prevalence*

ADHD, which is the most commonly diagnosed behavioral disorder of childhood, occurs in 3 to 5 percent of school-age children in a 6-month period (Anderson et al., 1987; Bird et al., 1988; Esser et al., 1990; Pelham et al., 1992; Shaffer et al., 1996c; Wolraich et al., 1996). Pediatricians report that approximately 4 percent of their patients have ADHD (Wolraich et al., 1990), but in practice the diagnosis is often made in children who meet some, but not all, of the criteria recommended in DSM-IV (Wolraich et al., 1990) (see also Treatment later in this section). Boys are four times more likely to have the illness than girls are (Ross & Ross, 1982). The disorder is found in all cultures, although prevalences differ; differences are thought to stem more from differences in diagnostic criteria than from differences in presentation (DSM-IV).

### *Causes*

The exact etiology of ADHD is unknown, although neurotransmitter deficits, genetics, and perinatal complications have been implicated. In the early post-World War II years, a number of pediatricians, neurologists, and child psychiatrists noted that brain-damaged children were often hyperactive (Strauss & Lehtinen, 1947; Eisenberg, 1957; Laufer & Denhoff, 1957). These observations led to the diagnostic concept of "minimal brain damage" (Wender, 1971), which was thought to be characterized by hyperactivity, inattention, learning difficulties, and a wide variety of behavior problems. However, large epidemiological studies (Rutter & Quinton, 1977) of grossly brain-damaged children with cerebral palsy, epilepsy, and so

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<sup>5</sup> Taylor, 1994; Cantwell, 1996; Waslick & Greenhill, 1997; Barkley, 1998; and NIH Consensus Statement 110, 1998.

forth, did not find an excess of hyperactivity, and more recent imaging studies have found no evidence of gross brain damage in children with ADHD (Swanson et al., 1998). The past view that ADHD is a form of minimal brain damage has therefore been abandoned by experts. Many brain-damaged children are, if anything, significantly underactive.

In the late 1970s, it was postulated that the core problem in hyperkinetic children was one of inattention (Douglas & Peters, 1979). This view led, in 1980, to the adoption, in the official DSM-III (American Psychiatric Association, 1980) nomenclature, of the new diagnostic label *attention-deficit disorder*.

Because the symptoms of ADHD respond well to treatment with stimulants, and because stimulants increase the availability of the neurotransmitter dopamine, the "dopamine hypothesis" has gained a wide following. The dopamine hypothesis posits that ADHD is due to inadequate availability of dopamine in the central nervous system. The neurotransmitter dopamine plays a key role in initiating purposive movement, increasing motivation and alertness, reducing appetite, and inducing insomnia, effects that are often seen when a child responds well to methylphenidate. The dopamine hypothesis has thus driven much of the recent research into the causes of ADHD.

The fact that ADHD runs in families suggests that inheritance is an important risk factor. Between 10 and 35 percent of children with ADHD have a first-degree relative with past or present ADHD. Approximately one-half of parents who had ADHD have a child with the disorder (Biederman et al., 1995). Over the past decade, a large number of twin studies have shown that, when ADHD is present in one twin, it is significantly more likely also to be present in an identical twin than in a fraternal twin (Goodman & Stevenson, 1989). These findings have led geneticists to estimate that genes are important in a high proportion of children with ADHD.

Research to pinpoint abnormal genes is honing in on two genes: a dopamine-receptor (DRD) gene on

chromosome 11 and the dopamine-transporter gene (DAT1) on chromosome 5 (Cook et al., 1995; Smalley et al., 1998). Several studies have found evidence that children with ADHD have genetic variations in one of the dopamine-receptor genes (DRD4), although the largest of these studies suggests that the presence of such a variation is associated with only a modest increase in the risk of developing ADHD (Smalley et al., 1998). Several other studies have found evidence for abnormalities of the dopamine-transporter gene (DAT1) in children with very severe forms of ADHD (Cook et al., 1995; Gill et al., 1997; Waldman et al., 1998).

Yet for most children with ADHD, the overall effects of these gene abnormalities appear small, suggesting that nongenetic factors also are important. Although none of the many imaging studies have found evidence of gross brain damage, some investigators have suggested that exposure to toxins, such as lead, or episodes of oxygen deprivation for the fetus, as may occur during some complications of pregnancy, may adversely affect dopamine-rich areas of the brain. These theories support observations that hyperactivity and inattention are more common in children whose mothers smoked during pregnancy (Nichols & Chen, 1981), in children who have been exposed to high quantities of lead (Needleman et al., 1990), and in children who had a lack of oxygen in the neonatal period (Whittaker et al., 1997).

Some investigators have noted that the parents of hyperactive children are often overintrusive and overcontrolling (Carlson et al., 1995). It has therefore been suggested that such parental behavior is another possible risk factor for ADHD. However, others have noted that, when children are treated with methylphenidate, there is a reduction in parental negativity and intrusiveness. This suggests that the observed overintrusive and overcontrolling behavior of the parent is a response to the child's behavior rather than the cause (Barkley et al., 1985).

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### Treatment

The American Academy of Child and Adolescent Psychiatry (AACAP) published “practice parameters” (i.e., guidelines for clinical practice) on the diagnosis and treatment of ADHD. The AACAP parameters include an extensive literature review, detailed descriptions of the clinical presentation of the disorder, and recommendations for treatment. The practice parameters state that “the cornerstones of treatment are support and education of parents, appropriate school placement, and pharmacology” (AACAP, 1991). These practice parameters evolved out of research relating to two major types of treatment: pharmacological treatment and psychosocial treatment, particularly behavioral modification, as well as multimodal treatment, the combination of psychosocial and pharmacological treatments.

### *Pharmacological Treatment*

#### *Psychostimulants*

Pharmacological treatment with psychostimulants is the most widely studied treatment for ADHD. Stimulant treatment has been used for childhood behavioral disorders since the 1930s (Bradley, 1937). Psychostimulants are highly effective for 75 to 90 percent of children with ADHD. At least four separate psychostimulant medications consistently reduce the core features of ADHD in literally hundreds of randomized controlled trials: methylphenidate, dextro-amphetamine, pemoline, and a mixture of amphetamine salts (Spencer et al., 1995; Greenhill, 1998a, 1998b; Greenhill et al., 1998).

These medications are metabolized, leave the body fairly quickly, and work for 1 to 4 hours. Administration is timed to meet the child’s school schedule, to help the child pay attention and meet his or her academic demands, and to mitigate side effects. These medications have their greatest effects on symptoms of hyperactivity, impulsivity, and inattention and the associated features of defiance, aggression, and oppositionality. They also improve classroom performance and behavior and promote increased interaction with teachers, parents, and peers. Small effects were found on learning and school achievement

(see reviews by Barkley, 1990; Pelham, 1993; Swanson et al., 1993, 1995b; Greenhill et al., 1998; Cantwell, 1996a; Spencer et al., 1996.) However, psychostimulants do not appear to achieve long-term changes in outcomes such as peer relationships, social or academic skills, or school achievement (Pelham et al., 1998).

Children who do not respond to one stimulant may respond to another (Elia et al., 1991; Elia & Rapoport, 1991). Children should be reevaluated without the medication to see if stimulant treatment is still indicated. Many families choose to have their child take a “drug holiday” on weekends and vacations to reduce overall exposure, but the utility of this strategy has not been demonstrated (AACAP, 1991).

#### *Dosing*

Stimulants are usually started at a low dose and adjusted weekly (AACAP, 1991). A recent study demonstrated that the practice of dosing methylphenidate on the basis of body weight fails to predict the optimal dose of medication (Rapport & Denney, 1997). One of the goals of the recently completed NIMH Multimodal Treatment Study of ADHD (described more fully below) was to develop medication strategies to guide “best dose,” dose changes, management of side effects, and integration with other treatments (Greenhill et al., 1996).

#### *Side Effects*

Common stimulant side effects include insomnia, decreased appetite, stomach aches, headaches, and jitteriness. Some children may develop tics, but a recent study suggests that they disappear with continued treatment (Gadow et al., 1995). Rebound activation (i.e., a sudden increase in attention deficit and hyperactivity) has been noted anecdotally after the child’s last dose of medication wears off (Johnston et al., 1988). Most of the side effects are mild, recede over time, and respond to dose changes. Children rarely experience cognitive impairment, which, if it does occur, can be resolved with reduction or cessation of the drug (Cantwell, 1996). A few cases of psychosis have been reported. Pemoline has been associated with hepatotoxicity, so monitoring of liver function is

necessary. Two studies have shown no long-term effects of stimulants on later height or weight (Klein & Mannuzza, 1988; Vincent et al., 1990). Nonetheless, regular precautionary monitoring of weight and height for children on stimulants is recommended.

#### *Other Medications*

For children with ADHD who do not respond to stimulants (10 to 30 percent) or cannot tolerate the side effects, there are other useful medications. The antidepressant bupropion has been found to be superior to placebo, although the response is not as strong as that found with stimulants (Cantwell, 1998). Bupropion can also be used as an adjunct to augment stimulant treatment. Well-controlled trials have shown tricyclic antidepressants to be superior to placebo but less effective than stimulants (Elia et al., 1991; Elia & Rapoport, 1991). Reports of sudden death of a few children in the early 1990s on the tricyclic compound desipramine led to great caution with the use of tricyclics in children (Riddle et al., 1991).

Considerable controversy surrounds the use of central alpha-adrenergic blocking drugs, such as clonidine and guanfacine, to treat ADHD. There is some evidence that clonidine is effective for ADHD when it occurs with a tic disorder (Hunt, 1987; Hunt et al., 1990, 1995). Caution is warranted in view of the four cases of sudden death that have been reported in children taking methylphenidate and clonidine together and of a number of reports of nonfatal cardiac side effects in children taking clonidine alone or in combination (Swanson et al., 1995a).

Neuroleptics have been found to be occasionally effective (Green, 1995), yet the risk of movement disorders, such as tardive dyskinesia, makes their use problematic. Lithium, fenfluramine, or benzodiazapines have not been found to be effective treatments for ADHD (Cantwell, 1996a; Green, 1995), nor have SSRIs, such as fluoxetine (Goldman et al., 1998). Furthermore, more than 20 studies have shown that dietary manipulation (e.g., the Feingold diet) is not efficacious (Mattes & Gittelman, 1981), and controlled studies failed to demonstrate that sugar exacerbates the

symptoms of children with ADHD (Milich & Pelham, 1986).

#### *Psychosocial Treatment*

Important options for the management of ADHD are psychosocial treatments, particularly in the form of training in behavioral techniques for parents and teachers. Behavioral techniques, which are described more fully below, typically employ "time-out," point systems and contingent attention (adults reinforcing appropriate behavior by paying attention to it). Psychosocial treatments are useful for the child who does not respond to medication at all or for whom the therapeutic benefits of the medication have worn off and for the child who responds only partially to medication or cannot tolerate medication. In addition, some families express a strong preference not to use medication. Even children who are receiving medication may continue to have residual ADHD symptoms or symptoms from other disorders, such as oppositional defiant disorder or depression, which make specialized child management skills necessary and helpful (see next section, Multimodal Treatments). Furthermore, children with ADHD can present a challenge that puts significant stress on the family. Skills training for parents can help reduce this stress on parents and siblings.

#### *Behavioral Approaches*

The main psychosocial treatments for ADHD are behavioral training for parent and teacher, as well as systematic programs of contingency management (this behavioral technique is described in more detail in the Treatment section later in this chapter). Of these options, systematic programs of intensive contingency management conducted in specialized classrooms or summer camps with the setting controlled by highly trained individuals is the most effective (Abramowitz et al., 1992; Carlson et al., 1992; Pelham & Hoza, 1996). The efficacy of behavioral training of teachers is *well-established*, while the evidence for parent training is less solid, according to the criteria, noted earlier, promulgated by the American Psychological

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Association Task Force (Pelham et al., 1998). There is, however, indirect support for the effectiveness of parent training in the literature, demonstrating the efficacy of parent training for children with oppositional defiant disorder who share many characteristics with children who have ADHD (see section on Disruptive Disorders).

A number of studies have compared parent training (Gittelman et al., 1980; Firestone et al., 1986; Horn et al., 1987, 1990, 1991; Pelham et al., 1988) or school-based behavioral modification (Gittelman et al., 1980; Pelham et al., 1988) with the use of stimulants. Most of the studies are of outpatient behavioral therapy programs in which parents meet in groups and are taught behavioral techniques such as time out, point systems, and contingent attention. Teachers are taught similar classroom strategies, as well as the use of a daily report card for parents that evaluates the child's in-school behavior. The improvements in the symptoms of ADHD achieved with psychosocial treatments are not as large as those found with psychostimulants (Pelham et al., 1998). Behavioral interventions tend to improve targeted behaviors or skills but are not as helpful in reducing the core symptoms of inattention, hyperactivity, or impulsivity. Questions remain about the effectiveness of these treatments in other settings. To be fully effective, treatments for ADHD need to be conducted across settings (school, home, community) and by different people (e.g., parents, teachers, therapists)—a consistency and comprehensiveness that can be hard to achieve.

### *Cognitive-Behavioral Therapy*

Cognitive-behavioral therapy (CBT), primarily training in problem solving and social skills, has not been shown to provide clinically important changes in behavior and academic performance of children with ADHD (Pelham et al., 1998). However, CBT might be helpful in treating symptoms of accompanying disorders such as oppositional defiant disorder, depression, or anxiety disorders (Abikoff, 1985; Hinshaw & Ehardt, 1991; Lochman, 1992).

### *Psychoeducation*

Although there are no studies evaluating the efficacy of psychoeducation as a treatment modality for ADHD, providing information to parents, children, and teachers about ADHD and treatment options is considered critical in the development of a comprehensive treatment plan (AACAP, 1991). Educational accommodations for children with ADHD are federally mandated, and mental health providers are required to ensure that patients and families have access to adequate and appropriate educational resources. Organizations such as Children and Adults with Attention Deficit Disorder (CHADD) and the National Attention Deficit Disorder Association can be helpful sources of information and support for families.

### *Multimodal Treatments*

Many researchers and families have long suspected that multimodal treatment—medication used together with multiple psychosocial interventions in multiple settings—should be more effective than medication alone. Multimodal treatment has thus been used in the absence of empirical support (Hechtman, 1993). To determine whether multimodal treatment is indeed effective, the recent NIMH Multimodal Treatment Study of ADHD (called the MTA Study) examined three experimental conditions: medication management alone, behavioral treatment alone, or a combination of medication and behavioral treatments. The study compared the effectiveness of these three treatment modes with each other and with standard care provided in the community (the control group). The behavioral treatment condition consisted of parent training, a school intervention, and a summer treatment program. The MTA Study was also designed to determine the relative benefits of these treatments over time (Richters et al., 1995). All subjects were treated for 14 months and then followed for an additional 22 months.

Results of the MTA Study comparing the 14-month outcomes of 579 children randomly assigned to one of the four treatment conditions were presented in the fall of 1998 (MTA Cooperative Group, 1998). At 14 months, medication and the combination treatment were generally more effective than the behavioral

treatment alone or the control treatment. Notably, the combined treatment resulted in significant improvement over the control condition in six outcome areas—social skills, parent child relations, internalizing (e.g., anxiety) symptoms, reading achievement, oppositional and/or aggressive symptoms, and parent and/or consumer satisfaction—whereas the single forms of treatment (medication *or* behavior therapy) were each superior to the control condition in only one to two of these domains. The conclusions from this major study are that carefully managed and monitored stimulant medication, alone or combined with behavioral treatment, is effective for ADHD over a period of 14 months. Addition of behavioral treatment yields no additional benefits for core ADHD symptoms but appears to provide some additional benefits for non-ADHD-symptom outcomes.

### ***Treatment Controversies***

#### *Overprescription of Stimulants*

Concerns have been raised that children, particularly active boys, are being overdiagnosed with ADHD and thus are receiving psychostimulants unnecessarily. However, recent reports found little evidence of overdiagnosis of ADHD or overprescription of stimulant medications (Goldman et al., 1998; Jensen et al., 1999). Indeed, fewer children (2 to 3 percent of school-aged children) are being treated for ADHD than suffer from it. Treatment rates are much lower for selected groups such as girls, minorities, and children receiving care through public service systems (Bussing et al., 1998a, 1998b). However, there have been major increases in the number of stimulant prescriptions since 1989 (Hoagwood et al., 1998), and methylphenidate is being manufactured at 2.5 times the rate of a decade ago (Goldman et al., 1998). Most researchers believe that much of the increased use of stimulants reflects better diagnosis and more effective treatment of a prevalent disorder. Medical and public awareness of the problem of ADHD has grown considerably, leading to longer treatment, fewer interruptions in treatment, and increased treatment of adults. Adolescents and

younger girls with ADHD, who were underdiagnosed in the past, are being identified and treated.

Nonetheless, some of the increase in use may reflect inappropriate diagnosis and treatment. In one study, the rate of stimulant treatment was twice the rate of parent-reported ADHD, based on a standardized psychiatric interview (Angold & Costello, 1998). While many children who do meet the full criteria for ADHD are not being treated, the majority of children and adolescents who are receiving stimulants did not fully meet the criteria. These findings may reflect a failure of proper, comprehensive evaluation and diagnosis rather than a failure of the diagnostic criteria, which are clear and validated by research (Angold & Costello, 1998). A diagnosis of ADHD requires the presence of impairing ADHD symptoms in *multiple* settings for at least 6 months. Although fidgeting and not paying attention are normal, common childhood behaviors, DSM-IV criteria reserve a diagnosis of ADHD for children in whom such frequent behavior produces persistent and pervasive dysfunction. An adequate diagnostic evaluation requires histories to be taken from multiple sources (parents, child, teachers), a medical evaluation of general and neurological health, a full cognitive assessment including school history, use of parent and teacher rating scales, and all necessary adjunct evaluation (such as assessment of speech, language). These evaluations take time and require multiple clinical skills. Regrettably, there is a dearth of appropriately trained professionals.

Family practitioners are more likely than either pediatricians or psychiatrists to prescribe stimulants and less likely to use diagnostic services, provide mental health counseling, or provide followup care (Hoagwood et al., 1998). The American Academy of Pediatrics published a policy statement in 1996 on the use of medication for children with attentional disorders, concluding that use of medication should not be considered the complete treatment program for children with ADHD and should be prescribed only after a careful evaluation (American Academy of Pediatrics Committee on Children With Disabilities and Committee on Drugs, 1996).

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### *Safety of Long-Term Stimulant Use*

Even though the MTA Study found no safety issues over a 14-month period (Greenhill et al., 1998), concerns have been raised about the longer term safety of stimulant treatment. Since ADHD has an early onset and requires an extended course of treatment, research is needed to examine the long-term safety of treatment and to investigate whether other forms of treatment could be combined with psychostimulants to lower their dose as well as to reduce other problem behaviors found with ADHD. Such combined treatments could be targeted for symptoms of disorders that often accompany ADHD, such as conduct disorder, substance abuse, and learning disabilities, and could be targeted to improve overall functioning (Laufer, 1971; Gittelman et al., 1985).

Because stimulants are also drugs of abuse and because children with ADHD are at increased risk for a substance abuse disorder, concerns have also been raised about the potential for abuse of stimulants by children taking the medication or diversion of the drug to others. While stimulants clearly have abuse potential, the rate of lifetime nonmedical methylphenidate use has not significantly increased since methylphenidate was introduced as a treatment for ADHD, suggesting that abuse is not a major problem (Goldman et al., 1998). Case reports describing abuse by children prescribed stimulants for ADHD are rare (Hechtman, 1985).

## Depression and Suicide in Children and Adolescents

In children and adolescents, the most frequently diagnosed mood disorders are major depressive disorder, dysthymic disorder, and bipolar disorder. Because mood disorders such as depression substantially increase the risk of suicide, suicidal behavior is a matter of serious concern for clinicians who deal with the mental health problems of children and adolescents. The incidence of suicide attempts reaches a peak during the midadolescent years, and mortality from suicide, which increases steadily through the teens, is the third leading cause of death at that age (CDC, 1999; Hoyert et al., 1999). Although

suicide cannot be defined as a mental disorder, the various risk factors—especially the presence of mood disorders—that predispose young people to such behavior are given special emphasis in this section, as is a discussion of the effectiveness of various forms of treatment. The evidence is strong that over 90 percent of children and adolescents who commit suicide have a mental disorder, as explained later in this section.

*Major depressive disorder* is a serious condition characterized by one or more major depressive episodes. In children and adolescents, an episode lasts on average from 7 to 9 months (Birmaher et al., 1996a, 1996b) and has many clinical features similar to those in adults. Depressed children are sad, they lose interest in activities that used to please them, and they criticize themselves and feel that others criticize them. They feel unloved, pessimistic, or even hopeless about the future; they think that life is not worth living, and thoughts of suicide may be present. Depressed children and adolescents are often irritable, and their irritability may lead to aggressive behavior. They are indecisive, have problems concentrating, and may lack energy or motivation; they may neglect their appearance and hygiene; and their normal sleep patterns are disturbed (DSM-IV).

Despite some similarities, childhood depression differs in important ways from adult depression. Psychotic features do not occur as often in depressed children and adolescents, and when they occur, auditory hallucinations are more common than delusions (Ryan et al., 1987; Birmaher et al., 1996a, 1996b). Associated anxiety symptoms, such as fears of separation or reluctance to meet people, and somatic symptoms, such as general aches and pains, stomachaches, and headaches, are more common in depressed children and adolescents than in adults with depression (Kolvin et al., 1991; Birmaher et al., 1996a, 1996b).

*Dysthymic disorder* is a mood disorder like major depressive disorder, but it has fewer symptoms and is more chronic. Because of its persistent nature, the disorder is especially likely to interfere with normal adjustment. The onset of dysthymic disorder (also called dysthymia) is usually in childhood or

adolescence (Akiskal, 1983; Klein et al., 1997). The child or adolescent is depressed for most of the day, on most days, and symptoms continue for several years. The average duration of a dysthymic period in children and adolescents is about 4 years (Kovacs et al., 1997a). Sometimes children are depressed for so long that they do not recognize their mood as out of the ordinary and thus may not complain of feeling depressed. Seventy percent of children and adolescents with dysthymia eventually experience an episode of major depression<sup>6</sup> (Kovacs et al., 1994). When a combination of major depression and dysthymia occurs, the condition is referred to as *double depression*.

*Bipolar disorder* is a mood disorder in which episodes of mania alternate with episodes of depression. Frequently, the condition begins in adolescence. The first manifestation of bipolar illness is usually a depressive episode. The first manic features may not occur for months or even years thereafter, or may occur either during the first depressive illness or later, after a symptom-free period (Strober et al., 1995).

The clinical problems of mania are very different from those of depression. Adolescents with mania or hypomania feel energetic, confident, and special; they usually have difficulty sleeping but do not tire; and they talk a great deal, often speaking very rapidly or loudly. They may complain that their thoughts are racing. They may do schoolwork quickly and creatively but in a disorganized, chaotic fashion. When manic, adolescents may have exaggerated or even delusional ideas about their capabilities and importance, may become overconfident, and may be "fresh" and uninhibited with others; they start numerous projects that they do not finish and may engage in reckless or risky behavior, such as fast driving or unsafe sex. Sexual preoccupations are increased and may be associated with promiscuous behavior.

*Reactive depression*, also known as adjustment disorder with depressed mood, is the most common form of mood problem in children and adolescents. In

children suffering from reactive depression, depressed feelings are short-lived and usually occur in response to some adverse experience, such as a rejection, a slight, a letdown, or a loss. In contrast, children may feel sad or lethargic and appear preoccupied for periods as short as a few hours or as long as 2 weeks. However, mood improves with a change in activity or an interesting or pleasant event. These transient mood swings in reaction to minor environmental adversities are not regarded as a form of mental disorder.

### Conditions Associated With Depression

Roughly two-thirds of children and adolescents with major depressive disorder also have another mental disorder (Angold & Costello, 1993; Anderson & McGee, 1994). The most commonly associated disorders are dysthymia (see above), an anxiety disorder, a disruptive or antisocial disorder, or a substance abuse disorder. When more than one diagnosis is present, depression is more likely to begin after the onset of the accompanying disorder, except when that disorder is substance abuse (Biederman et al., 1995; Kessler & Walters, 1998). This suggests that, in some cases, depression may arise in response to the associated disorder. In other instances, such as the co-occurrence of conduct disorder and depression, the two may arise independently in response to inadequate maternal supervision and control, raising the possibility that parental behavior may be a risk factor for both conditions (Downey & Coyne, 1990; Rutter & Sandberg, 1992; Harrington, 1994).

### Prevalence

#### *Major Depression*

Population studies show that at any one time between 10 and 15 percent of the child and adolescent population has *some* symptoms of depression (Smucker et al., 1986). The prevalence of the full-fledged diagnosis of major depression among all children ages 9 to 17 has been estimated at 5 percent (Shaffer et al., 1996c). Estimates of 1-year prevalence in children range from 0.4 and 2.5 percent and in adolescents, considerably higher (in some studies, as high as 8.3

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<sup>6</sup> Major depression refers to conditions marked by a major depressive episode, such as major depressive disorder, bipolar disorder, and related conditions. The word "major" refers to the number of symptoms. See Chapter 4 for DSM-IV diagnostic criteria.

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percent) (Anderson & McGee, 1994; Lewinsohn et al., 1994a; Garrison et al., 1997; Kessler & Walters, 1998). For purposes of comparison, 1-year prevalence in adults is about 5.3 percent (Murphy et al., 1988; Rorsman et al., 1990; Regier et al., 1993).

### ***Dysthymic Disorder***

The prevalence of dysthymic disorder in adolescents has been estimated at around 3 percent (Garrison et al., 1997). Before puberty, major depressive disorder and dysthymic disorder are equally common in boys and girls (Rutter, 1986). But after age 15, depression is twice as common in girls and women as in boys and men (Weissman & Klerman, 1977; McGee et al., 1990; Linehan et al., 1993).

### ***Suicide***

In 1996, the age-specific mortality rate from suicide was 1.6 per 100,000 for 10- to 14-year-olds, 9.5 per 100,000 for 15- to 19-year-olds (i.e., about six times higher than in the younger age group; in this age group, boys are about four times as likely to commit suicide than are girls, while girls are twice as likely to attempt suicide), compared with 13.6 per 100,000 for 20- to 24-year-olds (CDC, 1999). Hispanic high school students are more likely than other students to attempt suicide (CDC, 1998). There have been some notable changes in these rates over the past few decades: since the early 1960s, the reported suicide rate among 15- to 19-year-old males increased threefold but remained stable among females in that age group and among 10- to 14-year-olds (National Center for Health Statistics, 1998); the rate among white adolescent males reached a peak in the late 1980s (18.0 per 100,000 in 1986) and has since declined somewhat (16.0 per 100,000 in 1997), whereas among African American male adolescents, the rate increased substantially in the same period (from 7.1 per 100,000 in 1986 to 11.4 per 100,000 in 1997 (CDC, 1998). From 1979 to 1992, the Native American male adolescent and young adult suicide rate in Indian Health Service Areas was the highest in the Nation, with a suicide rate of 62.0 per 100,000 (Wallace et al., 1996).

It has been proposed that the rise in suicidal behavior among teenage boys results from increased availability of firearms (Boyd, 1983; Boyd & Moscicki, 1986; Brent et al., 1987; Brent et al., 1991) and increased substance abuse in the youth population (Shaffer et al., 1996c; Birckmayer & Hemenway, 1999). However, although the rate of suicide by firearms increased more than suicide by other methods (Boyd, 1983; Boyd & Moscicki, 1986; Brent et al., 1987), suicide rates also increased markedly in many other countries in Europe, in Australia, and in New Zealand, where suicide by firearms is rare.

### **Course and Natural History**

Most children with depression experience a recurrence. Twenty to 40 percent of depressed children relapse within 2 years, and 70 percent will do so by adulthood (Garber et al., 1988; Velez et al., 1989; Harrington et al., 1990; Fleming et al., 1993; Kovacs et al., 1994; Lewinsohn et al., 1994a; Garrison et al., 1997). The reasons for relapse are not known, but there is some evidence that experiencing a depression leaves behind psychological "scars" that may increase vulnerability throughout early life (see below).

The age of first onset of depression appears to play a role in its course. Children who first become depressed before puberty are at risk for some form of mental disorder in adulthood, while teenagers who first become depressed after puberty are most likely to experience another episode of depression (Harrington et al., 1990; McCracken, 1992a; Lewinsohn et al., 1994a, 1994b; Rao et al., 1995). These differences in outcome suggest that different mechanisms may lead to superficially similar but inherently different clinical conditions. Factors that worsen the prognosis for depressed children and adolescents include depression occurring in the context of conduct disorder (Harrington et al., 1990; Asarnow et al., 1994) and living in conflict-ridden families (Asarnow et al., 1994). Children and particularly adolescents who suffer from depression are at much greater risk of committing suicide than are children without depression (Shaffer et al., 1996b).

The prognosis for dysthymia (Klein et al., 1997a) is unfavorable, with most patients continuing to feel depressed and to have social difficulties even after they have apparently recovered. The prognosis for double depressives (major depressive disorder plus dysthymia) is worse than that for either condition alone (Kovacs et al., 1994).

Twenty to 40 percent of adolescents with depression eventually develop bipolar disorder. Factors that predict later bipolar disorder include young age at the time of the first depressive episode, psychotic features in the initial depression, a family history of bipolar illness, and symptoms of hypomania developing during treatment with antidepressant drugs (Garber et al., 1988; Strober et al., 1993).

### **Causes**

The precise causes of depression are not known. Extensive research on adults with depression generally points to both biological and psychosocial factors (Kendler, 1995). However, there has been substantially less research on the causes of depression in children and adolescents. Further discussion of the risk factors for depression can be found in Chapter 4, as well as the preceding Overview of Risk Factors and Prevention section.

### **Family and Genetic Factors**

Much of the research on children and adolescents with depression has been conducted with those who attend mental health clinics and with patients who tend to have the more severe and recurrent forms of depression, and thus they may not be representative of all children and adolescents with depression. With this limitation, research has shown that between 20 and 50 percent of depressed children and adolescents have a family history of depression (Puig-Antich et al., 1989; Todd et al., 1993; Williamson et al., 1995; Kovacs, 1997b). Family research has found that children of depressed parents are more than three times as likely as children with nondepressed parents to experience a depressive disorder (see Birmaher et al., 1996a, 1996b for a review). They also are more vulnerable to other mental and somatic disorders (Downey & Coyne,

1990). Conversely, estimates of the proportion of depressed parents who have a depressed child or adolescent vary from approximately one in six to just under a half (Hammen et al., 1990). It is not clear whether the relationship between parent and childhood depression derives from genetic factors, or whether depressed parents create an environment that increases the likelihood of a mental disorder developing in their children (see below).

### **Gender Differences**

One reason advanced to explain the greater prevalence of depression in adolescent girls (see above) is that they are more socially oriented, more dependent on positive social relationships, and more vulnerable to losses of social relationships than are boys (Allgood-Merten et al., 1990). This would increase their vulnerability to the interpersonal stresses that are common in teenagers. There is also evidence that the methods girls use to cope with stress may entail less denial and more focused and repetitive thinking about the event (Nolen-Hoeksema & Girgus, 1994). The higher prevalence, therefore, could be a result of greater vulnerability, combined with coping mechanisms different than those of boys.

### **Biological Factors**

Some of the core symptoms of depression, such as changes in appetite and sleep patterns, are related to the functions of the hypothalamus. The hypothalamus is, in turn, closely tied to the function of the pituitary gland. Abnormalities of pituitary function, such as increased rates of circulating cortisol and hypo- or hyperthyroidism, are well established features of depression in adults (Goodwin & Jamison, 1990). However, far less research has been done in this area among children and adolescents (see Birmaher et al., 1996a, 1996b for a review). It is in the neuroendocrine area that most research has been done on child and adolescent depression (see Birmaher et al., 1996a, b). In suicidal adults dysregulation of the serotonergic system is common (Mann, 1998; Pine et al., 1995), making them typically impulsive, intense, and given to extreme reactions. However, little is known about the

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association between abnormal serotonin metabolism and suicidal behavior in children and adolescents.

### *Cognitive Factors*

For over two decades there has been considerable interest in the relationship between a particular “mindset” or approach to perceiving external events and a predisposition to depression. The mindset in question is known as a pessimistic “attribution bias” (Abramson et al., 1978; Beck, 1987; Hops et al., 1990). A person with this mindset is one who readily assumes personal blame for negative events (“All the problems in the family are my fault”), who expects that one negative experience is part of a pattern of many other negative events (“Everything I do is wrong”), and who believes that a currently negative situation will endure permanently (“Nothing I do is going to make anything better”). Such pessimistic individuals take a characteristically negative view of positive events (i.e., that they are a result of someone else’s effort, that they are isolated events, and that they are unlikely to recur). Individuals with this mindset react more passively, helplessly, and ineffectively to negative events than those without a pessimistic mindset (Seligman, 1975).

There is uncertainty over whether this mindset precedes depression (and represents a permanent style of thinking as part of an individual’s personality), is a manifestation of depression that is only present when the patient is depressed, and/or is a consequence or “scar” of a previous, perhaps unnoticed, depressive episode (Lewinsohn et al., 1981). This pessimistic mode of thinking does not occur in children under age 5, which could be one of the reasons why depression and suicide are rare in early childhood (Rholes et al., 1980; Rotenberg, 1982).

There is evidence that children and adolescents who previously have been depressed may learn, during their depression, to interpret events in this fashion. This may make them prone to react similarly to negative events experienced after recovery, which could be one of the reasons why previously depressed children and adolescents are at continuing risk for depression (Nolen-Hoeksema et al., 1993).

Perceptions of hopelessness, negative views about one’s own competence, poor self-esteem, a sense of responsibility for negative events, and the immutability of these distorted attributions may contribute to the hopelessness that has been repeatedly found to be associated with suicidality (Overholser et al., 1995).

### *Risk Factors for Suicide and Suicidal Behavior*

There is good evidence that over 90 percent of children and adolescents who commit suicide have a mental disorder before their death (Shaffer & Craft, 1999). The most common disorders that predispose to suicide are some form of mood disorder, with or without alcoholism or other substance abuse problem, and/or certain forms of anxiety disorder (Shaffer et al., 1996b). Psychological postmortem studies also show that a significant proportion of suicide victims suffered from an anxiety disorder at the time of their death, but the number of victims has been too small to yield precise odds ratios for the calculation of an effect. Although the rate of suicide is greatly increased in schizophrenia, because of its rarity, it accounts for very few suicides in the child and adolescent age group.

Controlled studies of completed suicide suggest similar risk factors for boys and girls (Shafii et al., 1985; Brent et al., 1988; Groholt et al., 1997), but with marked differences in their relative importance (Shaffer et al., 1996c).

Among girls, the most significant risk factor is the presence of major depression, which, in some studies, increases the risk of suicide 12-fold. The next most important risk factor is a previous suicide attempt, which increases the risk approximately threefold. Among boys, a previous suicide attempt is the most potent predictor, increasing the rate over 30-fold. It is followed by depression (increasing the rate by about 12-fold), disruptive behavior (increasing the rate by twofold), and substance abuse (increasing the rate by just under twofold) (Shaffer et al., 1996c).

Stressful life events often precede a suicide and/or suicide attempt (de Wilde et al., 1992; Gould et al., 1996). As indicated earlier, these stressful life events include getting into trouble at school or with a law

enforcement agency; a ruptured relationship with a boyfriend or a girlfriend; or a fight among friends.<sup>7</sup> They are rarely a sufficient cause of suicide, but they can be precipitating factors in young people.

Controlled studies (Gould et al., 1996; Hollis, 1996) indicate that low levels of communication between parents and children may act as a significant risk factor. While family discord, lack of family warmth, and disturbed parent-child relationship are commonly associated with child and adolescent psychopathology (violent behavior, mood disorder, alcohol and substance abuse disorders) (Brent et al., 1994; Pfeffer et al., 1994), these factors do not play a specific role in suicide (Gould et al., 1998).

Evidence has accumulated that supports the observation that suicide can be facilitated in vulnerable teens by exposure to real or fictional accounts of suicide (Velting & Gould, 1997), including media coverage of suicide, such as intensive reporting of the suicide of a celebrity, or the fictional representation of a suicide in a popular movie or TV show. The risk is especially high in the young, and it lasts for several weeks (Gould & Shaffer, 1986; Phillips et al., 1989). The suicide of a prominent person reported on television or in the newspaper or exposure to some sympathetic fictional representation of suicide may also tip the balance and make the at-risk individual feel that suicide is a reasonable, acceptable, and in some instances even heroic, decision (Gould & Shaffer, 1986).

The phenomenon of suicide clusters is presumed to be related to imitation (Davidson, 1989). Suicide clusters nearly always involve previously disturbed young people who knew about each other's death but rarely knew the other victims personally (Gould, personal communication, 1999).

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<sup>7</sup> The relationship between sexual orientation, depression, and suicidal thoughts and behavior is not well understood. Several studies suggest a link (Faullener & Cranston, 1998; Garofolo et al., 1998; Garofolo et al., 1999).

## Consequences

Both major depressive disorder and dysthymic disorder are inevitably associated with personal distress, and if they last a long time or occur repeatedly, they can lead to a circumscribed life with fewer friends and sources of support, more stress, and missed educational and job opportunities (Klein et al., 1997). The psychological scars of depression include an enduring pessimistic style of interpreting events, which may increase the risk of further depressive episodes. Impairment is greater for those with dysthymic disorder than for those with major depression (Klein et al., 1997a), presumably because of the longer duration of depression in dysthymic disorder, which is also a prime risk factor for suicide. In a 10- to 15-year followup study of 73 adolescents diagnosed with major depression, 7 percent of the adolescents had committed suicide sometime later. The depressed adolescents were five times more likely to have attempted suicide as well, compared with a control group of age peers without depression (Weissman et al., 1999).

## Treatment

### Depression

#### *Psychosocial Interventions*

To be deemed effective and approved by the American Psychological Association, treatments for mental disorders have to meet very strict criteria. While interpersonal therapy and systemic family therapy show promise, they have not been studied sufficiently to evaluate their effectiveness by these standards. However, in a comprehensive review article (Kaslow & Thompson, 1998) that evaluated interventions for depression in children and adolescents against the American Psychological Association Task Force criteria, two forms of cognitive-behavioral therapy (CBT) were found to be "probably effective treatments," although none of the interventions for depression were deemed, as yet, to meet the Association's higher standard for a *well-established* intervention.

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In studies that focused on relieving symptoms of depression in preadolescents, only one form of CBT met the criteria for a *probably effective* intervention. In the first study, the relative efficacy of two types of CBT—12-session group interventions based on either self-control therapy or behavior-solving therapy—were compared with a “waiting list” control group (Stark et al., 1987). Children responded to both CBT interventions with fewer symptoms of depression and anxiety, whereas the waiting list group exhibited minimal change. Because improvement was greatest with self-control therapy, this intervention was compared in a later study with a traditional counseling condition. Self-control therapy, enhanced by doubling the number of sessions, entailed social skills training, assertiveness training, relaxation training and imagery, and cognitive restructuring. Monthly family meetings were also added to both the experimental and control conditions. Children receiving self-control therapy reported fewer symptoms at 7-month followup (Stark et al., 1991).

Among the numerous studies of adolescents reviewed by Kaslow and Thomson (1998), one form of CBT—coping skills—was judged *probably efficacious*. This intervention, based on the “Coping with Depression” course, was developed originally in Oregon for adults by Lewinsohn and colleagues (Lewinsohn et al., 1996) and adapted by Clarke and colleagues (1992) for school-based programs to treat adolescent depression. Compared with controls on the waiting list, adolescents who received CBT had lower rates of depression, less self-reported depression, improvement in cognitions, and increased activity levels (Lewinsohn et al., 1990, 1996). To achieve *well-established* status, as defined by the American Psychological Association Task Force, the intervention has to be studied by another team of investigators—which has not as yet been done.

### *Pharmacological Treatment*

Prior to 1996, the medications of choice for major depression in children and adolescents were the tricyclic antidepressants, a choice based on numerous studies in adults. However, 13 distinct trials in children and adolescents failed to demonstrate the efficacy of tricyclic antidepressants for younger ages. Tricyclic antidepressants also have a higher risk of toxicity than selective serotonin reuptake inhibitors (SSRIs) (Walsh et al., 1994; Kutcher, 1998). The current consensus is that tricyclic medications are not the medication of choice for depressed children and adolescents (Eisenberg, 1996; Fisher & Fisher, 1996).

Recent research indicates that young people with depressive disorders may respond more favorably to SSRIs than to tricyclic antidepressants. The first SSRI tested in children and adolescents was fluoxetine. In a study of 96 outpatients over 8 weeks, 56 percent receiving fluoxetine and 33 percent receiving placebo were “much” or “very much” improved on the Clinical Global Improvement Scale. Benefits were comparable across age groups. Complete symptom remission occurred for 31 percent of fluoxetine-treated patients compared with 23 percent of placebo-treated patients (Emslie et al., 1997). A recent open trial of fluoxetine for adolescents hospitalized for treatment of major depression found it to decrease depression scores more effectively than imipramine, a tricyclic antidepressant (Strober et al., 1999), with the further advantage that fluoxetine was well tolerated.

The safety of a second SSRI, paroxetine, was demonstrated in a multicenter double-blind placebo-controlled trial. Paroxetine was compared with imipramine and placebo in 275 adolescents who met the DSM-IV criteria for major depression. Preliminary results indicate that, mostly because of side effects, one-third of imipramine patients withdrew from the study, a proportion significantly higher than that for paroxetine (10 percent) and placebo (7 percent) (Wagner et al., 1998). One of the co-investigators of this study noted that paroxetine’s efficacy was superior

to that of imipramine and placebo on the Clinical Global Improvement Scale (Graham Emslie, personal communication, October 1998). However, final conclusions about the benefit of this second SSRI must await publication of the outcomes of this multicenter study.

In summary, psychosocial interventions for depressed children and adolescents indicate great promise, with several types of cognitive-behavioral therapy for the child or adolescent leading the way. With respect to pharmacotherapy, new studies attest to the safety and efficacy of two SSRIs. These promising findings are being extended in the recently begun NIMH-funded Treatment of Adolescents with Depression study.

### ***Bipolar Disorder***

#### *Pharmacological Treatment*

The treatment of bipolar disorder entails treating symptoms of both depression and mania. For decades, lithium has been the well-researched mainstay treatment for mania in adults. Mania in bipolar disorder of children is also treated with lithium, although the relevant research on children lags behind that on adults. Only in recent years have researchers begun to study lithium in children and adolescents, with good clinical response. Open trials of lithium were conducted in the late 1980s (Varanka et al., 1988; Strober et al., 1990). More recently, lithium proved to be more effective than placebo in treating adolescents who were bipolar and substance dependent (Geller et al., 1998).

Children experience the same safety problems with lithium as do adults: toxicity and impairment of renal and thyroid functioning (Geller & Luby, 1997). Lithium is therefore not recommended for families unable to keep regular appointments that would ensure monitoring of serum lithium levels and of adverse events. Patients who discontinue taking the drug have a high relapse rate (Strober et al., 1990).

As yet, there are no controlled studies on a number of other psychotropic agents also used clinically in children and adolescents with bipolar disorder,

including valproate, carbamazepine, methylphenidate, and low-dose chlorpromazine (Campbell & Cueva, 1995; Geller & Luby, 1997).

### ***Suicide***

#### *Psychotherapeutic Treatments*

Suicidal children and adolescents report feelings of intense emotional distress involving depression, anger, anxiety, hopelessness, and worthlessness and an inability to change problematic, frustrating circumstances or to find a solution to their problems (Kienhorst et al., 1995; Ohring et al., 1996). They feel so distraught that they often respond impulsively to their despair. Psychotherapeutic techniques aim to decrease such intolerable feelings and thoughts and to re-orient the cognitive and emotional perspectives of the suicidal child or adolescent (Kernberg, 1994; Spirito, 1997).

Cognitive-behavioral therapy (CBT) may be a useful intervention, considering that suicidal children and adolescents often experience negative cognitions about themselves, their environment, and their futures. Recent research suggests that CBT may be more effective than systemic behavior family therapy or individual nondirective supportive therapy in reducing depressive symptoms associated with suicidal ideation (Brent et al., 1997). Such treatment can focus on re-attribution of precipitating issues for suicidal behavior and enable the suicidal child or adolescent to rank stresses and to consider avenues of problem-solving (Rotheram-Borus et al., 1994; Brent et al., 1997; Spirito, 1997).

Interpersonal conflicts are important stresses related to the risk imparted by poor social adjustment of potentially suicidal children and adolescents. Treatment of interpersonal strife may significantly reduce suicidal risk. Recent research into the efficacy of interpersonal psychotherapy of depressed adolescents suggests beneficial effects (Kaslow & Thompson, 1998); it is a treatment that may be modified to address the risk factor issues related to interpersonal loss, conflicts, and need for restitution

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often reported by children and adolescents with suicidal tendencies.

A significant class of risk factors for suicide involves family discord, which is characterized by poor communication, disagreements, and lack of cohesive values and goals and of common activities (de Long, 1992; Miller et al., 1992; Wagner, 1997). Suicidal children and adolescents often feel that they are isolated within the family, exhibit problems in independence, and view themselves as expendable to the family, a perception that is a motivating force for self-annihilation (Sabbath, 1969; Pfeffer, 1986; Miller et al., 1992). Family intervention with suicidal children and adolescents is an important method to decrease such problems and to enhance effective family problem-solving and conflict resolution, so that blame is not directed toward the suicidal child or adolescent. Cognitive-behavioral approaches with suicidal children and adolescents and their families aim to reframe their understanding of family problems, alter the family style of maladaptive problem-solving techniques, and encourage positive family interactions (Rotheram-Borus et al., 1994). Time-limited home-based intervention to reduce suicidal ideation in children and adolescents and to improve family functioning has been reported to have limited efficacy for children and adolescents without major depressive disorder (Harrington et al., 1998). Psychoeducational approaches to reduce the extent of expressed anger may be helpful in lowering risk for suicidal behavior in children and adolescents (Fristad et al., 1996).

### *Psychopharmacological Treatments*

There is a dearth of research on the efficacy of pharmacological treatments for reducing suicidal thoughts or preventing suicide in children and adolescents. Most of the research on pharmacotherapies has been conducted in adults. In depressed adults, SSRIs have been found to reduce suicidal ideation (Letizia et al., 1996; Wernicke et al., 1997) and to reduce the frequency of suicide attempts in nondepressed patients who had previously made at least one suicide attempt (Verkes et al., 1998). In a

controlled trial of the experimental neuroleptic drug flupenthixol, researchers noted a significant reduction in suicide-attempt behavior in adults who had made numerous previous attempts (Montgomery & Montgomery, 1982). Similar studies have yet to be conducted on adolescents, although trials of SSRIs in depressed adolescents suggest that these drugs are effective for treating depression and for reducing suicidal ideas also in this age group (Emslie et al., 1997; Ryan & Varma, 1998). Because placebo-controlled, methodologically appropriate studies of tricyclic antidepressants have failed to find a significant effect in depressed children and adolescents (Ryan & Varma, 1998), it is reasonable to regard SSRIs as a first-choice medication in treating depressed suicidal children and adolescents (also see American Academy of Child and Adolescent Psychiatry, 1998). In contrast to tricyclic antidepressants, SSRIs have low lethal potential when taken in overdoses (Ryan & Varma, 1998).

In adults with major depressive disorder, controlled research suggests that lithium reduces suicide risk (Thies-Flechtner et al., 1996), but this has not yet been demonstrated in children and adolescents. Clinicians should be cautious about prescribing medications that may reduce self-control, such as the benzodiazapines, amphetamines, and phenobarbital. These drugs also have a high lethal potential if taken in overdose (Carlsten et al., 1996).

### *Intervention After a Suicidal Death of a Relative, Friend, or Acquaintance*

The suicidal death of a relative or acquaintance may increase the risk for childhood or adolescent suicidal behavior and other dysphoric states (Brent et al., 1992, 1994; Pfeffer et al., 1994, 1997; Clark & Goebel, 1996). Major depression, post-traumatic stress disorder, and suicidal ideation often occur after the death of an adolescent friend or acquaintance and relative (Brent et al., 1992, 1994, 1996).

The goal of the clinician is to decrease the likelihood that a child or adolescent comes to view the suicidal behavior of the deceased as a coping strategy in dealing with adversity (Brent et al., 1997). Psycho-

educational counseling may reduce the risk for suicidal behavior in these circumstances. Intervention is also needed to decrease the child's or teen's personal sense of guilt, trauma, and social isolation. This treatment can be given in individual meetings, at group sessions with other teens, or in conjunction with parents who need help to support the adaptive capacities of their children and adolescents. School professionals sometimes offer programs of this kind and can be invaluable in identifying grieving friends who may need help.

### *Community-Based Suicide Prevention*

The principal public health approaches to suicide prevention have been (1) crisis hotlines<sup>8</sup>; (2) restrictions covering access to suicide methods; (3) media counseling to minimize imitative suicide; (4) indirect case-finding by educating potential gate-keepers, teachers, parents, and peers to identify the warning signs of an impending suicide; (5) direct case-finding among high school or college students or among the patients of primary practitioners by screening for conditions that place teens at risk for suicide; and (6) training professionals to improve recognition and treatment of mood disorders. As discussed below, the level of evidence for these strategies varies. There is more support for direct case-finding and improved recognition and treatment of mood disorders than for the other strategies.

### *Crisis Hotlines*

Although crisis hotlines are available almost everywhere in the United States, research has failed to show that they reduce the incidence of suicide (Bleach & Clairborn, 1974; Apsler & Hodas, 1976; Miller et al., 1984; Shaffer et al., 1990a, 1990b). Possible reasons for this are that actively suicidal individuals (males and individuals with an acute mental disturbance) do not call hotlines because they are acutely disturbed, preoccupied, or intent on not being deflected from their intended course of action (Shaffer et al., 1989). Hotlines are often busy, and there may be a long wait

before a call is answered, so that callers disconnect; the advice individuals get on calling a hotline may be stereotyped, inappropriate for an individual's needs, and perceived as unhelpful by the caller. Gender preferences in seeking help result in the large majority of callers being females, whereas males are at greatest risk for suicide. While each of these deficiencies is potentially modifiable, there have been no systematic attempts to do so.

### *Method Restriction*

Method preference for suicide varies by gender and by nationality. In the United States, the most common method for committing suicide is by firearms, and it has been suggested that reducing firearms availability will reduce the incidence of suicide (Moscicki, 1995). However, a natural experiment in Great Britain suggests this is unlikely. The favored suicide method, self-asphyxiation with coal gas, became impossible after the introduction of natural gas. This resulted in a marked but short-lived decline in the suicide rate. Within a decade, the suicide rate had returned to previous levels, and suicides were being committed by other means (Farberow, 1985). Although reducing access to firearms with gun-security laws reduces accidental deaths from firearms (Cummings et al., 1997), there is no evidence to date that such laws have a significant impact on suicides attributable to firearms.

### *Media Counseling*

Even though it appears prudent for reporters and editors to minimize coverage of youth suicide in general and attention to individual suicides (O'Carroll & Potter, 1994), there is as yet no evidence that these guidelines, issued by the Centers for Disease Control and Prevention, are effective in reducing the suicide rate.

### *Indirect Case-Finding Through Education*

Controlled studies have failed to show that classes for high school students about suicide increase students' help-seeking behavior when they are troubled or depressed (Spirito et al., 1988; Shaffer et al., 1991; Vieland et al., 1991). On the other hand, there is evidence that previously suicidal adolescents are upset

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<sup>8</sup> Crisis hotlines are only one of the services offered through crisis services, a topic discussed subsequently.

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by exposure to such classes (Shaffer et al., 1990a, 1990b), even though this does not necessarily lead to a suicide attempt. Such educational programs seem, therefore, to be both an ineffective mode of case-finding and to carry with them an unjustified risk of activating suicidal thoughts.

### *Direct Case-Finding*

Judging from the high response rate to surveys about suicidal attempts and ideation (National Center for Health Statistics, 1997), adolescents will provide accurate information about their own suicidal thoughts and/or behaviors if asked directly in a nonthreatening way. A sensible approach to suicide prevention that needs further study, therefore, is to screen systematically 15- to 19-year-olds (the age group at greatest risk) for (1) previous suicide attempts; (2) recent, serious, suicidal preoccupations; (3) depression; or (4) complications of substance or alcohol use. Clearly, screening programs need to go beyond identifying a teen with a high-risk profile. Youth identified in this way should be referred for evaluation and, if necessary, treatment. Contingency arrangements may need to be made to assist uninsured adolescents with help if it is needed (Shaffer & Craft, 1999).

### *Aggressive Treatment of Mood Disorders*

Preliminary and as yet unreplicated studies in Sweden (Rihmer et al., 1995) suggest that education of primary medical practitioners to better identify the characteristics of mood disorders and to treat these effectively produced a significant reduction in suicide and suicide-attempt rates. Although the optimal treatment of adolescent depression is not yet as well understood as that of adult depression, this is an option that may prove to be useful.

### *Air Force Suicide Prevention Program—A Community Approach*

Combining many of the approaches for adolescents described above, the Air Force Surgeon General developed and implemented a community approach to suicide prevention for older adolescents and young adults on active duty. The program involved education

on suicide risk awareness, reducing barriers to mental health services, and stigma-reducing efforts.<sup>9</sup>

## Other Mental Disorders in Children and Adolescents

### **Anxiety Disorders**

The combined prevalence of the group of disorders known as anxiety disorders is higher than that of virtually all other mental disorders of childhood and adolescence (Costello et al., 1996). The 1-year prevalence in children ages 9 to 17 is 13 percent (Table 3-1). This section furnishes brief overviews of several anxiety disorders: separation anxiety disorder, generalized anxiety disorder, social phobia, and obsessive-compulsive disorder. Treatments for all but the latter are grouped together below.

### *Separation Anxiety Disorder*

Although separation anxieties are normal among infants and toddlers, they are not appropriate for older children or adolescents and may represent symptoms of separation anxiety disorder. To reach the diagnostic threshold for this disorder, the anxiety or fear must cause distress or affect social, academic, or job functioning and must last at least 1 month (DSM-IV). Children with separation anxiety may cling to their parent and have difficulty falling asleep by themselves at night. When separated, they may fear that their parent will be involved in an accident or taken ill, or in some other way be “lost” to the child forever. Their need to stay close to their parent or home may make it difficult for them to attend school or camp, stay at friends’ houses, or be in a room by themselves. Fear of separation can lead to dizziness, nausea, or palpitations (DSM-IV).

Separation anxiety is often associated with symptoms of depression, such as sadness, withdrawal, apathy, or difficulty in concentrating, and such children often fear that they or a family member might die.

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<sup>9</sup> In 1995, prior to implementation, suicide rates were almost 16 per 100,000; following 3 years of exposure to the program, suicide rates fell to below 2 per 100,000 (Air Force Surgeon General, personal communication, 1999)

Young children experience nightmares or fears at bedtime.

About 4 percent of children and young adolescents suffer from separation anxiety disorder (DSM-IV). Among those who seek treatment, separation anxiety disorder is equally distributed between boys and girls. In survey samples, the disorder is more common in girls (DSM-IV). The disorder may be overdiagnosed in children and teenagers who live in dangerous neighborhoods and have reasonable fears of leaving home.

The remission rate with separation anxiety disorder is high. However, there are periods where the illness is more severe and other times when it remits. Sometimes the condition lasts many years or is a precursor to panic disorder with agoraphobia. Older individuals with separation anxiety disorder may have difficulty moving or getting married and may, in turn, worry about separation from their own children and partner.

The cause of separation anxiety disorder is not known, although some risk factors have been identified. Affected children tend to come from families that are very close-knit. The disorder might develop after a stress such as death or illness in the family or a move. Trauma, especially physical or sexual assault, might bring on the disorder (Goenjian et al., 1995). The disorder sometimes runs in families, but the precise role of genetic and environmental factors has not been established. The etiology of anxiety disorders is more thoroughly discussed in Chapter 4.

### ***Generalized Anxiety Disorder***

Children with generalized anxiety disorder (or overanxious disorder of childhood) worry excessively about all manner of upcoming events and occurrences. They worry unduly about their academic performance or sporting activities, about being on time, or even about natural disasters such as earthquakes. The worry persists even when the child is not being judged and has always performed well in the past. Because of their anxiety, children may be overly conforming, perfectionist, or unsure of themselves. They tend to redo tasks if there are any imperfections. They tend to seek approval and need constant reassurance about

their performance and their anxieties (DSM-IV). The 1-year prevalence rate for all generalized anxiety disorder sufferers of all ages is approximately 3 percent. The lifetime prevalence rate is about 5 percent (DSM-IV).

About half of all adults seeking treatment for this disorder report that it began in childhood or adolescence, but the proportion of children with this disorder who retain the problem into adulthood is unknown. The remission rate is not thought to be as high as that of separation anxiety disorder.

### ***Social Phobia***

Children with social phobia (also called social anxiety disorder) have a persistent fear of being embarrassed in social situations, during a performance, or if they have to speak in class or in public, get into conversation with others, or eat, drink, or write in public. Feelings of anxiety in these situations produce physical reactions: palpitations, tremors, sweating, diarrhea, blushing, muscle tension, etc. Sometimes a full-blown panic attack ensues; sometimes the reaction is much more mild. Adolescents and adults are able to recognize that their fear is unreasonable or excessive, although this recognition does not prevent the fear. Children, however, might not recognize that their reaction is excessive, although they may be afraid that others will notice their anxiety and consider them odd or babyish.

Young children do not articulate their fears, but may cry, have tantrums, freeze, cling, appear extremely timid in strange social settings, shrink from contact with others, stay on the side during social events, and try to stay close to familiar adults. They may fall behind in school, avoid school completely, or avoid social activities among children their age. The avoidance of the fearful situations or worry preceding the feared event may last for weeks and interfere with the individual's daily routine, social life, job, or school. They may find it impossible to speak in social situations or in the presence of unfamiliar people (for review of social phobia, see DSM-IV; Black et al., 1997).

Social phobia is common, the lifetime prevalence ranging from 3 to 13 percent, depending on how great the fear is and on how many different situations induce

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the anxiety (DSM-IV; Black et al., 1997). In survey studies, the majority of those with the disorder were found to be female (DSM-IV). Often the illness is lifelong, although it may become less severe or completely remit. Life events may reassure the individual or exacerbate the anxiety and disorder.

### *Treatment of Anxiety*

Although anxiety disorders are the most common disorder of youth, there is relatively little research on the efficacy of psychotherapy (Kendall et al., 1997). For childhood phobias, contingency management<sup>10</sup> was the only intervention deemed to be *well-established*, according to an evaluation by Ollendick and King (1998), which applied the American Psychological Association Task Force criteria (noted earlier). Several psychotherapies are *probably efficacious* for treating phobias: systematic desensitization<sup>11</sup>; modeling, based on research by Bandura and colleagues, which capitalizes on an observational learning technique (Bandura, 1971; see also Chapter 2); and several cognitive-behavioral therapy (CBT) approaches (Ollendick & King, 1998).

CBT, as pioneered by Kendall and colleagues (Kendall et al., 1992; Kendall, 1994), is deemed by the American Psychological Association Task Force as *probably efficacious*. It has four major components: recognizing anxious feelings, clarifying cognitions in anxiety-provoking situations,<sup>12</sup> developing a plan for coping, and evaluating the success of coping strategies. A more recent study in Australia added a parent component to CBT, which enhanced reduction in post-treatment anxiety disorder significantly compared with CBT alone (Barrett et al., 1996). However, none of the interventions identified above as *well-established* or *probably efficacious* has, for the most part, been tested in real-world settings.

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<sup>10</sup> Contingency management attempts to alter behavior by manipulating its consequences through the behavioral principles of shaping, positive reinforcement, and extinction.

<sup>11</sup> A technique that trains people to "unlearn" fears by presentation of fearful stimuli along with nonfearful stimuli.

<sup>12</sup> This refers to understanding how cognitions are being distorted.

In addition, psychodynamic treatment to address underlying fears and worries can be helpful, and behavior therapy may reduce the child's fear of separation or of going to school; however, the experimental support for these approaches is limited.

Preliminary research suggests that selective serotonin reuptake inhibitors may provide effective treatment of separation anxiety disorder and other anxiety disorders of childhood and adolescence. Two large-scale randomized controlled trials are currently being undertaken (Greenhill, 1998a, 1998b). Neither tricyclic antidepressants nor benzodiazepines have been shown to be more effective than placebo in children (Klein et al., 1992; Bernstein et al., 1998).

### *Obsessive-Compulsive Disorder*

Obsessive-compulsive disorder (OCD), which is classified in DSM-IV as an anxiety disorder, is characterized by recurrent, time-consuming obsessive or compulsive behaviors that cause distress and/or impairment. The obsessions may be repetitive intrusive images, thoughts, or impulses. Often the compulsive behaviors, such as hand-washing or cleaning rituals, are an attempt to displace the obsessive thoughts (DSM-IV). Estimates of prevalence range from 0.2 to 0.8 percent in children, and up to 2% of adolescents (Flament et al., 1998).

There is a strong familial component to OCD, and there is evidence from twin studies of both genetic susceptibility and environmental influences. If one twin has OCD, the other twin is more likely to have OCD if the children are identical twins rather than fraternal twin pairs. OCD is increased among first-degree relatives of children with OCD, particularly among fathers (Lenane et al., 1990). It does not appear that the child is simply imitating the relative's behavior, because children who develop OCD tend to have symptoms different from those of relatives with the disease (Leonard et al., 1997). Many adults with either childhood- or adolescent-onset of OCD show evidence of abnormalities in a neural network known as the orbitofrontal-striatal area (Rauch & Savage, 1997; Grachev et al., 1998).

Recent research suggests that some children with OCD develop the condition after experiencing one type of streptococcal infection (Swedo et al., 1995). This condition is referred to by the acronym PANDAS, which stands for Pediatric Autoimmune Neuro-psychiatric Disorders Associated with Streptococcal infections. Its hallmark is a sudden and abrupt exacerbation of OCD symptoms after a strep infection. This form of OCD occurs when the immune system generates antibodies to the streptococcal bacteria, and the antibodies cross-react with the basal ganglia<sup>13</sup> of a susceptible child, provoking OCD (Garvey et al., 1998). In other words, the cause of this form of OCD appears to be antibodies directed against the infection mistakenly attacking a region of the brain and setting off an inflammatory reaction.

The selective serotonin reuptake inhibitors appear effective in ameliorating the symptoms of OCD in children, although more clinical trials have been done with adults than with children. Several randomized, controlled trials revealed SSRIs to be effective in treating children and adolescents with OCD (Flament et al., 1985; DeVeugh-Geiss et al., 1992; Riddle et al., 1992, 1998). The appropriate duration of treatment is still being studied. Side effects are not inconsequential: dry mouth, somnolence, dizziness, fatigue, tremors, and constipation occur at fairly high rates. Cognitive-behavioral treatments also have been used to treat OCD (March et al., 1997), but the evidence is not yet conclusive.

### Autism

Autism, the most common of the pervasive developmental disorders (with a prevalence of 10 to 12 children per 10,000 [Bryson & Smith, 1998]), is characterized by severely compromised ability to engage in, and by a lack of interest in, social interactions. It has roots in both structural brain abnormalities and genetic predispositions, according to family studies and studies of brain anatomy. The search for genes that predispose to autism is considered an

extremely high research priority for the National Institute of Mental Health (NIMH, 1998). Although the reported association between autism and obstetrical hazard may be due to genetic factors (Bailey et al., 1995), there is evidence that several different causes of toxic or infectious damage to the central nervous system during early development also may contribute to autism. Autism has been reported in children with fetal alcohol syndrome (Aronson et al., 1997), in children who were infected with rubella during pregnancy (Chess et al., 1978), and in children whose mothers took a variety of medications that are known to damage the fetus (Williams & Hersh, 1997).

Cognitive deficits in social perception likely result from abnormalities in neural circuitry. Children with autism have been studied with several imaging techniques, but no strongly consistent findings have emerged, although abnormalities in the cerebellum and limbic system (Rapin & Katzman, 1998) and larger brains (Piven, 1997) have been reported. In one small study (Zilbovicius et al., 1995), evidence of delayed maturation of the frontal cortex was found. The evidence for genetic influences include a much greater concordance in identical than in fraternal twins (Cook, 1998).

### Treatment

Because autism is a severe, chronic developmental disorder, which results in significant lifelong disability, the goal of treatment is to promote the child's social and language development and minimize behaviors that interfere with the child's functioning and learning. Intensive, sustained special education programs and behavior therapy early in life can increase the ability of the child with autism to acquire language and ability to learn. Special education programs in highly structured environments appear to help the child acquire self-care, social, and job skills. Only in the past decade have studies shown positive outcomes for very young children with autism. Given the severity of the impairment, high intensity of service needs, and costs (both human and financial), there has been an ongoing search for effective treatment.

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<sup>13</sup> Basal ganglia are groups of neurons responsible for motor and impulse control, attention, and regulation of mood and behavior.

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Thirty years of research demonstrated the efficacy of applied behavioral methods in reducing inappropriate behavior and in increasing communication, learning, and appropriate social behavior. A well-designed study of a psychosocial intervention was carried out by Lovaas and colleagues (Lovaas, 1987; McEachin et al., 1993). Nineteen children with autism were treated intensively with behavior therapy for 2 years and compared with two control groups. Followup of the experimental group in first grade, in late childhood, and in adolescence found that nearly half the experimental group but almost none of the children in the matched control group were able to participate in regular schooling. Up to this point, a number of other research groups have provided at least a partial replication of the Lovaas model (see Rogers, 1998).

Several uncontrolled studies of comprehensive center-based programs have been conducted, focusing on language development and other developmental skills. A comprehensive model, Treatment and Education of Autistic and Related Communication Handicapped Children (TEACCH), demonstrated short-term gains for preschoolers with autism who received daily TEACCH home-teaching sessions, compared with a matched control group (Ozonoff & Cathcart, 1998). A review of other comprehensive, center-based programs has been conducted, focusing on elements considered critical to school-based programs, including minimum hours of service and necessary curricular components (Dawson & Osterling, 1997).

The antipsychotic drug, haloperidol, has been shown to be superior to placebo in the treatment of autism (Perry et al., 1989; Locascio et al., 1991), although a significant number of children develop dyskinesias<sup>14</sup> as a side effect (Campbell et al., 1997). Two of the SSRIs, clomipramine (Gordon et al., 1993) and fluoxetine (McDougle et al., 1996), have been tested, with positive results, except in young autistic children, in whom clomipramine was not found to be therapeutic, and who experienced untoward side effects (Sanchez et al., 1996). Of note, preliminary studies of

some of the newer antipsychotic drugs suggest that they may have fewer side effects than conventional antipsychotics such as haloperidol, but controlled studies are needed before firm conclusions can be drawn about any possible advantages in safety and efficacy over traditional agents.

### Disruptive Disorders

Disruptive disorders, such as oppositional defiant disorder and conduct disorder, are characterized by antisocial behavior and, as such, seem to be a collection of behaviors rather than a coherent pattern of mental dysfunction. These behaviors are also frequently found in children who suffer from attention-deficit/hyperactivity disorder, another disruptive disorder, which is discussed separately in this chapter. Children who develop the more serious conduct disorders often show signs of these disorders at an earlier age. Although it is common for a very young children to snatch something they want from another child, this kind of behavior may herald a more generally aggressive behavior and be the first sign of an emerging oppositional defiant or conduct disorder if it occurs by the ages of 4 or 5 and later. However, not every oppositional defiant child develops conduct disorder, and the difficult behaviors associated with these conditions often remit.

*Oppositional defiant disorder (ODD)* is diagnosed when a child displays a persistent or consistent pattern of defiance, disobedience, and hostility toward various authority figures including parents, teachers, and other adults. ODD is characterized by such problem behaviors as persistent fighting and arguing, being touchy or easily annoyed, and deliberately annoying or being spiteful or vindictive to other people. Children with ODD may repeatedly lose their temper, argue with adults, deliberately refuse to comply with requests or rules of adults, blame others for their own mistakes, and be repeatedly angry and resentful. Stubbornness and testing of limits are common. These behaviors cause significant difficulties with family and friends and at school or work (DSM-IV; Weiner, 1997). Oppositional defiant disorder is sometimes a precursor of conduct disorder (DSM-IV).

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<sup>14</sup> Dyskinesia is an impairment of voluntary movement, such that it becomes fragmentary or incomplete.

In different studies, estimates of the prevalence of ODD have ranged from 1 to 6 percent, depending on the population sample and the way the disorder was evaluated, but not depending on diagnostic criteria. Rates are lower when impairment criteria are more strict and when information is obtained from teachers and parents rather than from the children alone (Shaffer et al., 1996a). Before puberty, the condition is more common in boys, but after puberty the rates in both genders are equal.

In preschool boys, high reactivity, difficulty being soothed, and high motor activity may indicate risk for the disorder. Marital discord, disrupted child care with a succession of different caregivers, and inconsistent, unsupervised child-rearing may contribute to the condition.

Children or adolescents with *conduct disorder* behave aggressively by fighting, bullying, intimidating, physically assaulting, sexually coercing, and/or being cruel to people or animals. Vandalism with deliberate destruction of property, for example, setting fires or smashing windows, is common, as are theft; truancy; early tobacco, alcohol, and substance use and abuse; and precocious sexual activity. Girls with a conduct disorder are prone to running away from home and may become involved in prostitution. The behavior interferes with performance at school or work, so that individuals with this disorder rarely perform at the level predicted by their IQ or age. Their relationships with peers and adults are often poor. They have higher injury rates and are prone to school expulsion and problems with the law. Sexually transmitted diseases are common. If they have been removed from home, they may have difficulty staying in an adoptive or foster family or group home, and this may further complicate their development. Rates of depression, suicidal thoughts, suicide attempts, and suicide itself are all higher in children diagnosed with a conduct disorder (Shaffer et al., 1996b).

The prevalence of conduct disorder in 9- to 17-year-olds in the community varies from 1 to 4 percent, depending on how the disorder is defined (Shaffer et al., 1996a). Children with an early onset of the disorder, i.e., onset before age 10, are predominantly

male. The disorder appears to be more common in cities than in rural areas (DSM-IV). Those with early onset have a worse prognosis and are at higher risk for adult antisocial personality disorder (DSM-IV; Rutter & Giller, 1984; Hendren & Mullen, 1997). Between a quarter and a half of highly antisocial children become antisocial adults.

The etiology of conduct disorder is not fully known. Studies of twins and adopted children suggest that conduct disorder has both biological (including genetic) and psychosocial components (Hendren & Mullen, 1997). Social risk factors for conduct disorder include early maternal rejection, separation from parents with no adequate alternative caregiver available, early institutionalization, family neglect, abuse or violence, parents' psychiatric illness, parental marital discord, large family size, crowding, and poverty (Loeber & Stouthamer-Loeber, 1986). These factors are thought to lead to a lack of attachment to the parents or to the family unit and eventually to lack of regard for the rules and rewards of society (Sampson & Laub, 1993). Physical risk factors for conduct disorder include neurological damage caused by birth complications or low birthweight, attention-deficit/hyperactivity disorder, fearlessness and stimulation-seeking behavior, learning impairments, autonomic underarousal, and insensitivity to physical pain and punishment. A child with both social deprivation and any of these neurological conditions is most susceptible to conduct disorder (Raine et al., 1998).

Since many of the risk factors for conduct disorder emerge in the first years of life, intervention must begin very early. Recently, screening instruments have been developed to enable earlier identification of risk factors and signs of conduct disorder in young children (Feil et al., 1995). Studies have shown a correlation between the behavior and attributes of 3-year-olds and the aggressive behavior of these children at ages 11 to 13 (Raine et al., 1998). Measurements of aggressive behaviors have been shown to be stable over time (Sampson & Laub, 1993). Training parents of high-risk children how to deal with the children's demands may help. Parents may need to be taught to reinforce

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appropriate behaviors and not harshly punish transgressing ones, and encouraged to find ways to increase the strength of the emotional ties between parent and child. Working with high-risk children on social interaction and providing academic help to reduce rates of school failure can help prevent some of the negative educational consequences of conduct disorder (Johnson & Breckenridge, 1982).

### **Treatment**

Several psychosocial interventions can effectively reduce antisocial behavior in disruptive disorders. A recent review of psychosocial treatments for children and adolescents identified 82 studies conducted between 1966 and 1995 involving 5,272 youth (Brestan & Eyberg, 1998). The criterion for inclusion was that the child was in treatment for conduct problem behavior, based on displaying a symptom of conduct disorder or oppositional defiant disorder, rather than on a DSM diagnosis of either, although children did meet DSM criteria for one of these conditions in about one-third of the studies.

By applying criteria established by the American Psychological Association Task Force (see earlier) to the 82 studies, two treatments met criteria for *well-established* treatment and 10 for *probably efficacious* treatment. Two *well-established* treatments, both directed at training parents, succeeded in reducing problem behaviors. The two treatments were a parent training program based on the manual *Living With Children* (Bernal et al., 1980) and a videotape modeling parent training (Spaccarelli et al., 1992). The first teaches parents to reward desirable behaviors and ignore or punish deviant behaviors, based on principles of operant conditioning. The second provides a series of videotapes covering parent-training lessons, after which a therapist leads a group discussion of the videotape lessons. The identification of 12 treatments as *well-established* or *probably efficacious* is very encouraging because of the potential to intervene effectively with youth at high risk of poor outcomes. A new and promising approach for the treatment of conduct disorder is multisystemic therapy, an intensive

home- and family-focused treatment that is described under Home-Based Services.

Despite strong enthusiasm for improving care for conduct-disordered youth, there are important groups of children, specifically girls and ethnic minority populations, who were not sufficiently represented in these studies to ensure that the identified treatments work for them. Other issues raised by Brestan and Eyberg (1998) are cost-effectiveness, the sufficiency of a given intervention, effectiveness over time, and the prevention of relapse.

No drugs have been demonstrated to be consistently effective in treating conduct disorder, although four drugs have been tested. Lithium and methylphenidate have been found (one double-blind placebo trial each) to reduce aggressiveness effectively in children with conduct disorder (Campbell et al., 1995; Klein et al., 1997b), but in two subsequent studies with the same design, the positive findings for lithium could not be reproduced (Rifkin et al., 1989; Klein, 1991). In one of the latter studies, methylphenidate was superior to lithium and placebo. A third drug, carbamazepine, was found in a pilot study to be effective, but multiple side effects were also reported (Kafantaris et al., 1992). The fourth drug, clonidine, was explored in an open trial, in which 15 of 17 patients showed a significant decrease in aggressive behavior, but there were also significant side effects that would require monitoring of cardiovascular and blood pressure parameters (Kempthorn et al., 1993).

### **Substance Use Disorders in Adolescents**

Since the early 1990s there has been a "sharp resurgence" in the misuse of alcohol and other drugs by adolescents (Johnston et al., 1996). A recent review, focusing particularly on substance abuse and dependence, synthesizes research findings of the past decade (Weinberg et al., 1998). The authors review epidemiology, course, etiology, treatment, and prevention and discuss comorbidity with other mental disorders in adolescents. All of these issues are important to public health, but none is more relevant to this report than the co-occurrence of alcohol and other

substance use disorders with other mental disorders in adolescents.

According to the National Comorbidity Study, 41 to 65 percent of individuals with a lifetime substance abuse disorder also have a lifetime history of at least one mental disorder, and about 51 percent of those with one or more lifetime mental disorders also have a lifetime history of at least one substance use disorder (Kessler et al., 1996). The rates are highest in the 15- to 24-year-old age group (Kessler et al., 1994). The cross-sectional data on association do not permit any conclusion about causality or clinical prediction (Kessler et al., 1996), but an appealing theory suggests that a subgroup of the population abuses drugs in an effort to self-medicate for the co-occurring mental disorder. Little is actually known about the role of mental disorders in increasing the risk of children and adolescents for misuse of alcohol and other drugs. Stress appears to play a role in both the process of addiction and the development of many of the comorbid conditions.

The review by Weinberg and colleagues (1998) provides more detail on epidemiology and assessment of alcohol and other drug use in adolescents and describes several effective treatment approaches for these problems. A meta-analysis and literature review (Stanton & Shadish, 1997) concluded that family-oriented therapies were superior to other treatment approaches and enhanced the effectiveness of other treatments. Multisystemic family therapy, discussed elsewhere in this chapter, is effective in reducing alcohol and other substance use and other severe behavioral problems among adolescents (Pickrel & Henggeler, 1996).

### Eating Disorders

Eating disorders are serious, sometimes life-threatening, conditions that tend to be chronic (Herzog et al., 1999). They usually arise in adolescence and disproportionately affect females. About 3 percent of young women have one of the three main eating disorders: anorexia nervosa, bulimia nervosa, or binge-eating disorder (Becker et al., 1999). Binge-eating disorder is a newly recognized condition featuring

episodic uncontrolled consumption, without compensatory activities, such as vomiting or laxative abuse, to avert weight gain (Devlin, 1996). Bulimia, in contrast, is marked by both binge eating and by compensatory activities. Anorexia nervosa is characterized by low body weight (< 85 percent of expected weight), intense fear of weight gain, and an inaccurate perception of body weight or shape (DSM-IV). Its mean age of onset is 17 years (DSM-IV).

The causes of eating disorders are not known with precision but are thought to be a combination of genetic, neurochemical, psychodevelopmental, and sociocultural factors (Becker et al., 1999; Kaye et al., 1999). Comorbid mental disorders are exceedingly common, but interrelationships are poorly understood. Comorbid disorders include affective disorders (especially depression), anxiety disorders, substance abuse, and personality disorders (Herzog et al., 1996). Anorexia nervosa has the most severe consequence, with a mortality rate of 0.56 percent per year (or 5.6 percent per decade) (Sullivan, 1995), a rate higher than that of almost all other mental disorders (Herzog et al., 1996). Mortality is from starvation, suicide, or electrolyte imbalance (DSM-IV). The mortality rate from anorexia nervosa is 12 times higher than that for other young women in the population (Sullivan, 1995).

Treatment of eating disorders entails psychotherapy and pharmacotherapy, either alone or in combination. Treatment of comorbid mental disorders also is important, as is treatment of medical complications. There are some controlled studies of the efficacy of specific treatments for *adults* with bulimia and binge-eating disorder (Devlin, 1996), but fewer for anorexia nervosa (Kaye et al., 1999). Controlled studies in adolescents are rare for any eating disorder (Steiner and Lock, 1998). Pharmacological studies in young *adult* women found conflicting evidence of benefit from antidepressants for anorexia and some reduction in the frequency of binge eating and purging with tricyclic antidepressants, monoamine oxidase inhibitors, and SSRIs (see Jimerson et al., 1993; Jacobi et al., 1997). Studies mostly of adult women find cognitive-behavioral therapy and interpersonal therapy to be effective for bulimia and binge-eating disorder

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(Fairburn et al., 1993; Devlin, 1996; Becker et al., 1999). Clearly, more research is warranted for the treatment of eating disorders, especially because a sizable proportion of those with eating disorders have limited response to treatment (Kaye et al., 1999).

## Services Interventions

### Treatment Interventions

This section examines the effectiveness of such treatment interventions as outpatient, partial hospitalization/day, residential, inpatient treatments, and medication. Much of the research on their effectiveness deals with children's outcomes largely independent of diagnosis. As noted earlier in this chapter (see Treatment Strategies), practitioners and researchers previously shied away from diagnosis because of the inherent difficulty of making a diagnosis, concerns about labeling children, and the limited usefulness of DSM classifications for children. Each intervention was developed to treat a *host* of mental health conditions in children and adolescents. Each also was delivered in a wide range of settings. Over time, the combination of interventions and settings, with the exception of medication, became conceptualized as "treatments," which stimulated research on their effectiveness (Goldman, 1998). They are not, however, treatments in the conventional sense of the term because they are less specific than other treatments with respect to indications, intensity (i.e., "dose"), and elements of the intervention. There is little research describing treatment in actual clinical settings.

### Outpatient Treatment

The term "outpatient treatment" covers a large variety of therapeutic approaches, with most falling into the broad theoretical categories of the psychodynamic, interpersonal, and behavioral psychotherapy. Outpatient psychotherapy is the most common form of treatment for children and adolescents, utilized annually by an estimated 5 to 10 percent of children and their families in the United States (Burns et al., 1998). It is also the most extensively studied intervention and, with over 300 studies, has the

strongest research base (Weisz et al., 1998). Outpatient therapy is offered to individuals, groups, or families, usually in a clinic or private office. The duration of treatment varies from 6 to 12 weekly sessions to a year or longer. Newer outpatient interventions (e.g., case management, home-based therapy) that were developed more recently for youth with severe disorders are provided with greater frequency (i.e., daily) in the home, school, or community. Those interventions are reviewed later in this chapter.

The strongest support for the effectiveness of outpatient treatment comes from a series of meta-analyses. Meta-analyses are an important type of research methodology, described in Chapter 1, that enable one to combine research findings from separate studies. Nine meta-analyses, published between 1985 and 1995, probed the effectiveness of research on individual, group, and family therapy for children and adolescents (Casey & Berman, 1985; Hazelrigg et al., 1987; Weisz et al., 1987; Kazdin et al., 1990; Baer & Nietzel, 1991; Grossman & Hughes 1992; Shadish et al., 1993; Weisz & Weiss, 1993; Weisz et al., 1995). Although these meta-analyses vary in time period, age groups, and meta-analytic approach, they were largely restricted to studies of treatment given in a research clinical setting, and their findings are relatively consistent. The major findings indicated that the improvements with outpatient therapy are greater than those achieved without treatment; the treatment is highly effective, as was found in meta-analyses of adults (Brown, 1987); and the effects of treatment are similar, whether applied to problems such as anxiety, depression, or withdrawal (internalizing problems) or to hyperactivity and aggression (externalizing problems) (Kazdin, 1996).

Given strong evidence of efficacy for outpatient treatment, the question of applicability to real-world settings has been examined. A meta-analysis was performed on studies of the effectiveness of various types of outpatient treatment, regardless of whether their efficacy had been established through research (Weisz et al., 1995). The researchers were able to identify only nine studies of treated children in nonresearch clinical settings where therapy was a

regular service of the clinic and was carried out by practicing clinicians. Those nine studies demonstrated little or no effect. Clearly, real-world therapy was found to be less effective than that provided through a research protocol. A variety of factors may account for the gap, including less attention in real-world settings to careful matching of patients with treatments, less adherence to a treatment protocol, and less followup care.

### ***Partial Hospitalization/Day Treatment***

Partial hospitalization, also called day treatment and partial care, has been a growing treatment modality for youth with mental disorders. Research on partial hospitalization as an alternative to inpatient treatment generally finds benefit from a structured daily environment that allows youth to return home at night to be with their family and peers.

Partial hospitalization is a specialized and intensive form of treatment that is less restrictive than inpatient care but is more intensive than the usual types of outpatient care (i.e., individual, family, or group treatment). The most frequently used type of partial hospitalization is an integrated curriculum combining education, counseling, and family interventions. The setting, be it a hospital, school, or clinic, may be tied to the theoretical orientation of the treatment, which ranges from psychoanalytic to behavioral. Partial hospitalization has also been used as a transitional service after either psychiatric hospitalization or residential treatment, at the point when the child no longer needs 24-hour care but is not ready to be integrated into the school system. It also is used to prevent institutional placement.

Overall, the research literature points to positive gains from adolescent use of day treatment, but most of the studies are uncontrolled. Gains relate to academic and behavioral improvement; reduction in, or delay of, hospital and residential placement; and a return to regular school for about 75 percent of patients (Baenen et al., 1986; Gabel & Finn, 1986). Day treatment programs are not being used as frequently as they might be because third-party payers are reluctant to support this form of treatment. They claim that the modality is

ambiguous, that it induces demand among those who would not otherwise seek treatment, and that its length, treatment outcomes, and costs are unpredictable (Kiser et al., 1986). Research is needed to address these issues.

To date, the only controlled study of partial hospitalization compared outcomes for young children (ages 5 to 12) with disruptive behavior disorders who received intensive day treatment with children who received traditional outpatient treatment services (in fact, a waiting list control) (Grizenko et al., 1993). The results at 6 months favored day treatment in reducing behavior problems, decreasing symptoms, and improving family functioning.

Findings from uncontrolled studies of partial hospitalization are informative, although not conclusive. Based on approximately 20 studies, multiple benefits have been reported even over the long term (see reviews by Kutash & Rivera, 1996; Grizenko, 1997). In general, child behavior and family functioning improve following partial hospitalization. Findings for improved academic achievement are mixed and possibly suggest that implementation of school-based models should be considered. About three-fourths of youth are reintegrated into regular school, often with the help of special education or other school- or community-based services. Several uncontrolled studies found that day treatment could prevent youth from entering other costly placements (particularly inpatient and residential treatment centers), which suggests that partial hospitalization may reduce overall costs of treatment (Kutash & Rivera, 1996). Finally, family participation during and following day treatment is essential to obtaining and maintaining results (Kutash & Rivera, 1996).

### ***Residential Treatment Centers***

Residential treatment centers are the second most restrictive form of care (next to inpatient hospitalization) for children with severe mental disorders. Although used by a relatively small percentage (8 percent) of treated children, nearly one-fourth of the national outlay on child mental health is spent on care in these settings (Burns et al., 1998).

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However, there is only weak evidence for their effectiveness.

A residential treatment center (RTC) is a licensed 24-hour facility (although not licensed as a hospital), which offers mental health treatment. The types of treatment vary widely; the major categories are psychoanalytic, psychoeducational, behavioral management, group therapies, medication management, and peer-cultural. Settings range from structured ones, resembling psychiatric hospitals, to those that are more like group homes or halfway houses. While formerly for long-term treatment (e.g., a year or more), RTCs under managed care are now serving more seriously disturbed youth for as briefly as 1 month for intensive evaluation and stabilization.

Concerns about residential care primarily relate to criteria for admission; inconsistency of community-based treatment established in the 1980s; the costliness of such services (Friedman & Street, 1985); the risks of treatment, including failure to learn behavior needed in the community; the possibility of trauma associated with the separation from the family; difficulty reentering the family or even abandonment by the family; victimization by RTC staff; and learning of antisocial or bizarre behavior from intensive exposure to other disturbed children (Barker, 1998). These concerns are discussed below.

In the past, admission to an RTC has been justified on the basis of community protection, child protection, and benefits of residential treatment per se (Barker, 1982). However, none of these justifications have stood up to research scrutiny. In particular, youth who display seriously violent and aggressive behavior do not appear to improve in such settings, according to limited evidence (Joshi & Rosenberg, 1997). One possible reason is that association with delinquent or deviant peers is a major risk factor for later behavior problems (Loeber & Farrington, 1998). Moreover, community interventions that target change in peer associations have been found to be highly effective at breaking contact with violent peers and reducing aggressive behaviors (Henggeler et al., 1998). Although removal from the community for a time may be necessary for some, there is evidence that highly targeted behavioral

interventions provided on an outpatient basis can ameliorate such behaviors (Brestan & Eyberg, 1998). For children in the second category (i.e., those needing protection from themselves because of suicide attempts, severe substance use, abuse, or persistent running away), it is possible that a brief hospitalization for an acute crisis or intensive community-based services may be more appropriate than an RTC. An intensive long-term program such as an RTC with a high staff to child ratio may be of benefit to some children, especially when sufficient supportive services are not available in their communities. In short, there is a compelling need to clarify criteria for admission to RTCs (Wells, 1991). Previous criteria have been replaced and strengthened (i.e., with an emphasis on resources needed after discharge) by the National Association of Psychiatric Treatment Centers for Children (1990).

The evidence for outcomes of residential treatment comes from research published largely in the 1970s and 1980s and, with three exceptions, consists of uncontrolled studies (see Curry, 1991).

Of the three controlled studies of RTCs, the first evaluated a program called Project Re-Education (Re-Ed). Project Re-Ed, a model of residential treatment developed in the 1960s, focuses on training teacher-counselors, who are backed up by consultant mental health specialists. Project Re-Ed schools are located within communities, facilitating therapeutic work with the family and allowing the child to go home on weekends. Camping also is an important component of the program, inspired by the Outward Bound Schools in England. The first published study of Project Re-Ed compared outcomes for adolescent males in Project Re-Ed with untreated disturbed adolescents and with nondisturbed adolescents. Treated adolescents improved in self-esteem, control of impulsiveness, and internal control compared with untreated adolescents, according to ratings by Project Re-Ed staff and by families (Weinstein, 1974). A 1988 followup study of Project Re-Ed found that when adjustment outcomes were maintained at 6 months after discharge from Project Re-Ed, those outcomes were predicted more by community factors at admission (e.g., condition of the family and school, supportiveness of the local

community) than by client factors (e.g., diagnosis, school achievement, age, IQ). This suggested that interventions in the child's community might be as effective as placement in the treatment setting (Lewis, 1988).

The only other controlled study compared an RTC with therapeutic foster care through the Parent Therapist Program. Both client groups shared comparable backgrounds and made similar progress in their respective treatment program. However, the residential treatment cost twice as much as therapeutic foster care (Rubenstein et al., 1978).

Despite strong caveats about the quality, sophistication, and import of uncontrolled studies, several consistent findings have emerged. For most children (60 to 80 percent), gains are reported in areas such as clinical status, academic skills, and peer relationships. Whether gains are sustained following treatment appears to depend on the supportiveness of the child's post-discharge environment (Wells, 1991). Several studies of single institutions report maintenance of benefits from 1 to 5 years later (Blackman et al., 1991; Joshi & Rosenberg, 1997). In contrast, a large longitudinal six-state study of children in publicly funded RTCs found at the 7-year followup that 75 percent of youth treated at an RTC had been either readmitted to a mental health facility (about 45 percent) or incarcerated in a correctional setting (about 30 percent) (Greenbaum et al., 1998).

In summary, youth who are placed in RTCs clearly constitute a difficult population to treat effectively. The outcomes of not providing residential care are unknown. Transferring gains from a residential setting back into the community may be difficult without clear coordination between RTC staff and community services, particularly schools, medical care, or community clinics. Typically, this type of coordination or aftercare service is not available upon discharge. The research on RTCs is not very enlightening about the potential to substitute RTC care for other levels of care, as this requires comparisons with other interventions. Given the limitations of current research, it is premature to endorse the effectiveness of residential treatment for adolescents. Moreover, research is needed

to identify those groups of children and adolescents for whom the benefits of residential care outweigh the potential risks.

### *Inpatient Treatment*

Inpatient hospitalization is the most restrictive type of care in the continuum of mental health services for children and adolescents. Questions about excessive and inappropriate use of hospitals were raised in the early 1980s (Knitzer, 1982) and clearly documented thereafter in rising admission rates from the 1980s into the mid-1990s, without evidence of increased social or clinical need for such treatment (Weller et al., 1995). Inpatient care consumes about half of child mental health resources, based on the latest estimate available (Burns, 1991), but it is the clinical intervention with the weakest research support. Nevertheless, because some children with severe disorders *do* require a highly restrictive treatment environment, hospitals are expected to remain an integral component of mental health care (Singh et al., 1994). More concerted attention to the risks and benefits of hospital use is critical, however, along with development of community-based alternative services.

Research on inpatient treatment mostly consists of uncontrolled studies (Curry, 1991). Factors that are likely to predict benefit have been identified from such studies. Beneficial factors were found to include higher child intelligence; the quality of family functioning and family involvement in treatment; specific characteristics of treatment (e.g., completion of treatment program and planned discharge); and the use of aftercare services. Neither age nor gender affected prognosis after hospitalization. The prognosis was poor for several clinical characteristics, including children with a psychotic diagnosis and antisocial features with conduct disorder (Kutash & Rivera, 1996).

Only three controlled studies evaluated the effectiveness of inpatient treatment: one that randomized antisocial children to specific interventions on an inpatient unit (Kazdin et al., 1987a, 1987b) and two older clinical trials (Flomenhaft, 1974; Winsberg et al., 1980). All three studies demonstrated that community care was at least as effective as inpatient treatment.

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More recently there have been preliminary favorable findings from a randomized trial of inpatient treatment versus multisystemic therapy (MST), an intensive home-based intervention. For example, MST was more effective than psychiatric hospitalization in reducing antisocial behavior, improving family structure and cohesion, improving social relationships, and keeping children in school and out of institutions (after the initial period when the control group was in the hospital). Hospitalized youth reported improved self-esteem, and youth in both treatment conditions showed comparable decreases in emotional distress (Henggeler et al., 1998). A great deal more research is needed on inpatient hospitalization, as it is by far the costliest and most restrictive form of care. Recent changes in health care management have resulted in short lengths of stay for children and adolescents. Preliminary results from the study of MST indicate that intensive home-based services may be a viable alternative to hospitalization. However, even when such services are available, there may be a need for brief 24-hour stabilization units for handling crises (see Crisis Services).

### Newer Community-Based Interventions

Since the 1980s, the field of children's mental health has witnessed a shift from institutional to community-based interventions. The forces behind this transformation are presented in a subsequent section, Service Delivery. This section attempts to answer the question of whether community-based interventions are effective. It covers a range of comprehensive community-based interventions, including case management, home-based services, therapeutic foster care, therapeutic group homes, and crisis services. Although the evidence for the benefits of some of these services is uneven at best, even uncontrolled studies offer a starting point for studying the effectiveness and feasibility of their implementation. Many of the evaluations to date offer a first glimpse into the benefits of these services and the extent to which they may be valuable for further examination. Of these interventions, the most convincing evidence of effectiveness

is for home-based services and therapeutic foster care, as discussed below.

There is a special emphasis throughout this section on "children with serious emotional disturbances," as many of these community-based services are targeted to this population of the most serious severely affected children. The term serious emotional disturbance refers to a diagnosed mental health problem that substantially disrupts a child's ability to function socially, academically, and emotionally. It is not a formal DSM-IV diagnosis but rather a term that has been used both within states and at the Federal level to identify a population of children with significant functional impairment due to mental, emotional, and behavioral problems who have a high need for services. The official definition of children with serious emotional disturbance adopted by the Substance Abuse and Mental Health Services Administration is "persons from birth up to age 18 who currently or at any time during the past year had a diagnosable mental, behavioral, or emotional disorder of sufficient duration to meet diagnostic criteria specified within the DSM-III-R, and that resulted in functional impairment which substantially interferes with or limits the child's role or functioning in family, school, or community activities" (SAMHSA, 1993, p. 29425).<sup>15</sup> The term is used in a variety of Federal statutes in reference to children fitting that description and does not signify any particular diagnosis per se; rather, it is a legal term that triggers a host of mandated services to meet the needs of these children (see Service Delivery section).

### Case Management

Case management is an important and widespread component of mental health services, especially for children with serious emotional disturbances. The main purpose of case management is to coordinate the provision of services for individual children and their families who require services from multiple service providers. Case managers take on roles ranging from brokers of services to providers of clinical services.

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<sup>15</sup> This definition is also used with newer diagnostic systems, such as DSM-IV.

There is a considerable amount of variation in models of case management. In one important model, called "wraparound," case managers involve families in a participatory process of developing an individualized plan focusing on individual and family strengths in multiple life domains. Research on wraparound is still in its early stages (Burns & Goldman, 1999).

There have been controlled studies of three programs that used case managers who work individually rather than as part of an interdisciplinary team (discussed later). In one study of the Partner's Project in Oregon, case management was compared with "usual services," which did not include case management (Gratton et al., 1995). The authors found at 1-year followup that children in the Partner's Project scored significantly higher on measures of social competence and had received more individualized, comprehensive services, and a greater degree of service coordination.

The second study compared the outcomes of intensive case management and regular case management for mentally ill homeless children in Seattle (Cauce et al., 1994). The case managers in the intensive condition had lower caseloads, were required to spend more hours supervising the youth, had flexible funds (for clothing, transportation, etc.) at their disposal, spent more hours in consultation with psychologists, and were of higher educational status. After 1 year, the study found that both groups showed substantial yet similar improvement in mental health and social adjustment.

A model known as Children and Youth Intensive Case Management (CYICM) was evaluated in two controlled studies. The program has been described as an Expanded Broker Model, which means that the case manager, in addition to brokering services, is responsible for assessment, planning, linking, and advocating on behalf of the youth and family. Case managers, with caseloads of 10 children, are given \$2,000 of flexible funds per child each year to purchase treatment and ancillary services (e.g., transportation and educational aids). In the first study, the authors

found that children in the program spent significantly more days in the community between episodes of psychiatric hospitalization and were hospitalized for fewer days than before enrollment (Evans et al., 1994). A subsequent study evaluated a random sample of 199 children enrolled in CYICM (Evans et al., 1996b). Findings at 3-year followup indicated significant behavioral improvements and decreases in unmet medical, recreational, and educational needs compared with findings at enrollment. As in the previous study, children who had been in CYICM for 2 years had spent fewer days in psychiatric hospitals and more days in community settings during the intervals between hospitalizations. This study went further to compare their hospital utilization with that by children not enrolled in the program. Although CYICM clients spent more days in psychiatric hospitals before enrollment, they used inpatient services after enrollment significantly less than did non-enrollees. CYICM clients' hospital admissions declined fivefold after enrollment whereas among non-enrollees the decline in admission rates was less than half that value. This difference translated into a savings of almost \$8,000,000 for New York State, where the project took place.

Some research has investigated the effects of extending case management on children with a dual diagnosis of a mental disorder and a substance abuse problem. Within the CYICM program, researchers looked at whether adolescents with mental disorders and substance abuse problems derived comparable benefits from the program as did those without substance abuse problems (Evans et al., 1992). No significant differences were found in the average number of inpatient admissions both before and after enrollment. There was also no significant difference between groups in the average decrease from pre- to postenrollment in the number of days spent in hospitals. These results indicate that case management can be as effective for youth presenting with substance abuse problems as for youth presenting with other psychiatric disorders.

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### *Team Approaches to Case Management*

Several studies assessed the value of case management as part of a treatment team. In a randomized trial in North Carolina (Burns et al., 1996), youth served by an interdisciplinary treatment team led by a case manager were compared with a control group of youth served by a treatment team led by their primary clinician in the role of case manager (also called clinician case manager). At 1-year followup, case managers in the experimental group reported spending significantly more time with their clients, as well as significantly more time on the core functions of case management (e.g., outreach; assessment of strengths, needs, and resources; service planning and monitoring; linking, referral, and advocacy; and crisis intervention). The experimental group also remained in the case-managed program longer, spent fewer days in psychiatric hospitals, and received more community-based services and a more comprehensive array of services. Although both groups showed similar clinical and functional improvements, parents of youth in the experimental group reported more satisfaction with the service system. The study concluded that traditional case managers, rather than clinician case managers, provide a more cost-effective method for attaining positive behavioral outcomes and access to mental health services.

Another example of a team approach to case management is the Family Centered Intensive Case Management (FCICM) program. This was originally created as a variation of Child and Youth Intensive Case Management in New York, with the later addition of a wraparound approach. The wraparound approach is based on a belief that the child and family should be placed at the center of an array of coordinated health and mental health, educational, and other social welfare services and resources, which a case manager wraps around the patient and family. In a randomized trial, children were assigned to either FCICM or Family-Based Treatment (Evans et al., 1996a). Family-Based Treatment included training, support, and respite care for foster families but did not include case managers.

The findings at 18 months (or at discharge) indicated that children in FCICM had significantly fewer behavioral symptoms and significantly greater improvements in overall functioning than those in Family-Based Treatment. In addition, the average annual cost of FCICM was less than half that of Family-Based Treatment.

The Fostering Individualized Assistance Program (FIAP) is an example of case management provided through a wraparound approach. The effectiveness of this model, which used clinical case managers, was compared with standard foster care in a randomized trial involving 131 children and their families (Clark et al., 1998). The most important duty of the FIAP case managers was to arrange monthly team meetings for the monitoring of individualized service plans. Although both groups showed significant improvement in their behavioral adjustment over a 3½-year period, children in the FIAP group were less likely to change placements, and boys in the group reported better social adjustment and fewer delinquencies. Older youth in the group were more likely to maintain placements in homes of relatives and less likely to run away. Youth in FIAP were also absent from school less often and spent fewer days suspended from school. Overall, youth in the FIAP group showed more improvement than did youth in standard foster care. Multiple uncontrolled studies of case management using a wraparound approach were summarized in a recent monograph focusing on the wraparound process (Burns & Goldman, 1999). Overall, the reviewed studies, although using uncontrolled methods, offer emerging evidence of the potential effectiveness of case management using a wraparound process.

While evidence is limited and many of the positive outcomes focus on service use rather than clinical status, there is some indication that case management is an effective intervention for youth with serious emotional disturbances. Studies in this area are difficult to conduct because of resource limitations and of varying approaches to case management. Agreement on standards for specific case management models is

needed in order to proceed with efficient and reliable controlled research in this area. In addition, future research needs to address the issue of cost-effectiveness, as some evidence presented above has shown savings from less utilization of institutional care.

### ***Home-Based Services***

This section describes the strong record of effectiveness for home-based services, which provide very intensive services within the homes of children and youth with serious emotional disturbances. A major goal is to prevent an out-of-home placement (i.e., in foster care, residential, or inpatient treatment). Home-based services are usually provided through the child welfare, juvenile justice, and/or mental health systems. They are also referred to as in-home services, family preservation services, family-centered services, family-based services, or intensive family services.

Stroul (1988) identified three major goals of home-based services: to preserve the family's integrity and prevent unnecessary out-of-home placements; to put adolescents and their families in touch with community agencies and individuals, thus creating an outside support system; and to strengthen the family's coping skills and capacity to function effectively in the community after crisis treatment is completed. The specific services provided most often include evaluation, assessment, counseling, skills training, and coordination of services. The historical evolution of home-based services is discussed further under Support and Assistance for Families in Service Delivery.

The evidence for the benefits of home-based services was recently evaluated in a meta-analysis of controlled studies only (Fraser et al., 1997). The analysis referred to home-based services as "family preservation services"; these were sponsored either by the child welfare or juvenile justice systems. For 22 studies the authors analyzed specific measures such as out-of-home placement, family reunification, arrest, incarceration, and hospitalization, with the control group defined as youth receiving "usual" or "routine" services. While a majority of the studies demonstrated marginal gains in effectiveness, other services appeared to be significantly more effective than usual services.

The findings are presented below according to their organizational sponsorship by either child welfare or juvenile justice system.

### *Family Preservation Programs Under the Child Welfare System*

Within the child welfare system, particularly effective family reunification programs were the Homebuilders Program in Tacoma, Washington, which was designed to reunify abused and neglected children with their families by providing family-based services (Fraser et al., 1996), and the family reunification programs in Washington State and in Utah (Pecora et al., 1991). Studies suggested that 75 to 90 percent of the children and adolescents who participated in such programs subsequently did not require placement outside the home. The youths' verbal and physical aggression decreased, and cost of services was reduced (Hinckley & Ellis, 1985). The success of these family preservation programs is based on the following: services are delivered in a home and community setting; family members are viewed as colleagues in defining a service plan; back-up services are available 24 hours a day; skills are built according to the individual needs of family members; marital and family interventions are offered; community services are efficiently coordinated; and assistance with basic needs such as food, housing, and clothing is given (Fraser et al., 1997).

### *Multisystemic Therapy*

Multisystemic therapy programs within the juvenile justice system have demonstrated effectiveness. MST is an intensive, short-term, home- and family-focused treatment approach for youth with severe emotional disturbances. MST was originally based on risk factors that were identified in the published literature and was designed for delinquents. MST intervenes directly in the youth's family, peer group, school, and neighborhood by identifying and targeting factors that contribute to the youth's problem behaviors. The main goal of MST is to develop skills in both parents and community organizations affecting the youth that will endure after brief (3 to 4 months) and intensive

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treatment. MST was constructed around a set of principles that were put into practice and then expanded upon in a manual (Henggeler et al., 1998). Elaborate training, supervision, and monitoring for treatment adherence make this an exemplary approach. Furthermore, publication of an MST manual and the high level of clinical training in MST distinguish this model from other types of family preservation services.

The efficacy of MST has been established in three randomized clinical trials for delinquents within the juvenile justice system. The first of these studies took place in Memphis, Tennessee, and revealed that MST was more effective than usual community services in decreasing adolescent behavioral problems and in improving family relations (Henggeler et al., 1986). The second was conducted in Simpsonville, South Carolina, and compared outcomes for 84 juvenile offenders randomly assigned to either MST or usual services. At 59 weeks after referral, youth who had received MST had fewer arrests and self-reported offenses and had spent an average of 10 fewer weeks incarcerated than did the youth in usual services. In addition, families served by MST reported increased family cohesion and decreased youth aggression in peer relations (Henggeler et al., 1992). In the third study, MST was compared with individual therapy in Columbia, Missouri, and was found to be more effective in ameliorating adjustment problems in individual family members. A 4-year followup of rearrest data indicated that MST was more effective than individual therapy in preventing future criminal behavior, including violent offenses (Borduin et al., 1995). Studies found improved behavior, fewer arrests, and lower costs. These findings encouraged the investigators to test the effectiveness of MST in other organizational settings (e.g., child welfare and mental health), allowing them to target other clinical populations, including youthful sex offenders (Borduin et al., 1990), abused and neglected youth (Brunk et al., 1987), and child psychiatric inpatients (see Inpatient Treatment section). Initial results are promising for youth receiving MST instead of psychiatric hospitalizations (Henggeler et al., 1998). As expected, some adjustments to MST are required to handle

children who are dangerous to themselves and who do not respond as quickly to treatment as the delinquent youth in previous studies. The efficacy of MST was demonstrated in real-world settings but only by one group of investigators; thus, the results need to be reproduced by others and future effectiveness research needs to determine whether the same benefits can be demonstrated with less support from experts.

### *Therapeutic Foster Care*

Therapeutic foster care is considered the least restrictive form of out-of-home therapeutic placement for children with severe emotional disorders. Care is delivered in private homes with specially trained foster parents. The combination of family-based care with specialized treatment interventions creates “a therapeutic environment in the context of a nurturant family home” (Stroul & Friedman, 1988). These programs, which are often funded jointly by child welfare and mental health agencies, are responsible for arranging for foster parent training and oversight. Although the research base is modest compared with other widely used interventions, some studies have reported positive outcomes, mostly related to behavioral improvements and movement to even less restrictive living environments, such as traditional foster care or in-home placement.

While therapeutic foster care programs vary considerably, they have some features in common. Children are placed with foster parents who are trained to work with children with special needs. Usually, each foster home takes one child at a time, and caseloads of supervisors in agencies overseeing the program remain small. In addition, therapeutic foster parents are given a higher stipend than that given to traditional foster parents, and they receive extensive preservice training and in-service supervision and support. Frequent contact between case managers or care coordinators and the treatment family is expected, and additional resources and traditional mental health services may be provided as needed.

Therapeutic foster care programs are inexpensive to start (few requirements for facilities or salaried staff) and have lower costs than more restrictive programs. In

Ontario, a study found that therapeutic foster care cost half that of residential treatment center placement for the same period of time (Rubenstein et al., 1978).

There have been four efficacy studies, each with randomized, controlled designs. In the first study, 20 youths who had been previously hospitalized were assigned to either therapeutic foster care or other out-of-hospital settings, such as residential treatment centers or homes of relatives. The youths in therapeutic foster care showed more improvements in behavior and lower rates of reinstitutionalization, and the costs were lower than those in other settings (Chamberlain & Reid, 1991). In another study, which concentrated on youths with histories of chronic delinquency, those in therapeutic foster care were incarcerated less frequently and for fewer days per episode than youths in other residential placements. Thus, at 2-year followup, 44 percent fewer children in therapeutic foster care were incarcerated (Chamberlain & Weinrott, 1990). In a third study, outcomes for children in therapeutic foster care were compared with those of children in standard foster care. Children in therapeutic foster care were less likely during a 2-year study to run away or to be incarcerated and showed greater emotional and behavioral adjustment (Clark et al., 1994). In the most recent study, therapeutic foster care was compared with group care: children receiving the former showed significantly fewer criminal referrals, returned to live with relatives more often, ran away less often, and were confined to detention or training schools less often (Chamberlain & Reid, 1998).

All four studies of treatment effectiveness showed that youths in therapeutic foster care made significant improvements in adjustment, self-esteem, sense of identity, and aggressive behavior. In addition, gains were sustained for some time after leaving the therapeutic foster home (Bogart, 1988; Hawkins et al., 1989; Chamberlain & Reid, 1991).

There are also promising indications from uncontrolled studies. Looking at 18 reports from 12 therapeutic foster care programs across the country, Kutash and Rivera (1996) concluded that between about 60 and 90 percent of youth treated in therapeutic foster homes are discharged to less restrictive settings.

Three programs also reported followup data, indicating that about 70 percent of youth treated in therapeutic foster homes remained in less restrictive settings for a substantial amount of time after treatment.

It is clear from these studies that therapeutic foster care produces better outcomes at lower costs than more restrictive types of placement. Furthermore, with the fairly recent development of standards for therapeutic foster care, as well as a standards review instrument (Foster Family-Based Treatment Association, 1995), services can be monitored for quality and fidelity to the therapeutic approach, making it easier to ascertain if the approach taken produces the favorable outcomes.

### *Therapeutic Group Homes*

For adolescents with serious emotional disturbances the therapeutic group home provides an environment conducive to learning social and psychological skills. This intervention is provided by specially trained staff in homes located in the community, where local schools can be attended. Each home typically serves 5 to 10 clients and provides an array of therapeutic interventions. Although the types and combinations of treatment vary, individual psychotherapy, group therapy, and behavior modification are usually included.

There are two major models of therapeutic group homes. The first is the teaching family model, developed at the University of Kansas, then moved to Boys Town in Omaha, Nebraska (Phillips et al., 1974). The second is the Charley model, developed at the Menninger Clinic. Both models use their staff as the key agents for change in the disturbed youth; selection and training of the staff are emphasized. Both models employ couples who live at the homes 24 hours a day. The teaching family model emphasizes structured behavioral interventions through teaching new skills and positively reinforcing improved behavior. Other group homes use individual psychotherapy and group interaction.

There is a dearth of research on the effectiveness of therapeutic group home programs targeted toward emotionally disturbed adolescents. These homes have been developed primarily for children under the care of

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juvenile justice or social welfare. A dissertation (Roose, 1987) studied the outcomes of 20 adolescents treated in a group home. Adolescents with severe character pathology or major psychiatric disorders were not admitted. Twenty group home adolescents were compared with 20 untreated adolescents. At an 18-month followup, 90 percent of the treated group had fair or good functioning, defined by improved relationships with parents, peers, and fellow workers. Only 45 percent of the untreated group achieved similar functioning. The treated group experienced a significant decrease in psychopathology, while the untreated group did not.

Therapeutic group homes were compared with therapeutic foster care in two studies. The first study found equivalent gains for youth in the two interventions, but group home placement was twice as costly as therapeutic foster care (Rubenstein et al., 1978). A second study, a randomized clinical trial, compared the outcomes for 79 males with histories of juvenile delinquency placed in either group homes or therapeutic foster homes (Chamberlain & Reid, 1998). The boys treated in therapeutic foster homes had significantly fewer criminal referrals and returned more often to live with relatives, suggesting this to be a more effective intervention. The implication of these studies is that if therapeutic foster care is available, and if the foster parents are willing to take youth with serious behavioral problems, therapeutic foster care may be a better treatment choice for youth who previously would have been placed in group homes.

Existing research suggests that therapeutic group home programs produce positive gains in adolescents while they are in the home, but the limited research available reveals that these changes are seldom maintained after discharge (Kirigin et al., 1982). The conclusion may be similar to that for residential treatment center placement: long-term outcomes appear to be related to the extent of services and support after discharge. Adolescents who have been placed in therapeutic group homes because of mental disorders frequently have histories of multiple prior placements (particularly in foster homes), a situation that is associated with a poor prognosis. Thus, future

programs would benefit from assessing alternative strategies for treatment after discharge from group homes.

### Crisis Services

Crisis services are used in emergency situations either to furnish immediate and sufficient care or to serve as a transition to longer term care within the mental health system. These services are extremely important because many youth enter the mental health service system at a point of crisis. Crisis services include three basic components: (1) evaluation and assessment, (2) crisis intervention and stabilization, and (3) followup planning. The goals of crisis services include intervening immediately, providing brief and intensive treatment, involving families in treatment, linking clients and families with other community support services, and averting visits to the emergency department or hospitalization by stabilizing the crisis situation in the most normal setting for the adolescent. Crisis services include telephone hotlines, crisis group homes, walk-in crisis intervention services, runaway shelters, mobile crisis teams, and therapeutic foster homes when used for short-term crisis placements.

Crisis programs are small in order to facilitate close relationships among the staff, child, and family. Crisis staff are required to have skills and experience in the areas of assessment, emergency treatment, and family support. Short-term services are provided, with the staff meeting more frequently with the client at the outset of the crisis. A typical treatment plan consists of 10 sessions over a period of 4 to 6 weeks. Crisis services usually are available 24 hours a day, 7 days a week (Goldman, 1988).

Research on crisis services consists exclusively of uncontrolled studies. Kutash and Rivera (1996) reviewed 12 studies with pre-post<sup>16</sup> designs. Positive behavioral and adjustment outcomes for youth presenting to crisis programs and emergency departments across the country were reported in all of

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<sup>16</sup> Pre-post design: a research design in which a measure is compared on the same individual research subjects before and after an intervention.

the studies. Most programs also demonstrated the capacity to prevent institutionalization.

The most recent studies examine three different models: a mobile crisis team, short-term residential services, and intensive in-home service. The first study examined the Youth Emergency Services (YES) program in New York. This program included a mobile crisis team that sent clinicians directly to the scene of the crisis. The data showed that YES prevented emergency department visits and out-of-home placements (Shulman & Athey, 1993).

A second crisis program, in Suffolk County, New York, involved short-term residential services. In a study of 100 children served by the program over a 2-year period, more than 80 percent were discharged in less than 15 days. Most were diverted from inpatient hospitalization, and inpatient admissions to the state children's psychiatric center for Suffolk County were reduced by 20 percent after the program was established (Schweitzer & Dubey, 1994).

In the third study, records were analyzed from a large sample of youth (nearly 700) presenting to the Home Based Crisis Intervention (HBCI) program in New York over a 4-year period. Youth received short-term, intensive, in-home emergency services. After an average service episode of 36 days, 95 percent of the youth were referred to, or enrolled in, other services (Boothroyd et al., 1995). The HBCI program was established at eight locations across the State of New York. Overall, programs with more access to community resources reported shorter average lengths of services.

Although crisis and emergency services represent a promising intervention, the research done so far only includes uncontrolled studies, limiting the conclusions that can be drawn. Kutash and Rivera (1996) recommend additional effectiveness research using controlled study designs and comparing differences between the various types of crisis services. Finally, there remains a need for investigation of cost-effectiveness as well as an exploration of the integration of crisis services into systems of care.

## Service Delivery

The focus of this section is on service systems—their origins, nature, and financing and also their effectiveness, delivery, and utilization—rather than on individual interventions and treatments, which were covered in previous sections of this chapter.

About 20 years ago it became clear that children and families were failing to receive adequate care from the public sector, whose services were fragmented, inadequate, and overreliant on institutional care. As a result, the emphasis of service delivery has shifted to systems of care that are designed to provide culturally competent, coordinated services; community-based services; new financing arrangements in the private and public sectors; family participation in decisionmaking about care for their children; and individualized care drawing on treatment and social supports called wraparound services, described above. Thus, there has been progress in transforming the nature of service delivery and its financing, but the central question of the effectiveness of systems of care has not yet been resolved.

At the outset, it is important to note that while systems of care are designed to provide the appropriate level of services for all children, it is children with serious emotional disturbances, particularly children who are involved in multiple service sectors, who are likely to benefit the most. There are approximately 6 million to 9 million children and adolescents in the United States with serious emotional disturbances (Friedman et al., 1996a; Lavigne et al., 1996), accounting for 9 to 13 percent of all children (Friedman et al., 1996a; Friedman et al., 1998).

The system for delivering mental health services to children and their families is complex, sometimes to the point of inscrutability—a patchwork of providers, interventions, and payers. Much of the complexity stems from the multiple pathways into treatment and the multiple funding streams for services. However, once care has begun, the interventions and settings themselves are generally the same as those covered in previous sections of this chapter.

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### **Service Utilization**

This section presents research findings about the utilization of mental health services by children and adolescents. The foremost finding is that most children in need of mental health services do not get them. Another finding refutes the common perception that children who do not need specialty mental health services are more likely to receive such services than those who really do need them. This section also discusses children's high dropout rates from treatment and the significance of this problem for children of different cultural backgrounds.

### ***Utilization in Relation to Need***

The conclusion that a high proportion of young people with a diagnosable mental disorder do not receive any mental health services at all (Burns et al., 1995; Leaf et al., 1996) reinforces an earlier report by the U.S. Office of Technology Assessment (1986), which indicated that approximately 70 percent of children and adolescents in need of treatment do not receive mental health services. Only one in five children with a serious emotional disturbance used mental health specialty services, although twice as many such children received some form of mental health intervention (Burns et al., 1995). Thus, about 75 to 80 percent fail to receive specialty services, and the majority of these children fail to receive any services at all, as reported by their families. The most likely reasons for underutilization relate to the perceptions that treatments are not relevant or are too demanding or that stigma is associated with mental health services; the reluctance of parents and children to seek treatment; dissatisfaction with services; and the cost of treatment (Pavuluri et al., 1996; Kazdin et al., 1997).

Studies do, however, demonstrate a clear and strong relationship between use of services and presence of a diagnosis and/or presence of impaired functioning. In the study by Leaf and colleagues (1996), young people with both a diagnosis and impaired functioning were 6.8 times more likely to see a specialist than were those with no diagnosis and a higher level of functioning.

The study by Burns and colleagues also showed where children were receiving treatment. Of those who received services and had both a diagnosis and impaired functioning, about 40 percent received services in the specialty mental health sector, about 70 percent received services from the schools, about 11 percent from the health sector, about 16 percent from the child welfare sector, and about 4 percent from the juvenile justice sector. For nearly half the children with serious emotional disturbances who received services, the public school system was the sole provider (Burns et al., 1995). After reviewing these findings and the findings from other studies, Hoagwood and Erwin (1997) also concluded that schools were the primary providers of mental health services for children.

### ***Early Termination of Treatment***

Among children and adolescents who begin treatment, the dropout rate is high, although estimates vary considerably. According to Kazdin and colleagues (1997), 40 to 60 percent of families who begin treatment terminate it prematurely. Armbruster and Fallon (1994) found that the great majority of children who enter outpatient treatment attend for only one or two sessions. One of the explanations for the high dropout rate and for failure to keep the first appointment is that referrals are often made not by children and adolescents or their families, but by schools, courts, or other agencies. Most of the research on dropping out has focused exclusively on examining demographic or diagnostic correlates of dropping out, and few researchers have directly asked the children or their parents about their reasons for discontinuing treatment.

There are a number of effective interventions to reduce dropout from treatment and to increase enrollment and retention (Szapocznik et al., 1988; McKay et al., 1996; Santisteban et al., 1996). Offering services in the schools improves treatment access (Catron & Weiss, 1994). A variety of case management approaches can also improve engagement of low-income families in the treatment of their children (Burns et al., 1996; Koroloff et al., 1996a; Lambert & Guthrie, 1996).

### ***Poverty and Utilization***

Poverty status has been associated with both dropping out of services and shorter lengths of treatment (Hoberman, 1992). This relationship between underutilization of mental health services and poverty is especially significant for minority children and families. Youths receiving community mental health services supported by public agencies tend to be male, poor, and referred by social agencies (Canino et al., 1986; Costello & Janiszewski, 1990). Furthermore, investigators have found this pattern particularly true for African Americans as compared with Caucasians. Hoberman (1992) has found that 90 percent of African American youths entering the mental health system live in poverty.

### ***Culture and Utilization***

Although it is clear that an insufficient number of children receive mental health services, it is not clear whether utilization of services varies by race or ethnicity. The majority of studies have found that African Americans tend to use some mental health services, particularly inpatient care, more than would be expected from their proportion in the population. However, research findings are conflicting, probably due to divergent methodological approaches (Attkisson et al., 1995; McCabe et al., 1998; Quinn & Epstein, 1998). Furthermore, as Attkisson and colleagues (1995) point out, consistent with the study by McCabe and colleagues (1998), it is difficult to interpret these findings in the absence of epidemiologic data on the prevalence of a mental disorder in different racial and ethnic groups. Recent reviews of epidemiological findings concluded that present data are inadequate to determine the relationship between race or ethnicity and prevalence of a mental disorder (Friedman et al., 1996b; Roberts et al., 1998).

The task of understanding treatment patterns is made even more difficult because there are racial and ethnic differences in family preferences and family-initiated patterns of help-seeking (see also Culturally Appropriate Social Support Services). For example, parents from various cultural backgrounds have been found to differ in the degree to which they identify

child behavioral and emotional problems as disturbed (Weisz & Weiss, 1991). Differences also have been found across cultural groups in their beliefs about whether these child problems are likely to improve in the absence of professional support. Weisz and Weiss (1991) have also identified cultural differences in the power of various children's behavioral and emotional problems to motivate a parent's search for professional help.

Differences also arise indirectly from the multiplicity of service systems with authority and responsibility for protecting the well-being of children. These systems have different criteria for initiating treatment and different patterns of utilization. African American children and youth are considerably more likely than those of other ethnic groups to enter the child welfare system (National Research Council, 1993). Their greater chances of having parents compelled to surrender them or of suffering abuse or neglect lead them in greater numbers to be referred to child welfare authorities, to be placed out-of-home, and to be involved with the child welfare system longer. Studies in one California county have found that African American youths are overrepresented in arrests, detention, and incarceration in the juvenile justice system, and in the schools they are overrepresented in educational classes for the severely emotionally disturbed. Hispanic/Latino children and youths are no more likely than whites to come under supervision of the child welfare system but, once involved, remain longer. They are also more likely than whites to be detained in juvenile justice facilities (McCabe et al., 1998).

As a group, Hispanic/Latino and African American children more often leave mental health services prematurely than do Caucasian children (Sue et al., 1991; Bui & Takeuchi, 1992; Takeuchi et al., 1993; Viale-Val et al., 1984). Many factors contribute to premature termination, such as insensitivity of mental health providers to the culture of children and families (Woodward et al., 1992). In general, even after demonstrated success with middle-class Caucasians, mental health treatments should not be applied without

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culturally appropriate modification to people from other cultures and races (Rosado & Elias, 1993).

Specialized programs and supports linked with the culture of the community being served have been found to be successful in promoting favorable patterns of service utilization for all ages (Snowden & Hu, 1997). It is becoming clear that the children and families served by mental health programs designed to be linked to community cultures are less likely to drop out of treatment compared with similar families in mainstream programs (Takeuchi et al., 1995). For example, Asian American children at an Asian community- or culture-focused program were found to use more services, drop out less often, and improve more than did Asian American children at mainstream programs (Yeh et al., 1994).

In summarizing the relationship between race and ethnicity, need for service, and use of service, Isaacs-Shockley and colleagues (1996) raised the concern that minority children are less likely to receive the care they need than nonminority children—a concern that should energize advocacy for the development of systems of care tailored to the needs of distinct cultures (Cross et al., 1989; Hernandez & Isaacs, 1998).

### **Service Systems and Financing**

In the past, mental health services paid for by the private sector were viewed as separate entities from those funded by the public sector, particularly since the public sector only paid for services that it itself delivered. As this section explains below, the distinction between public and private sectors has been blurred by the advent of publicly supported payment systems such as Medicaid and grants of public funds to private organizations and providers. Now in the public sector, services are paid for with governmental resources but delivered either by public or private organizations in institutional or community-based settings.

#### ***Private Sector***

The private sector uses a health insurance model that reimburses for acute medical problems. Under this traditional model, mental health coverage usually

entails outpatient counseling, medication treatments, and short-term inpatient hospitalization. Under more generous insurance plans, including some managed care plans, intermediate services, such as crisis respite and day hospitalization (also called partial hospitalization or day treatment), are becoming more popular although more traditional insurance plans continue to restrict their use. The drive to reduce the cost of inpatient care is sparking an expansion in the range of services supported by the private sector.

When children and adolescents have complex and long-term mental health problems, required services are not usually covered by private sector insurance plans. Families must either pay for the services themselves or obtain the services through the public sector. In many states, parents are forced to give up custody of their children to the state child welfare system in order to obtain needed residential services (Cohen et al., 1991). This unfortunate choice results from a limited supply of public sector services and special requirements for gaining access to them.

Over the past decade, managed care has become a major payer for private health care. Managed care provision of mental health services emerged partially in response to the overutilization of costly inpatient hospitalization by adolescents in the 1980s (Lourie et al., 1996). The purpose of managed care has been to control spiraling mental health service costs, mostly by limiting hospital stays and rigorously managing outpatient service usage (Stroul et al., 1998). Managed care can offer advantages in terms of cost-effective services to meet the needs of children with flexible benefits. It may also lead to denial of needed treatment. While its potential negative effect on the efficacy of mental health care delivered under its aegis is a hotly debated issue, for the most part managed care furnishes the same traditional services available under fee-for-service insurance. The drive for efficiency, however, has led to the introduction of intermediate services designed to divert children from hospitalization. Managed care has shortened hospital stays and increased the use of short-term therapy models (Eisen et al., 1995; Merrick, 1998). Managed care also has lowered reimbursements for services provided by both

individual professionals and institutions. This has been accompanied by the construction of provider networks, under which professionals and institutions agree to accept lower than customary fees as a tradeoff for access to patients in the network.

### **Public Sector**

Mental health services provided by the public sector are more wide-ranging than those supported by the private sector, and the types of payers are more diverse. Some public agencies, such as Medicaid and state and local departments of mental health, are mandated to support mental health services. Others provide mental health services to satisfy mandates in special education, juvenile justice, and child welfare, among others.

Medicaid is a major source of funding for mental health and related support services. For the most part, Medicaid has supported the traditional mix of outpatient and inpatient services. However, unlike private sector insurance, Medicaid also funds long-term services for those children who need more intensive or restrictive services, often through hospitalizations and residential treatments. Some states cover in-home services, school-based services, and case management through a variety of Medicaid options. Medicaid also supports the Early Periodic Screening, Diagnosis, and Treatment (EPSDT) program.

Trapped between the private and public sectors is a group of uninsured individuals and families who do not qualify for the public sector programs, cannot afford to pay for services themselves, and have no access to private health insurance. The American Academy of Pediatrics estimates that in 1999 there will be 11 million uninsured children, about 3 million of whom do not qualify for existing public programs (American Academy of Pediatrics website [www.aap.org](http://www.aap.org)). State and local mental health authorities fund some mental health services for these children, often offered through the same community mental health centers that are funded by Medicaid. Mental health departments in some jurisdictions also fund a broader array of mental health services than the traditional acute service package. These "intermediate" services include intensive case management with and

without individualized wraparound provisions, early intervention programs, crisis stabilization, in-home therapy, and day programs. Since there has never been a mandate to states to provide mental health services to children and adolescents, the state or local support for such services has been variable. Thus, one might find a well-supported, innovative array of mental health services for children in one state or community, and almost no services in the next. The new State Child Health Insurance Program (CHIP) is an attempt by Congress to address the health care needs of low-income, uninsured children. States have great flexibility in their approach to coverage, and it remains to be seen how they will deal with mental health services.

States and communities have sweeping mandates to serve children and adolescents in schools and under child welfare and juvenile service auspices. Many of these state and community programs, however, lack the expertise to recognize, refer, or treat mental health problems that trigger mandated services. When they do recognize problems, some of the needed mental health services are paid for by Medicaid, by the federal Maternal and Child Block Grant, or by a state or local mental health authority; often, however, they are not. Under these circumstances, the school, welfare, or juvenile justice agency ends up paying the bill for the mental health services.

Under the Federal special education law, the Individuals with Disabilities Education Act<sup>17</sup> (IDEA; see also *New Roles for Families in Systems of Care*), school systems are mandated to provide special education services to children and adolescents whose disabilities interfere with their education. When these disabilities take the form of serious emotional or behavioral disturbances, school systems are required to respond through assessment, counseling, behavior management, and special classes or schools. When school systems lack sufficient capacity to meet such needs directly, school funds are used to send children and youths to specialized private day schools or to long-term residential schools, even if such schools are out of the child's state or community. In this way,

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<sup>17</sup> Public Law 94-142; Public Law 101-476; Public Law 105-17.

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school systems support an extensive array of mental health services in the public and private sectors.

Preschool children with developmental and emotional disabilities are covered by some state and local legislation. Services for them also are mandated under IDEA. Whereas some states coordinate this education-based mandate through school systems, others administer the preschool programs through mental health or developmental disability agencies, an interagency coordinating body, or other state agency.

Child welfare agencies in states and communities also have powerful mandates to protect children and to ensure that they receive the services they need, including mental health services. Child welfare agencies primarily serve poor children who are separated from their parents because they are orphaned, abandoned, abused, or neglected. Although many mental health services are provided either under Medicaid or through state and locally supported community mental health centers, many are not and are paid for directly by child welfare agencies. This happens most often when children and adolescents have severe, complicated conditions. As with education agencies, when funding is not available through Medicaid or other mental health funds, child welfare agencies directly pay for group home care, therapeutic foster care, or residential treatment.

The same is true for juvenile justice agencies, which have strong mandates to protect children and the public. Many children and adolescents in the juvenile justice system have serious mental health problems. Beyond the more traditional "training schools" and "detention centers," run by state and local juvenile authorities, respectively, these agencies also purchase care from the same group home, therapeutic foster care, and residential providers as do child welfare agencies.

### ***Children Served by the Public Sector***

Children needing services are identified under the auspices of five distinct types of service sectors: schools, juvenile justice, child welfare, general health, and mental health agencies. These agencies are mostly publicly supported, each with different mandates to serve various groups and to provide somewhat varied

levels of services. Many of these agencies arose historically for another purpose, only to recognize later that mental disorders cause, contribute to, or are effects of the problem being addressed. In the past, these sectors operated somewhat autonomously, with little ongoing interaction. Catalyzed by the NMHA's Invisible Children's Project (NMHA, 1987, 1993), the combined impetus of Federal policies and managed care more recently has begun to forge their integration.

Two recent review articles examined the characteristics of children served in public systems. Based on an appraisal of six prior studies, it was concluded that, in addition to emotional and behavioral functioning, these young people have problems in life domains such as intellectual and educational performance and social and adaptive behavior (Friedman et al., 1996b). Frequently, such children and their families have contact not only with the mental health system, but also with special education, child welfare, and juvenile justice (Landrum et al., 1995; Duchnowski et al., 1998; Greenbaum et al., 1998; Quinn & Epstein, 1998).

It is estimated that in a 1-year period more than 700,000 children nationwide are in out-of-home placements, mostly under the supervision of either the child welfare or to some extent the juvenile justice system (Glisson, 1996). Also, during the 1996–1997 school year more than 400,000 emotionally disturbed children and youths between the ages of 6 and 21 were served in the public schools nationwide (U.S. Department of Education, 1997). This is just under 1 percent of the school enrollment for ages 6 to 17, and 8.5 percent of all children with disabilities receiving any kind of special education service (Oswald & Coutinho, 1995; U.S. Department of Education, 1997). These figures and percentages have remained relatively constant since national data were first collected about 20 years ago, although there are great variations between states. For example, in 1992–1993, 0.4 percent of school-enrolled children in Mississippi were identified as having a serious emotional disturbance compared with 2.08 percent in Connecticut (Coker et al., 1998).

In addition to children with a serious emotional disturbance served by the special education system, children served by child welfare and juvenile justice systems also have need for mental health services (Friedman & Kutash, 1986; Cohen et al., 1990; Greenbaum et al., 1991, 1998; Otto et al., 1992; Glisson, 1996; Claussen et al., 1998), because they are much more likely to have emotional and behavioral disorders than is the general population (Duchnowski et al., 1998; Quinn & Epstein, 1998). Thus, the emphasis on interagency community-based systems of care is warranted and essential (see Integrated System Model).

### ***Managed Care in the Public Sector***

Since 1992, managed care has begun to penetrate the public sector (Essock & Goldman, 1995). The prime impetus for this has been an attempt to control the costs of Medicaid, in both the general health and mental health arenas. Since Medicaid appears, on the surface, to be similar to a private health insurance plan, administrators of state Medicaid programs have recently implemented managed care approaches and structures to reduce health care costs. However, Medicaid populations tend to have a higher prevalence of children with serious emotional disturbance than that seen in privately insured populations. Those children generally need longer-term care (Friedman et al., 1996b; Broskowski & Harshbarger, 1998). Managed care strategies, which developed in the private sector, are geared toward a relatively low utilization of mental health services by a population whose mental health needs tend to be short term and acute in nature. As a result, the kinds of cost-cutting measures used by managed care organizations, such as reduction of hospital days and encouragement of short-term outpatient therapies, have not worked as well in the public sector with seriously emotionally disturbed children as they have in the private sector (Stroul et al., 1998).

Advocates express concern that the restrictions of public managed care on mental health services shift costs of diagnosis and treatment to other agencies, a process known as cost-shifting. Under public managed care, hospitalization for mental disorders is being

substantially cut, with youths being discharged from the hospital before adequate personal and/or community safety plans can be instituted. Child welfare and juvenile justice agencies have been compelled to create and pay for services to support those children who are no longer kept in hospitals. Thus, while Medicaid's mental health costs may be decreasing in such cases, there may be a substantial cost increase to the other agencies involved, resulting in little if any overall cost saving (Stroul et al., 1998).

Similarly, management of only the Medicaid portion of a complex funding system that includes Medicaid, mental health, special education, child welfare, and juvenile justice funds not only creates the cost-shifting described above, but also underestimates the need to manage the funds spent by all agencies. Demonstration programs of managed care strategies for children and adolescents with severe emotional disturbances have included the creation of an interagency funding pool, shared by all affected agencies, to meet the full range of needs of this population. Under the demonstration program, the funds in such a pool are capitated<sup>18</sup> to ensure that the most appropriate services are purchased, regardless of which agency's mandate they come under. In this way, long-term, complex care can be offered in an efficient way that reduces costs for all of the involved child and youth agencies.

An excellent example of an approach in a managed care setting is "Wraparound Milwaukee," one of the Center for Mental Health Services' Comprehensive Community Mental Health Services for Children and Their Families Programs (Stroul et al., 1998; Goldman & Faw, 1998). Wraparound Milwaukee, a coordinated system of community-based care and resources for families of children with severe emotional, behavioral, and mental health problems, is operated by the Children and Adolescent Services Branch of the Milwaukee County Mental Health Division. The features of this care management model are a provider network that furnishes an array of mental health and child welfare services; an individualized plan of care; a care

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<sup>18</sup> Capitation: a fixed sum per individual per month.

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coordinator management system to ensure that services are coordinated, monitored, and evaluated; a Mobile Urgent Treatment Team to provide crisis intervention services; a managed care approach including preauthorization of services and service monitoring; and a reinvestment strategy in which dollars saved from decreased use of inpatient or residential care are invested in increased service capacity.

Since its inception in 1994, one of the goals of the program has been to blend funding streams. Wraparound Milwaukee operates as a behavioral health care “carve-out”<sup>19</sup> that blends funds from a monthly capitation rate from Medicaid, a case rate from county child welfare and juvenile justice funds, and a Center for Mental Health Services child mental health services grant. The Wraparound Milwaukee capitated rate of approximately \$4,300 covers all mental health and substance abuse services, including inpatient hospitalization. Additional funds from child welfare and/or juvenile justice are used for children with serious emotional disturbances in the child welfare and juvenile justice systems in Milwaukee County to cover residential treatment, foster care, group home and shelter care costs, and nontraditional mental health community services (e.g., mentors, job coaches, after-school programs). Wraparound Milwaukee is at “full risk” for all services costs, meaning it is responsible for charges in excess of the capitated rate. The average monthly costs, including administrative costs, are \$3,400 per child. Medicaid-eligible children constituted 80 percent of the population served by the program in 1998.

### Culturally Appropriate Social Support Services

One of the fundamental requirements of culturally appropriate services is for mental health providers to identify and then to work in concert with natural support systems within the diverse communities they serve (Greenbaum, 1998). (Background information on cultural diversity and culturally competent services is

provided in Chapter 2.) If they are culturally appropriate, services can transcend mental health’s focus on the “identified client” to embrace the community, cultural, and family context of a client (Szapocznik & Kurtines, 1993; Hernandez et al., 1998). According to Greenbaum (1998), considering a client’s context is important because people who live close to each other frequently have developed ways of coping with similar personal problems. Becoming aware of these natural systems and adapting formal services to be congruent with them are ways to make services more accessible and useful to diverse populations.

Community- and neighborhood-based social networks act as important resources for easing emotional stress and for facilitating the process of seeking professional help (Saunders, 1996). Often natural social supports ameliorate emotional distress and have been found to reduce the need for formal mental health treatment (Linn & McGranahan, 1980; Birkel & Reppucci, 1983; Cohen & Wills, 1985). According to Saunders (1996), obtaining social support is not a single event but rather an ongoing process. In general, people use their neighborhood and familial supports many times before they decide they have a problem and determine what type of help they will seek (Rew et al., 1997). A key to the success of mental health programs is how well they use and are connected with established, accepted, credible community supports. The more this is the case, the less likely families view such help as threatening and as carrying stigma; this is particularly true for families who are members of racial and ethnic minority groups (Bentelspacher et al., 1994).

Minority parents are more likely than nonminority parents to seek input regarding their children from family and community contacts (Briones et al., 1990; Hoberman, 1992). In a study by McMiller and Weisz (1996), two-thirds of the parents of minority children did not seek help from professionals and agencies as their first choice. For example, in Hispanic/Latino families, important decisions related to health and mental health are often made by the entire family network rather than by individuals (Council of Scientific Affairs, 1991). According to Ruiz (1993), health care settings that are not modified to work with

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<sup>19</sup> Carve-out: separation of funding for mental health services and their management from those of general health.

Hispanic/Latino family networks find that their clients do not comply with medical advice; as a result, their health status can be compromised.

In sum, mental health programs attempting to serve diverse populations must incorporate an understanding of culture, traditions, beliefs, and culture-specific family interactions into their design (Dasen et al., 1988) and form working partnerships with communities in order to become successful (Kretzman & McKnight, 1993). Ultimately, the solution offered by professionals and the process of problem resolution or treatment should be consistent with, or at least tolerable to, the natural supportive environments that reflect clients' values and help-seeking behaviors (Lee, 1996).

Such partnerships sometimes fail, however, because they concentrate on neighborhood and community problems. According to Kretzman and McKnight (1993), this approach often reinforces the negative stereotypes of violent, drug- and gang-ridden, and poverty-stricken communities. A more effective alternative approach to working with communities is to focus on community strengths (Kretzman & McKnight, 1993). This approach works best when community residents themselves are interested in participating in the partnership. Mental health providers who approach minority communities in a paternalistic manner fail to engage residents and fail to recognize whether the community wants their assistance (Gutierrez-Mayka & Contreras-Neira, 1998). Service providers who attend to the wishes of community residents are more likely to be respectful in their delivery of services, a respect that is a prerequisite to cultural responsiveness and competence in service planning and delivery to diverse communities (Gutierrez-Mayka & Contreras-Neira, 1998).

### **Support and Assistance for Families**

Any parent or guardian of a child with an emotional or behavioral disorder can testify to the challenging, sometimes overwhelming, task of caring for and raising such a child. In the past, support from public agencies has been inadequate and disjointed. Compounding the problem was the view that parents were partly, if not completely, to blame for their child's condition

(Friesen & Stephens, 1998). In 1982, a particularly incisive description of the problems faced by families raising children with emotional or behavioral disorders was published. It concluded that parents received little assistance in finding services for their children and were either ignored or coerced by public agencies; respite and support services to relieve the stress on parents were unavailable; parents with children needing residential care were compelled to give up custody to get them placed; and few advocacy efforts were aimed at relieving their problems (Knitzer, 1982).

Over the past two decades, however, recognition and response to the plight of families have become increasingly widespread. The role of families has been redefined as that of a partner in care. Furthermore, there was growing awareness of the difficulties families faced because services are provided by so many different public sources. In addition to problems with coordination, parents and caregivers encountered conflicting requirements, different atmospheres and expectations, and contradictory messages from system to system, office to office, and provider to provider (Knitzer, 1982). Although some agencies began to provide families with training, information, education, and financial assistance, there was often a gap between what families needed and what agencies provided. Also, service agencies themselves began to recognize that putting children into institutions may not have served the child, the family, or the state and that keeping a child with his or her family could reduce the ever-growing costs of institutionalization (Stroul, 1993a, 1993b). Emerging awareness of these foregoing problems galvanized advocacy for a better way to care for children with emotional and behavioral disorders. Reforms were instituted in many Federal programs, as discussed later in this section.

According to Knitzer and colleagues (1993), family participation promotes four changes in the way children are served: increased focus on families; provision of services in natural settings; greater cultural sensitivity; and a community-based system of care. Research is accumulating that family participation improves the process of delivering services and their outcomes. For example, Koren and coworkers (1997) found that, for

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children with serious mental health problems, the more the family participates in planning services, the better family members feel their children's needs are being met; participation in service planning also helps service coordination. Curtis and Singh (1996) and Thompson and colleagues (1997) also found that family involvement in services was a determinant of the level of parental empowerment, that is, how much control parents felt they had over their children's treatment.

### ***New Roles for Families in Systems of Care***

Over the past two decades, the Federal government established a series of initiatives to support families. Parents were given progressively greater roles as decisionmakers with the passage of the Education of the Handicapped Act in 1975 and its successor legislation, the Individuals with Disabilities Education Acts of 1991 and 1997. For simplicity, these pieces of legislation are collectively referred to hereinafter as the IDEA Act. This act requires parent involvement in decisions about educating children with disabilities. It guarantees that all children with disabilities receive free and appropriate public education. It also provides funding assistance to states for implementation.

A novel approach taken by some community-level systems of care to encouraging involvement of families is to train and hire family members into a wide range of well-paying, career-ladder jobs as outreach workers, service coordinators (sometimes called case managers), and direct support services providers. These positions are critical to achieving major program goals because they make it possible for children and families to remain together and to participate in the more clinical components of their service plan. Family members are also employed as supervisors of services, involved in hiring staff, providing them with orientation and on-the-job training (e.g., of case managers), overseeing their work, and evaluating their performance. They also participate in research.

Beginning in 1989, the Child and Adolescent Service System Program, a component of the Center for Mental Health Services, began providing some support for statewide family organizations through a series of funding and technical assistance mechanisms (Koroloff

et al., 1991; Briggs et al., 1994; also see Integrated System Model). Such organizations were funded to develop statewide networks of information and support for families, to coordinate with other organizations that shared common goals, and to promote needed changes. Currently, Federal funding for 22 statewide family organizations is provided through the Child and Family Branch, Center for Mental Health Services, Substance Abuse and Mental Health Services Administration. Support and technical assistance to community-level family organizations are also provided by the Federation of Families for Children's Mental Health, the National Alliance for the Mentally Ill, and other family-run consumer organizations.

### ***Family Support***

Family support is defined here as the assistance given to families to cope with the extra stresses that accompany caring for a child with emotional disabilities. In addition to the stress of raising a child with an emotional disability, families often face other difficulties such as poverty, joblessness, substance abuse, and victimization. Family support often helps keep families together by assisting them with the practicalities of living and by attending to the needs of all family members (Will, 1998). The main goal of family support services is to strengthen adults in their roles as parents, nurturers, and providers (Weissbourd & Kagan, 1989). Too often, family support services are not available within local communities.

Natural support systems are often diminished for families of children with serious emotional, behavioral, or physical disorders or handicaps because of the stigma of, or embarrassment about, their child's problems, or because caregivers have insufficient energy to reach out to others. Not surprisingly, most parents report that limited social support decreases their quality of life (Crowley & Kazdin, 1998) and that they feel less competent, more depressed, worried, and tired and have more problems with spouses and other family relationships than other parents (Farmer et al., 1997), although a few families do feel enriched by caring for these children (Yatchmenoff et al., 1998).

In a national survey of parents of children with an emotional or behavioral disorder, 72 percent of respondents indicated that emotional support (irrespective of its form) was the most helpful aspect of family support services (Friesen, 1990). Benefits included increased access to information, improved problem-solving skills, and more positive views about parenting and their children's behavior (Friesen & Koroloff, 1990).

Family support services occur in several forms: assistance with daily tasks and psychosocial support and counseling; informal or professional provision of services; and practical support such as housing assistance, food stamps, income support, or respite care (i.e., temporary relief for family members caring for individuals with disabilities).

Efforts to stop blaming parents for children's problems have resulted in parents becoming viewed less as patients than as partners, actively involved in every phase of the treatment process (e.g., home-based care, case management) and as a resource for their children, as discussed above. For the self-help and professionally led family support services described subsequently, parents may function either as partners or as providers. As "partners," parents act as a resource, active contributor, or decisionmaker; as "providers," they are viewed as contributing to the welfare and growth of other members of the family.

Results of research on the effectiveness of family services are only beginning to appear, in the form of some controlled studies and evaluations of support services for families of children with emotional and behavioral disorders (although there is a larger literature on families whose children have other types of disability and illness). Although this database on family support programs is still limited, many positive effects have been reported. The following paragraphs cover family support groups as well as concrete services. For the latter, only two types of interventions, respite care and the family associate, are included. Family therapy is covered in this chapter under Outpatient Treatment. Furthermore, several forms of parent training were found to be effective for individual

diagnoses, such as conduct disorder (see section on Selected Mental Disorders in Children).

### ***Family Support Groups***

The primary focus of family support groups is to provide information and emotional support to members who share a common problem or concern (e.g., disability, substance abuse, bereavement). Support groups for families of children with emotional or behavioral disorders are expanding. Although there is a wide variation in membership, format, and duration of these groups, most share some characteristics. Usually, from 4 to 20 parents meet regularly to discuss the problems and issues associated with parenting a child with emotional and behavioral disorders and to provide mutual encouragement and suggestions for dealing with problematic situations. Support services may be informal, organized, and parent led and are often associated with organizations such as the National Mental Health Association, Children and Adults with Attention Deficit Disorders, the National Alliance for the Mentally Ill, or the Federation of Families for Children's Mental Health. Mental health professionals may also participate in support groups (Koroloff & Friesen, 1991).

It was found that support groups for parents of children hospitalized with mental illness make parents feel more positive about themselves and increase their understanding of and communication with their children (Dreier & Lewis, 1991). Participation in a six-session education and support group for parents of adolescents with schizophrenia led to increased relaxation and concentration, less worry, changed attitudes toward discipline, and greater ease in discussing feelings. The support from parents in similar situations was highly valued (Sheridan & Moore, 1991).

Another approach to support for parents of children receiving mental health services is education: knowledge of the services; skills needed to interact with the system; and the caregivers' confidence in their ability to collaborate with service providers (self-efficacy). A training curriculum for parents was tested in a randomized controlled trial involving more than

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200 parents who either did or did not receive the training curriculum. Three-month and 1-year followup results demonstrated significant improvement in parents' knowledge and self-efficacy with the training curriculum, whereas there was no effect on the mental health status of their children, service use, or caregiver involvement in treatment (Heflinger & Bickman, 1996; Bickman et al., 1998).

### ***Practical Support***

Respite care is a type of concrete support that provides temporary relief to family caregivers. An investigation of the benefit of respite care is under way in New York in families with children at risk of hospital placement. When respite care was available, families preferred in-home to out-of-home care. The younger the children, the greater the child's functional impairment, and the fewer the social supports (Boothroyd et al., 1998), the more respite care was used. Outcomes have not yet been reported.

Another form of concrete support is exemplified by the Family Associate Intervention, which was developed in Oregon. It appears to be an inexpensive way to assist children in actually obtaining care after they have been identified as needing care. The goal is to use paraprofessionals (known as family associates), rather than professionals, to facilitate entry into an often intimidating service system. In a controlled study, family associates were found to be effective in helping families initiate mental health service use. Families receiving this support service were more likely to make and keep a first appointment at the mental health clinic. The effectiveness of the intervention was moderate but sufficient to encourage further development of such a low-cost intervention (Koroloff et al., 1996b; Elliot et al., 1998).

### **Integrated System Model**

Within the public mental health system, the 1980s and 1990s have seen an increased emphasis on developing interagency community-based systems of care (Stroul & Friedman, 1986). This focus is driven by awareness that a large number of children are served in systems other than mental health, as well as by children's

complex and interrelated needs, as indicated earlier (Friedman et al., 1996a, 1996b; Quinn & Epstein, 1998). In 1984, the Child and Adolescent Service System Program (CASSP) was launched to respond to the fragmentation of public services (Stroul & Friedman, 1986). It was funded by the services component of the National Institute of Mental Health, which later became the Center for Mental Health Services under the Alcohol and Drug Abuse and Mental Health Administration Reorganization Act of 1992 (Public Law 102-321).

CASSP recognized the need for public sector programs to become more integrated in their attempts to meet more fully and efficiently the needs of children and adolescents with a serious emotional disturbance and their families. This Federal program pioneered the concept of a "system of care" for this population, as delineated by Stroul and Friedman (1986, 1996). A system of care, described further below, is a comprehensive approach to coordinating and delivering a far-reaching array of services from multiple agencies. All 50 states and numerous communities have received CASSP grants to improve the organization of their response to the mental health needs of the most severely affected children and adolescents. Although CASSP principles have become a standard for program design, many communities do not offer comprehensive services according to the CASSP model.

CASSP provided the conceptual framework for the Robert Wood Johnson Foundation's Mental Health Services Program for Youth and the Annie E. Casey Foundation's Urban Mental Health Initiative. These foundation programs were devoted to the development of local interagency models (Cole, 1990). They were followed in 1992 by the authorization for what was to become the largest Federal program for child mental health, the Comprehensive Community Mental Health Services for Children and Their Families Program (also known as the Children's Services Program), sponsored by the Center for Mental Health Services (Public Law 102-321).

The Children's Services Program provides grants to states, communities, territories, and Indian tribes and tribal organizations to improve and expand systems of

care to meet the needs of approximately 6.3 million children and adolescents with serious emotional disturbance and their families. The program now supports 45 sites across the country.

Built on the principles of CASSP, the Children's Services Program promotes the development of service delivery systems through a "system of care" approach. The system of care approach embraced by this initiative is defined as a comprehensive spectrum of mental health and other services and supports organized into a coordinated network to meet the diverse and changing needs of children and adolescents with serious emotional disturbance and their families (Stroul & Friedman, 1996). The system of care model is based on three main elements: (1) the mental health service system must be driven by the needs and the preferences of the child and family; (2) the locus and management of services must be within a multiagency collaborative environment, grounded in a strong community base; and (3) the services offered, the agencies participating, and the programs generated must be responsive to children's different cultural backgrounds. The Children's Services Program requires a national cross-site evaluation, which has been continuously implemented since the spring of 1994. Preliminary evidence from the uncontrolled evaluation indicates some improvements in outcomes, such as fewer law enforcement contacts and better school grades, living arrangements, and mental health status. As part of the evaluation, comparisons are being made between system of care sites and comparable communities without systems of care (Holden et al., 1999).

### **Effectiveness of Systems of Care**

The previous sections have highlighted the transformations that have taken place since the early 1980s to create comprehensive, interagency, community-based systems of care. This section reviews the findings of research into the effectiveness of such systems of care as compared with more traditional systems.

Several studies on the effectiveness of systems of care have been conducted in recent years (Stroul, 1993a, 1993b; Bruns et al., 1995; Rosenblatt, 1998).

Although findings are encouraging, their effectiveness has not yet been demonstrated conclusively, largely because evaluation studies have not had a control group. Most evaluations indicate that systems of care reduce rates of reinstitutionalization after discharge from residential settings, reduce out-of-state placements of children, and improve other individual outcomes such as number of behavior problems and satisfaction with services. After reviewing findings from the demonstration project of the Robert Wood Johnson Foundation, their own work in Vermont, research in California and Alaska, and early findings from the Fort Bragg evaluation, Bruns, Burchard, and Yoe (1995) conclude that "initial findings are encouraging, especially with the history of disappointing results of outcome studies for child and adolescent services" (p. 325). Details are available in the individual studies (Attkisson et al., 1997; Illback et al., 1998; Santarangelo et al., 1998).

Reviews (Stroul, 1993a, 1993b; Rosenblatt, 1998) of uncontrolled studies of community-based systems of care showed that young people with serious emotional disturbances who were served under community-based systems of care consistently showed improvement across a range of outcomes. However, most of these studies used a so-called pre-post evaluation design that does not answer the question of whether the changes occurring over time (pre to post) are a consequence of the intervention or of the passage of time itself. Indeed, when comparison groups are studied, such as in the Fort Bragg demonstration project, results tend to be less favorable (see below).

### ***The Fort Bragg Study***

The Fort Bragg study, conducted by Bickman and his colleagues (Bickman et al., 1995; Bickman, 1996a; Hamner et al., 1997), merits detailed discussion because of the basic issues it raises and the controversy it engendered. The Fort Bragg study is an evaluation of a large-scale system change project initiated by the State of North Carolina and the Department of Defense in the early 1990s; it was designed to determine what systemic, clinical, and functional outcomes could be

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achieved if a wide range of individualized and family-centered services were provided without any barriers to their availability. The project involved replacing the traditional CHAMPUS benefit for children who were military dependents in the Fort Bragg area with a continuum of care that included a broad range of services, a single point of entry, comprehensive assessments, and no copayment or benefit limit. The provider agency at Fort Bragg was reimbursed for costs. The impact of this change on children was assessed by comparing outcomes at Fort Bragg with those at two other military installations in the Southeast where the traditional CHAMPUS benefit package remained in effect. The comparison sites restricted services to outpatient treatment, placement in a residential treatment center, or treatment in an inpatient hospital setting; regular copayment and benefit limits were in effect at the comparison sites.

Over a 3-year period, the evaluators collected service use, cost, satisfaction, clinical, and functional data for 984 young people served either at Fort Bragg (574) or the comparison sites (410). Overall, there were a number of favorable findings for the demonstration site at Fort Bragg: access for children was increased; children referred for services were indeed in need of help; parents and adolescents were more satisfied with the services they received than were parents and adolescents at the comparison sites; children received services sooner; care was provided in less restrictive environments; there was heavy use of intermediate-level services; fewer clients received only one session of outpatient treatment; overall, children stayed in treatment longer (although the length of stay in hospitals and residential treatment centers was shorter); and there were fewer disruptions in services (Bickman, 1996a). Thus, the major findings were that the expanded continuum of care resulted in greater access, higher satisfaction with services by patients, and less use of inpatient hospitalization and residential treatment. Bickman also concluded, however, that despite the fact that the intervention was well implemented at Fort Bragg, there were no differences between sites in clinical outcomes (emotional-

behavioral functioning), and the cost was considerably greater at Fort Bragg.

The interpretation of the results by the project's principal investigator has generated much discussion and controversy in the children's mental health field, both in support of and questioning the study's conclusions (Friedman & Burns, 1996; Behar, 1997; Feldman, 1997; Hoagwood, 1997; Lourie, 1997; Pires, 1997; Saxe & Cross, 1997; Sechrest & Walsh, 1997; Weisz et al., 1997). Most of the controversy surrounds study interpretation, implementation, methodology, and the interpretation of the cost data (Behar, 1997; Feldman, 1997; Heflinger & Northrup, 1997; Langmeyer, 1997). Furthermore, it has been pointed out that Fort Bragg was not a multiagency community-based system of care (Friedman & Burns, 1996), a point that has been acknowledged by the principal investigator of the study (Bickman, 1996b). Overall, despite the controversy surrounding it, the Fort Bragg evaluation has challenged the notion that changes at the system level have consequences at the practice level and, ultimately, improve outcomes for children and families. The results have stimulated an increased focus on practice-level issues.

### *The Stark County Study*

The shift in focus to the practice level is being reinforced by results from another study by Bickman and colleagues (1997, 1999) of children with emotional disturbances who were served in Stark County, Ohio. In this study, participating children were served within the public mental health system by a multiagency system of care; this was in contrast to the Fort Bragg sample of military dependents seen in a mental health-funded and -operated continuum of care. Children and families who consented to participate in the study were randomly assigned to one of two groups. The first group was immediately eligible to receive services within the existing community-based system of care in Stark County. Families in the second group were required to seek services on their own rather than to receive them within the system of care. The major differences in services provided were that significantly

more children and families in the system of care group received case management and home visits than those in the comparison group. Findings indicate no differences in clinical or functional status 12 months after intake. These results are similar to those of the Fort Bragg study and suggest that attention should be paid to the effectiveness of services delivered *within* systems of care rather than only to the organization of these systems.

### Summary: Effectiveness of Systems of Care

Collectively, the results of the evaluations of systems of care suggest that they are effective in achieving important system improvements, such as reducing use of residential placements, and out-of-state placements, and in achieving improvements in functional behavior. There also are indications that parents are more satisfied in systems of care than in more traditional service delivery systems. The effect of systems of care on cost is not yet clear, however. Nor has it yet been demonstrated that services delivered within a system of care will result in better clinical outcomes than services delivered within more traditional systems. There is clearly a need for more attention to be paid to the relationship between changes at the system level and changes at the practice level.

### Conclusions

1. Childhood is characterized by periods of transition and reorganization, making it critical to assess the mental health of children and adolescents in the context of familial, social, and cultural expectations about age-appropriate thoughts, emotions, and behavior.
2. The range of what is considered "normal" is wide; still, children and adolescents can and do develop mental disorders that are more severe than the "ups and downs" in the usual course of development.
3. Approximately one in five children and adolescents experiences the signs and symptoms of a DSM-IV disorder during the course of a year, but only about 5 percent of all children experience what professionals term "extreme functional impairment."
4. Mental disorders and mental health problems appear in families of all social classes and of all backgrounds. No one is immune. Yet there are children who are at greatest risk by virtue of a broad array of factors. These include physical problems; intellectual disabilities (retardation); low birth weight; family history of mental and addictive disorders; multigenerational poverty; and caregiver separation or abuse and neglect.
5. Preventive interventions have been shown to be effective in reducing the impact of risk factors for mental disorders and improving social and emotional development by providing, for example, educational programs for young children, parent-education programs, and nurse home visits.
6. A range of efficacious psychosocial and pharmacologic treatments exists for many mental disorders in children, including attention-deficit/hyperactivity disorder, depression, and the disruptive disorders.
7. Research is under way to demonstrate the effectiveness of most treatments for children in actual practice settings (as opposed to evidence of "efficacy" in controlled research settings), and significant barriers exist to receipt of treatment.
8. Primary care and the schools are major settings for the potential recognition of mental disorders in children and adolescents, yet trained staff are limited, as are options for referral to specialty care.
9. The multiple problems associated with "serious emotional disturbance" in children and adolescents are best addressed with a "systems" approach in which multiple service sectors work in an organized, collaborative way. Research on the effectiveness of systems of care shows positive results for system outcomes and functional outcomes for children; however, the relationship between changes at the system level and clinical outcomes is still unclear.
10. Families have become essential partners in the delivery of mental health services for children and adolescents.
11. Cultural differences exacerbate the general problems of access to appropriate mental health

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services. Culturally appropriate services have been designed but are not widely available.

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