



## **SECTION I**

**COLLECTION  
OF EVIDENCE-BASED  
TREATMENT MODALITIES  
FOR  
CHILDREN AND ADOLESCENTS  
WITH  
MENTAL HEALTH TREATMENT NEEDS**

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# TABLE OF CONTENTS

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<b>Introduction</b> .....	3
<b>Role of the Family in Treatment Programs</b> .....	8
<b>Evidence-based Treatments</b> .....	12
<b>Key Components of Successful Treatments</b> .....	18
<b>Reference Chart of Disorders and Evidence-based Treatments</b> .....	21
<b>Mental Retardation</b> .....	28
<b>Pervasive Developmental Disorders</b> .....	38
<b>Adjustment Disorders</b> .....	52
<b>Behavior Disorders</b> .....	57
<i>Attention Deficit Hyperactivity Disorder</i>	
<i>Oppositional Defiant &amp; Conduct Disorders</i>	
<b>Maladaptive Behaviors</b> .....	71
<i>Sexual Offending</i>	
<i>Eating Disorders</i>	
<i>Juvenile Firesetting</i>	
<i>Self Injury</i>	
<b>Tourette’s Disorder</b> .....	97
<b>Anxiety Disorders</b> .....	103
<b>Mood Disorders</b> .....	111
<b>Schizophrenia</b> .....	120
<b>Co-occurrence of Substance Abuse and Mental Illness</b> .....	133
<b>Youth Suicide</b> .....	147
<b>School-based Mental Health Services</b> .....	156
<b>Juvenile Offenders</b> .....	163
<b>Implications for Policy Makers</b> .....	168
<b>General Description of Providers</b> .....	173
<b>Providers Licensed in Virginia</b> .....	175
<b>Frequently Used Terms in Virginia’s Mental Health Delivery System</b> .....	178
<b>Commonly Used Acronyms</b> .....	195

# INTRODUCTION

The 2002 General Assembly, through Senate Joint Resolution 99, directed the Virginia Commission on Youth to coordinate the collection and dissemination of empirically-based information that would identify the treatment modalities and practices recognized as effective for the treatment of children<sup>1</sup>, including juvenile offenders, with mental health treatment needs, symptoms and disorders. This initiative originated from recommendations made to the 2002 General Assembly by the Virginia Commission on Youth as part of a two-year study of Children and Youth with Serious Emotional Disturbance Requiring Out-of-Home Placement and by the Committee Studying Treatment Options for Offenders with Mental Illness or Substance Abuse Disorders (House Document 23, Senate Document 25, respectively).

## **Background of Children and Adolescents' Mental Health**

The recognition that children and adolescents suffer from mental illness is a relatively recent occurrence. Throughout history, childhood was considered a happy period. Children were not thought to suffer from mental disorders or emotional distresses due to the notion that they were spared the stresses that plague most adults (American Psychiatric Association, 2002). It is now well-recognized that these disorders are not just a stage of childhood or adolescence, but a result of genetic, developmental and physiologic factors.

Research conducted in the 1960's revealed that children suffer from mental disorders (American Psychiatric Association, 2002). It was not until the third edition of the DSM (the Diagnostic and Statistical Manual of Mental Disorders) of the American Psychiatric Association in 1980 that child and adolescent mental disorders were assigned a separate and distinct section within the classification system (National Institute of Mental Health, 2001). The development of treatments, services and methods for preventing mental disorders in children and adolescents has also gradually evolved over the past several decades.

The National Alliance for the Mentally Ill (NAMI) defines mental illness as a disorder of the brain that may disrupt a person's thinking, feeling, moods, and ability to relate to others (NAMI, 2002). Mental disorders and mental health problems appear in families of varying social classes and backgrounds. However, there are children who are at greatest risk due to other 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 (U.S. Department of Health and Human Services, 1999).

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<sup>1</sup> *Child and children* are used throughout this document to connote *children and adolescents*.

Woodruff et. al (1999) have indicated that, to date, child and adolescent mental health has emerged as a distinct arena for service delivery, drawing on the philosophies and practices that characterized other childhood fields, such as early intervention. With the increase in attention given children's mental health and the development of systems of care for children with serious emotional disorders and their families in the last two decades, mental health is emerging as a new focus in the field of early childhood (Woodruff, et. al, 1999). Family members, practitioners, and researchers are becoming increasingly aware that mental health services are an important and necessary support for young children who experience mental, emotional, or behavioral challenges and their families.

*Table 1*

### **Risk Factors Related to Children's Mental Health**

- |   |
|---|
| <ul style="list-style-type: none"><li>• <b>Biological Influences</b></li><li>• <b>Psychosocial Influences</b></li><li>• <b>Family and Genetic Factors</b></li><li>• <b>Stressful Life Events</b></li><li>• <b>Childhood Maltreatment</b></li><li>• <b>Peer and Sibling Influences</b></li></ul> |
|---|

Source: Austin/Travis County Community Action Network – Prescription for Wellness, National Institute of Mental Health, 2000.

### **Prevalence of Mental Disorders among Children and Adolescents**

Clearly, the widespread prevalence of mental illness in children and youth has been established. According to estimates compiled by the Center for Mental Health Services, 11 percent of children in the United States have at least one significant mental illness that is accompanied by impairment in home, school or peer contexts (U. S. Department of Health and Human Services, 2001).

Although the awareness of children's mental health issues has developed, knowledge about treating disorders is still emerging. According to the American Psychiatric Association (APA), 12 million American children suffer from mental illness; however, only one in five receives treatment (American Psychiatric Association, 2002).

In 1999, as reported by Jenson (2002), the Office of the Surgeon General indicated that only 30 percent of all children with a mental or emotional disorder were receiving treatment. Only one in three to five children receive any specialty mental health services. Finally, for children meeting the criteria for serious emotional disturbance, school systems are the only provider of services for 50 percent.

In Virginia, according to estimates by the state's Department of Mental Health, Mental Retardation and Substance Abuse Services (DMHMRSAS), each year more than 75,000 children experience the disabling symptoms of serious mental illness or emotional disturbance (NAMI, 2001). These prevalence rates were applied, using 2000 Census data, to Virginia's population data to extrapolate the estimated prevalence of children suffering from serious emotional disturbance. According to the census, Virginia's child and adolescent population aged 9-17 is 885,411. The prevalence with serious emotional disturbance among children and adolescents is estimated to be between 79,687 and 97,395 (DMHMRSAS, 2001). And at least one half million Virginians have relatives with a serious mental illness (NAMI, 2001).

## Meeting the Need for Treatment

Acknowledgment of children's and adolescents' mental health needs has prompted further study of the specific disorders that plague this group, as well as the interventions utilized for treatment. Increased activity in this area can be directly attributed to the 1999 Surgeon General's Report *Mental Health: A Report of the Surgeon General*. This report includes a chapter on children and adolescents and is the first such report to reference mental health. A follow-up effort was released one year later, entitled *A Report of the Surgeon General's Conference on Children's Mental Health: A National Action Agenda*. This publication set the tone for policy and research for children's mental health. Another recent federal initiative that is closely aligned to the philosophy and findings set forth in the Surgeon General's Report is the 2001 NIMH *Blueprint for Change: Research on Child and Adolescent Mental Health*.

The Surgeon General's Report outlines the importance of mental health in children and the view that the treatment of mental disorders should be a major public health goal. In the National Action Agenda, the Surgeon General asserted that three steps must be taken to improve services for children with mental health needs: improving early recognition and appropriate identification of disorders within all systems serving children; improving access to services by removing barriers faced by families; and closing the gap between research and practice, ensuring evidence-based treatments for children (U.S. Department of Health and Human Services, 1999).

The Surgeon General's Report also specifies the need for utilizing scientific evidence for mental disorders and describes a system plagued by treatment barriers, including stigma, discriminatory health insurance practices and the unavailability of appropriate services. Other guiding principles are that 1) families should be involved as full participants in all aspects of the planning, delivery and evaluation of services and supports and 2) treatments should be sensitive and responsive to racial, ethnic, linguistic and cultural differences. Other important features include improving or remedying environmental factors that put children at risk for developing mental, emotional or behavioral problems.

Without appropriate treatment, these childhood mental disorders can lead to more serious mental disorders. Untreated childhood disorders can also be predictors of other future difficulties, such as increased potential for involvement in the juvenile justice system, the loss of custody and even placement outside of the home. Less serious outcomes include other destructive, ambiguous or dangerous behaviors and mounting parental frustration.

The Surgeon General's efforts encourage further testing and refining of programs in a real-world context. A preventive and developmental approach to children's mental health problems must be taken. While many programs try to provide coordinated care for children with mental health needs, the children's mental health system remains splintered. The principle that mental health is an essential part of children's health is emphasized throughout this report.

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## **Resources**

Mental Health: A Report of the Surgeon General  
[www.surgeongeneral.gov/library/mentalhealth/chapter3/sec6.html](http://www.surgeongeneral.gov/library/mentalhealth/chapter3/sec6.html)

National Institute for Mental Health (NIMH)  
[www.nimh.nih.gov/publicat/violence.cfm](http://www.nimh.nih.gov/publicat/violence.cfm)

National Alliance for the Mentally Ill (NAMI)  
[www.nami.org/helpline/oed.htm](http://www.nami.org/helpline/oed.htm)

American Academy of Child and Adolescent Psychiatry  
[www.aacap.org/clinical/Anxtysum.htm](http://www.aacap.org/clinical/Anxtysum.htm)  
[www.aacap.org/clinical/Ptsdsum.htm](http://www.aacap.org/clinical/Ptsdsum.htm)  
[www.aacap.org/clinical/Ocdsum.htm](http://www.aacap.org/clinical/Ocdsum.htm)

### **Disclosure Statement**

The information contained herein is strictly for informational and educational purposes and is not designed to replace the advice and counsel of a physician or mental health provider. The Commission on Youth makes no representations regarding the suitability of the information contained herein for any purpose.

# ROLE OF THE FAMILY IN TREATMENT PROGRAMS

The involvement of family members in child and adolescent services is crucial to successful treatment outcomes (Kutash & Rivera, 1995; Pfeifer & Strzelecki, 1990). The effectiveness of services for children and adolescents is believed to hinge less on the particular type of treatment provided than on the participation of the family in planning, implementing, and evaluating the services. Research indicates that, for children with serious mental health problems, the more the family participates in planning services, the more likely the family members are to feel that their child's needs are being met (Koren et al., 1997) and that they have control over the child's treatment (Curtis & Singh, 1996; Thompson et al., 1997). Furthermore, family participation promotes an increased focus on families, the provision of services in natural settings, a greater awareness of cultural sensitivity, and a community-based system of care. There is also a growing body of research that has found that family participation improves the process of delivering services and their outcomes (Knitzer et al., 1993).

Nevertheless, there is a growing body of evidence indicating that children from vulnerable populations (children of single mothers, children who live in poverty, and minority children) who exhibit the most serious problems are also the most likely to terminate their treatment early (Kadzin & Mazurick, 1994). Additional research is necessary to determine the factors that contribute to this early termination. In recognition of this problem, however, it is important for mental health providers to ensure that these families are actively recruited and engaged in the services that the child receives in order to maximize the potential for successful outcomes.

This goal is complicated, however, by the fact that both families and providers may be confused and hesitant about the role that family members should play in treatment efforts. As a result, they often are not incorporated to the extent that would be most beneficial to the child. In an attempt to combat this problem, researchers have identified six broad roles that families should play in the treatment process. Members of the family should act as contributors to the environment, recipients of service, partners in the treatment process, service providers, advocates, and evaluators and researchers (Friesen & Stephens, 1998). It is important that family members assume each of these roles in order to provide the effective support network that is necessary for the child's continued improvement.

Friesen & Stephens (1998) outline these six roles for families:

**Contributors to the Environment** – Family members are the key component of the environment in which a child resides. Consequently, treatment providers often try to identify ways in which the behavior and interactions between family members influence the child's emotional and behavioral problems. With the assistance of the treatment provider, family members should consider ways to improve the home environment and the relationships in the family in order to provide the child with the most stable, supportive environment possible. In addition, family members should seek external support from their extended family and members of the community in order to reduce the stress of raising a child with emotional or behavioral difficulties.

**Recipients of Service** – Family members are also an important part of the therapeutic process.

Service providers often focus on the family unit as a whole, creating interventions and strategies that target the health of the entire family. These interventions are intended to assess the strengths and weaknesses that exist within the family structure, to enhance the well-being of

parents and other family members, and to help families locate support mechanisms in the community. The provider also assists family members in developing the skills necessary to support the special needs of the child. Services may include supportive counseling, parental training and education, development of coping skills and stress management techniques, respite care, parental support groups, transportation, and financial assistance.

**Partners in the Treatment Process** – Family members also serve as equal contributors in the problem-solving process. They should work with treatment providers to identify the goals of treatment and to plan realistic strategies to achieve these goals. Additionally, family members should play a key role in implementing these strategies to ensure that the treatment goals are met. When performing these functions, caregivers should not be afraid to ask questions and to voice their opinions and preferences. It is crucial that they are fully informed and that their preferences are considered in all treatment decisions.

**Service Providers** – The treatment process is incomplete without the direct services provided to the child by family members. They are responsible for providing emotional support and information to the child and other family members, and for filling in the gaps in the services being received by the child. Furthermore, they often coordinate the services being received by the child by requesting, convening, and scheduling meetings, and transporting the child to appointments. It is a crucial role, the importance of which cannot be understated. Parents and caregivers need to remain vigilant and involved in all aspects of the child's treatment. This includes keeping all follow-up appointments, becoming knowledgeable about any prescribed medications, and keeping track of all treatments that have been tried unsuccessfully.

**Advocates** – Family members often serve as the child's only voice in the mental health system. They should therefore actively advocate for the child in order to ensure that he receives the appropriate services, and should voice any concerns regarding undesirable practices and policies. There are several local, state, and national organizations that can assist parents and caregivers in these efforts, allowing them to serve as part of a larger voice in the community.

**Evaluators and Researchers** – It is important that families participate in research and evaluation activities so that their opinions can be heard regarding which treatments and services are most beneficial and convenient. The input of family members is crucial to ensure that all children receive services that are efficient and effective. While much of this research requires the involvement of the family for a significant length of time, the input of caregivers and other family members is extremely important.

It is crucial that families remain actively involved in all aspects of their child's mental health treatment. Without family involvement, it will be extremely difficult for service providers to ensure that the gains achieved by the child in treatment are maintained and solidified. Moreover, the combined efforts of service providers, family members, and advocates are necessary to ensure that the services provided in the community effectively meet the needs of all children and families.

## Questions that Parents or Caregivers Should Ask About Treatment Services:

It's important that parents and caregivers understand the results of any evaluation, the child's diagnosis, and the full range of treatment options. If parents are not comfortable with a particular clinician, treatment option, or are confused about specific recommendations, they should consider a second opinion.

Before a child begins treatment, parents should ask the following:

- Does my child need additional assessment and/or testing (medical, psychological etc.)?
- What are the recommended treatment options for my child?
- Why do you believe treatment in this program is indicated for my child? How does it compare to other programs or services which are available?
- What are the advantages and disadvantages of the recommended service or program?
- What will treatment cost, and how long will it take?
- How much of the cost is covered by insurance or public funding? Will we reach our insurance limit before treatment is completed?
- How will my child continue education while in treatment?
- Does my child need medication? If so, what is the name of the medication that will be prescribed? How will it help my child? How long before I see improvement? What are the side effects which commonly occur with this medication?
- What are the credentials and experience of the members of the treatment team?
- How frequently will the treatment sessions occur?
- Will the treatment sessions occur with just my child or the entire family?
- How will I be involved with my child's treatment?
- How will we know if the treatment is working? What are some of the results I can expect to see?
- How long should it take before I see improvement?
- What should I do if the problems get worse?
- What are the arrangements if I need to reach you after-hours or in an emergency?
- As my child's problem improves, does this program provide less intensive/step-down treatment services?
- How will the decision be made to discharge my child from treatment?
- Once my child is discharged, how will it be decided what types of ongoing treatment will be necessary, how often, and for how long?

Source: American Academy of Child & Adolescent Psychiatry, 2000.

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# EVIDENCE-BASED TREATMENTS

## Overview

The field of mental health is multi-disciplinary, with a diverse service system. Today there is a multitude of theories about which treatments work best, making it is very difficult for service providers to make informed choices. It is imperative that treatments for mental health disorders be examined based on clinical research in order to ascertain whether they are effective. Detailed study of mental health treatments allows for greater acceptability of the intervention, better replication in different settings and greater specificity for trainees (Christophersen & Mortweet, 2001). These interventions which have strong empirical support are referred to as “evidence-based” treatments.

Empirical or evidence-based treatments are interventions for which there is consistent scientific evidence showing that they improve client outcomes [National Association of State Mental Health Program Directors (NASMHPD) Research Institute, Inc. (NRI) Center for Evidence-Based Practices, 2000]. In the field of children’s mental health science and service delivery, the term *evidence-based* refers to a body of knowledge, obtained through carefully implemented scientific methods, about the prevalence, incidence, or risk for mental disorders or about the impact of treatments or services on mental health problems [National Institute of Mental Health (NIMH), 2001]. It represents the quality and soundness of the scientific evidence regarding questions of etiology, distribution, or risk for disorders or on outcomes of care for children with mental health problems (NIMH). In the past, many decisions with important consequences have been uninformed by quality research findings. This form of decision-making lacks accountability. Evidence-based practices offer practitioners a different decision-making process, according them the satisfaction of staying on top of research findings and a means of making decisions that are publicly accountable. Evidence-based practices enable service providers to identify and utilize “best practices” in treatment (New York State Office for Mental Health, 2001).

In order for treatments to be considered evidence-based, they must be consistent with the characteristics of the evidence-based guidelines developed by the National Institute of Mental Health, highlighted in the Surgeon General’s Report on Mental Health (1999) and outlined by Burns (1999):

- At least two control group design studies or a large series of single-case design studies;
- Minimum of two investigators;
- Use of a treatment manual;
- Uniform therapist training and adherence;
- True clinical samples of youth;
- Tests of clinical significance of outcomes applied;
- Both functioning and symptom outcomes reviewed; and
- Long-term outcomes beyond termination.

Recent debate has focused on the degree of support required for determining which interventions are of value in treating specific disorders (Lonigan et al., 1998). To answer questions of evidence, suggested approaches have been implemented in order to demonstrate what interventions work for particular disorders. Table 1 shows the two classifications of research studies on treatments.

Table 1

### Efficacy vs. Effectiveness

**Effective** (or well-established) treatments are those that have beneficial effects when delivered to heterogeneous samples of clinically referred individuals treated in clinical settings by clinicians other than researchers.

**Efficacious** (or clinical utility) studies are directed at establishing how well a particular intervention works in the environment and under the conditions in which treatment is typically offered.

Source: Lonigan et al., 1998.

Most efficacy studies are directed at establishing whether a particular intervention works and whether the research for the trial is conducted under tightly controlled condition (Lonigan et al., 1998). Interventions identified as efficacious can later be subject to effectiveness trials.

Distinguishing between these two classifications is significant because the evidence is frequently ambiguous. This may be because the evidence is preliminary rather than well-established. Also, treatments may be newer and their long term effects, still unclear. Assessments of the effectiveness of a treatment may vary and the patient's other medical conditions must be taken into account when considering what is an effective treatment.

One of the major goals outlined in the Surgeon General's *National Action Agenda*, is the continued development, dissemination, and implementation of scientifically-proven prevention and treatment services in the field of children's mental health. Other action steps include increasing the research on proven treatments, practices, and services developed in the laboratory to assess their effectiveness in real-world settings. The evaluation of model programs that can be disseminated and sustained in the community is also emphasized. Promotion of private and public partnerships to facilitate this dissemination is crucial. Unfortunately, the report indicates that there is a growing gap between knowledge and practice and between what is known through experience and what is actually implemented in many public mental health systems across the country.

### Benefits of Evidence-based Treatments

"The best care results from the conscientious, explicit, and judicious use of current best evidence and knowledge of patient values by well-trained experienced clinicians" (Corrigan, 2001). Evidence-based treatments allow patients, clinicians and families to see the difference between alternative treatment decisions and to ascertain what is the best treatment approach for a successful outcome (Donald, 2002). Treatments that are evidence-based and research driven can compliment a clinician's experience. Evidence-based medicine has emerged as an invaluable method of informing clinical and policy decisions about the numerous faces and aspects of healthcare. Evidence-based medicine provides data for questions that do not have intuitive answers or for those items which may do "more harm than good" (Donald). It has significantly aided clinicians in the decision-making process by providing a fair, scientifically rigorous method of evaluating treatment options.

Evidence-based medicine has also assisted professional bodies in developing clearer and more concise working practices, as well as establishing treatment guidelines and practices. Professional accountability and technical complexity are two current issues facing the medical community.

Over the past decade, medicine has come under increased scrutiny. Evidence-based medicine is considered a necessary tool for treating patients, while demands for effective treatment have increased (Donald, 2002). Evidence-based medicine emerged from the notion that decisions about the care of

individual patients should involve the conscientious and judicious use of current best evidence (Fonagy, 2000). Use of evidence-based medicine can bring all players in the medical industry together and significantly aid in the decision making process about treatments and benefits. This can be done with a reduction in litigation and conflict due to varying interests.

The current emphasis in evidence-based medicine for mental health treatments is on promoting effective use of resources and simultaneously allowing for improvements in clinician's knowledge-base (Fonagy, 2000). Ethically, the strongest argument in support of this practice is that it allows the best evaluated methods of health care to be identified.

Another driving force in the utilization of evidence-based medicine is the potential for cost savings (Fonagy, 2000). With rising awareness on mental health issues and the demand by purchasers to know they are obtaining the best treatment for the best price, emphasis on evidence-based practices is both practical and justified. Few people have time to visit libraries and evaluate best practices. Evidence-based medicine provides a structured process for clinicians and patients to access information on what is effective. Treatment interventions produce the intended or expected results.

## **Limitations of Evidence-Based Treatments**

Negative reactions also have emerged due to the assessment of the practices surrounding evidence-based medicine and the utilization of evidence-based treatments. Currently, there are several obstacles to evidence-based decision-making.

One criticism pertains to the vast amount of information available to clinicians. The rapid emergence of data regarding evidence-based treatments has made it difficult for clinicians to both access and disseminate (Burns et al., 1999). While deluged with unstructured information, clinicians and decision-makers alike are able to identify few procedures or systems to enable them to find quickly and accurately the necessary information to address treatment concerns. "Few people have time to visit libraries and no one has time to read, let alone prioritize and store, the thousands - even millions - of articles and books on healthcare that might one day be useful to them. Journals containing useful information are too numerous for most decision-makers to subscribe to, and may be written using too much medical jargon for many people to follow easily" (Burns et al.).

Another criticism relates to the fact that the evidence may be preliminary, rather than well-established, thus the treatments may be so new that their long-term effects are not yet known. Accordingly, assessments of the effectiveness of a treatment may vary across studies depending on the population studied, the questions asked, or the methodology employed (Rodwin, 2001). Even when an area is carefully studied, there frequently is significant uncertainty and vagueness about what treatment is the most effective. Also, the benefits and limitations of a particular treatment vary depending upon the child's other medical conditions. In these instances, there may be concessions between the effectiveness of the treatment and safety/quality of life issues (Rodwin).

In utilizing evidence-based treatments, clinicians need to be retrained, first in using the science-based treatments and secondly in making them more usable for other practitioners (Burns et al., 1999). The authors indicate that "the progression from effective treatments to their implementation and dissemination into real world practice settings is through largely uncharted scientific territory." Efforts to disseminate knowledge to stakeholder groups or implement evidence-based interventions have often failed partly due to their poor fit with the target audience or setting context. The issue of "poor fit" must be examined, along with a variety of issues, before evidence-based interventions can be effectively employed.

The variable quality of research findings makes it difficult for clinicians and policy makers to discriminate between them. Many of the studies utilized in evidence-based medicine have excluded very important variables such as training, staff turnover, minimal family involvement and comorbidity of conditions (Burns et al., 1999). Also, the study process for particular treatment interventions can be long and painstaking, whereas policy decisions need to be made almost immediately. Although there are specific evidence-based treatments for mental disorders and recommendations for their use in official treatment guidelines, such as the American Psychiatric Association's Practice Guidelines for the treatment of psychiatric disorders, it is still very difficult to track the kinds of treatment methods actually being practiced (Donald, 2002).

## Issues for Consideration

Efforts to disseminate knowledge to stakeholder groups or implement evidence-based interventions must address a variety of factors in order to be successful. These issues are discussed below:

- *Differences between science and practice.* Dissemination and implementation efforts require the joining of two, very often distinct, communities. While scientific research seeks to first advance knowledge, clinical practice seeks to do what is immediately best for individual patients.
- *Understanding the target audience.* When disseminating new knowledge, understanding one's target audience is critical. In the mental health community, this target audience varies widely from policy makers and state administrations to local providers or family consumers.
- *The impact of culture.* The "fit" of new information or intervention models within a local context will likely facilitate or impede their implementation.
- *Individual information-processing.* The accurate individual receipt and processing of information is critical to dissemination efforts; unfortunately, this process often goes unmeasured.
- *Organizational change.* Dissemination and implementation efforts should consider organizational change strategies along with those targeting individual beliefs and behaviors since providers are embedded within organizations and efforts towards change may be obstructed by administrative hurdles.

Source: National Institute of Mental Health, 2002.

## Conclusion

Effective psychosocial treatments are available for treating a wide range of commonly encountered disorders in both controlled-research trials and real-world settings. However, these treatments are frequently not widely used by clinicians in the field. The conclusion is that the development of evidence-based treatments does not necessarily lead to their use (Donald, 2002). The dissemination of treatments from research settings to actual clinical practice is a vital step without which evidence-based treatments will be used only by clinical researchers—thus, the general public will not benefit from psychotherapeutic advances.

The majority of mental health providers agree on the necessity of providing empirical support for their interventions. Additionally, the public expects to receive effective treatment from mental health professionals. Therefore, one would expect clinicians to incorporate and accept evidence-based treatment into practice settings.

Several factors have been identified to account for this inconsistency. First, the training that mental health professionals receive does not require that they receive comprehensive training in evidence-based treatments; consequently, when they enter practice, they do not have the skills to

administer these treatments (Donald, 2002). Second, continuing-education programs do not require training in evidence-based treatments; therefore, there is no way to incorporate treatments from research settings to clinical practice. Third, many clinicians in the field are negatively biased toward evidence-based treatments (Donald).

Evidence-based practices can be utilized in “real world settings” and are effective for children suffering and at risk for suffering with mental disorders (Donald, 2002). The failure to disseminate evidence-based treatments to clinical practitioners in the field has resulted in the lack of availability of many of these treatments. This, in turn, has caused a lack of training for appropriate evidence-based treatments for mental disorders in children. With increased accountability in the medical field, the failure to train practitioners in evidence-based treatments will prevent effective utilization and adoption of effective evidence-based treatments.

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# KEY COMPONENTS OF SUCCESSFUL TREATMENTS

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While studies have identified numerous strategies and techniques that are effective in the treatment of different mental health issues, a growing body of research shows that there are three guiding principles that should provide the foundation for any treatment program: integrated programming; engagement of families in treatment efforts; and culturally competent service delivery.

## **Integrated Programming – The “Systems” Approach**

Research continues to support the idea that the mental health needs of children and adolescents are best served within the context of a “system of care,” in which multiple service providers work together in an organized, collaborative way. The system of care approach encourages agencies to provide services that are child-centered and family-focused, community-based, and culturally competent. The guiding principles also call for services to be integrated, with linkages between the child-serving agencies and programs that allow for collaborative planning, development, and implementation of services.

In order to assure continuity of treatment, communities must establish a framework that ensures that a child can transition with ease among the different services. The efficiency of these transitions is enhanced through the creation of effective individualized service plans. These plans are targeted to the child’s specific needs and identify problems, establish goals, and specify appropriate interventions and services.

Providers have found that a breakdown in the system of care is frequently encountered in the area of discharge planning. A discharge plan should be created whenever a child is transitioning from inpatient or residential treatment back into the community. These plans should be updated in consultation with the child’s family or guardian before the child is released from treatment. They should describe the therapy and services begun in the facility and recommend any necessary follow-up services, which should then be coordinated by a case manager. While frequently overlooked, discharge plans are a key component of a comprehensive system of care, as they help to ensure that the gains made in an inpatient or residential setting are continued once the child returns to the community.

Systems of care have been found to produce important system improvements. For example, studies have shown reductions in the use of residential and out-of-state placements, as well as improvements in functional behavior. Parents also appear to be more satisfied with services provided within systems of care than in more traditional service delivery systems. However, the effect of systems of care on costs remains uncertain, and there is little evidence to demonstrate that the system of care framework results in improved clinical outcomes when compared to services delivered within more traditional systems (U.S. Department of Health and Human Services, 1999).

## **Engagement of Families in Treatment Efforts**

During the last two decades, service providers and researchers have increasingly come to realize the important role that families play in mental health treatment services for children. The child mental health system has responded by making families essential partners in the delivery of mental health services for children and adolescents (U.S. Department of Health and Human Services, 1999). For further discussion of the roles that families should play in treatment services, see “Role of the Family in Treatment Programs.”

## **Culturally Competent Service Delivery**

Virginia’s population of racial minorities grew from approximately 23 to 28 percent between 1990 and 2000 (U.S. Census Bureau). This growth in diversity has significant implications for service providers here in the Commonwealth, as cultural factors are becoming increasingly important in the evaluation and treatment of mental disorders.

Culture has been found to impact many aspects of mental illness. Patients from specific cultures may express and manifest their symptoms in different ways, and may differ in their styles of coping, their family and community supports, and their willingness to seek and continue with treatment. Moreover, clinicians may also be influenced by their own cultural values, and this may impact diagnosis, treatment, and service delivery decisions (U.S. Department of Health and Human Services, 2001).

These cultural differences may exacerbate the general problems of access to appropriate mental health services in the community. The mental health treatment setting relies significantly on language, communication, and trust between patients and providers. Therapeutic success may therefore hinge on the clinician’s ability to understand a patient’s identity, social supports, self-esteem, and perception of stigma. Consequently, mental health service providers must recognize underlying cultural influences in order to effectively meet the mental health needs of each segment of the community (U.S. Department of Health and Human Services, 1999).

Culturally competent treatment programs are founded upon an awareness of and respect for the values, beliefs, traditions, customs, and parenting styles of all of the people served in the community. Providers are aware of the impact of their own culture on the therapeutic relationship with their clients, and therefore make sure that they consider these factors when planning and delivering the services for youth and their families. Furthermore, culturally competent programs ideally include multilingual, multicultural staff and provide extensive community outreach (Cross et al., 1989).

The services offered within a community should also reflect a respect for cultural diversity; for example, the inclusion of extended family members in treatment efforts should be incorporated within certain treatment approaches, when appropriate. It would also be beneficial for mental health agencies to display culturally relevant pictures and literature in order to show respect and increase consumer comfort with services. Furthermore, agencies should consider the holidays or work schedules of the consumers when scheduling office hours and meetings (Cross et al., 1989).

In addition, cultural differences other than ethnicity must be considered. For example, Americans living in rural areas display unique characteristics that present barriers to mental health care as well. Some individuals living in these areas do not seek care due to the difficulties of stigma, a lack of understanding about mental illnesses and their treatments, a lack of information about where to go for

treatment, and an inability to pay for care. Furthermore, factors such as poverty, geographic isolation, and cultural differences may hinder the amount and quality of mental health care available to these individuals. These issues are further complicated by the limited access to and availability of mental health specialists, such as psychiatrists, psychologists, psychiatric nurses and social workers in rural areas (NIMH, 2000).

It is important to consider the impact of culture on mental health service delivery. Specialized cultural programming has been found to promote service utilization for all ages, including children (Snowden & Hu, 1997). Furthermore, children and families enrolled in mental health programs that are linked to community culture have been found to be less likely to drop out of treatment than families in mainstream programs (Takeuchi et al., 1995). Cultural training and service planning serve as important components of the mental health delivery system.

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# REFERENCE CHART OF DISORDERS AND EVIDENCE-BASED TREATMENTS

## EVIDENCE-BASED CHILDREN'S MENTAL HEALTH FINDINGS BY TREATMENT TYPE<sup>2</sup>

Disorders/Behavior	Support for Treatment	Positive Effects -- Consistent Evidence	Inconsistent Evidence – Unproven	Comments
ADHD	Evidence-based treatments	<i>Psychosocial</i> Parent Management Clinical behavior therapy <i>Pharmacological Treatments</i> Methylphenidate (MPH)	Dietary replacement, exclusion; various vitamin, mineral, or herbal regimens; biofeedback; and perceptual stimulation	Not necessary to select one treatment at the expense of the other.
Adjustment Disorders	Promising treatments	<i>Psychosocial</i> Cognitive Behavioral Therapy Stress Management Family Therapy Group Therapy		Medication is seldom used as a singular treatment for adjustment disorders due to the fact that child requires assistance in coping with the stressor that is causing the maladaptive behavior.
Anorexia Nervosa	Evidence-based treatments	<i>Psychosocial</i> Nutritional rehabilitation – Considerable evidence suggests that nutritional monitoring is effective in Family psychotherapy Inpatient behavioral programs <i>Pharmacological Treatments</i> SSRIs	Individual Psychotherapy Group therapy 12 Step Programs Somatic treatments	It is important to note that many patients display a limited response to treatment and will require long-term monitoring and intervention.

<sup>2</sup> The information contained in herein is strictly for informational purposes and is not intended to replace the advice and counsel of a medical professional.

<b>Disorders/Behavior</b>	<b>Support for Treatment</b>	<b>Positive Effects -- Consistent Evidence</b>	<b>Inconsistent Evidence – Unproven</b>	<b>Comments</b>
Anxiety Disorders	Evidence-based treatments	<i>Psychosocial</i> Cognitive Behavioral Therapy Modeling CBT and Family Component CBT and Group Component Systemic Desensitization <i>Pharmacological Treatments</i> SSRIs	Herbal Supplements which may impede diagnosis	Phobias may be treated through systematic desensitization. Parenting strategies and behavior management strategies are also effective. Medication should not be utilized as the sole intervention.
Binge Eating Disorder	None Available			The treatment goals and strategies for binge eating disorder are similar to those for bulimia nervosa except patients with binge eating disorder present difficulties associated with being overweight rather than being malnourished.
Bipolar Disorders	Evidence-based treatments	<i>Psychosocial</i> No consistent studies on psychosocial treatments with children <i>Pharmacological Treatments</i> Lithium	Electroconvulsive therapy (no research with children)	Some evidence supporting the use of lithium in the acute phase, no evidence for or against the use of electroconvulsive therapy.
Bulimia Nervosa	Evidence-based treatments	<i>Psychosocial</i> Cognitive Behavioral Therapy Combined Treatments Group Therapy <i>Pharmacological Treatments</i> SSRIs	Bupropion Monoamine oxidase inhibitors (MAOIs)	Treatment includes treatment of co-occurring disorders the establishment of regular, non-binge meals and improvement of attitudes related to the disorder.
Fire Setting	Promising treatments	<i>Psychosocial</i> Cognitive Behavioral Therapy Fire Safety Education		Leaving the child untreated is not beneficial as children usually do not outgrow this behavior.

<b>Disorders/Behavior</b>	<b>Support for Treatment</b>	<b>Positive Effects -- Consistent Evidence</b>	<b>Inconsistent Evidence – Unproven</b>	<b>Comments</b>
Major Depressive Disorder and Dysthymia	Evidence-based treatments	<i>Psychosocial</i> Cognitive Behavioral Therapy Family Systemic Therapy Interpersonal therapy Combined Treatments Group Therapy <i>Pharmacological Treatments</i> SSRIs	Dietary supplements such as Omega-3, St. John's Wort, SAM-e which may have harmful side effects	Most studies fail to accommodate developmental differences in children, lack of culturally sensitive perspective, little attention paid to cultural relevance of materials used.
Mental Retardation	Evidence-based treatments	<i>Psychosocial</i> Individual therapy Family therapy Social skills training Cognitive therapy		Treatment is tailored for co-occurring disorders and is based on two guiding principles: normalization and community-based care.
Oppositional Defiant & Conduct Disorder	Evidence-based Treatments	<i>Psychosocial</i> Parent Training Based on Living w/Children Videotape Modeling Parent Training Multisystemic Therapy Anger Coping Therapy Assertiveness Training Delinquency Prevention Program Rational Emotive Therapy <i>Pharmacological Treatments</i> Stimulants Mood Stabilizers	Boot camps, psychiatric hospitalization, medication trials, brief courses of cognitive-behavioral therapy	Interventions usually performed in school or home Various treatment modalities are utilized for treating these disorders as well as the comorbid disorders which accompany ODD and CD Medications must only be prescribed in conjunction with psychological interventions such as parent training.

<b>Disorders/Behavior</b>	<b>Support for Treatment</b>	<b>Positive Effects -- Consistent Evidence</b>	<b>Inconsistent Evidence – Unproven</b>	<b>Comments</b>
Pervasive Developmental Disorders (Autism & Asperger's disorders)	Promising treatments	<i>Behavior Interventions</i> Educational and Communication Focused Interventions Treatment and Education of Autistic and Related Communication Handicapped Children (TEACCH) approach Natural Language Methods Picture Exchange Communication System Behavior Intervention <i>Pharmacological Treatments</i> Antipsychotics Psychostimulants		(TEACCH) Treatment and Education of Autistic and Related Communication Handicapped Children Home Based Behavior Therapy a good option Low Prevalence of autism, approaches to treatment are 2 types: 1. Focus on specific symptoms or learning needs, 2. Focus on reversing the level of impairment Home based behavior.
Schizophrenia	Evidence-based treatments	<i>Psychosocial</i> Psychoeducational Therapy for the child and for the family Family Intervention Programs <i>Pharmacological Treatments</i> Antipsychotics		Few well conducted trials in Psychopharmacology and children the superiority of atypical over neuroleptic medication. Concerns with side effects. Best Practice guidelines based on extrapolation from adult studies or consensus of child clinicians.
Self Injury	Promising Treatments	<i>Psychosocial</i> Cognitive Behavioral Therapy Behavior Modification Addictions Model <i>Pharmacological Treatments</i> SSRIs		Research continuing on psychosocial interventions and medications. Hospitalization used as last resort.

Disorders/Behavior	Support for Treatment	Positive Effects -- Consistent Evidence	Inconsistent Evidence – Unproven	Comments
Sex Offending	Promising Treatments	Multisystemic Therapy Residential Sex Offender Treatment		Promising sex offender treatment programs often combine an intensive, multi-modal approach with early intervention. Comprehensive cognitive-behavior programs often focus on taking responsibility for one's sexual behavior, developing victim empathy, and developing skills to prevent future offending. Approaches to the treatment of juvenile sex offenders can vary.
Substance Abuse	Evidence-based treatments	<i>Psychosocial</i> Cognitive Behavioral Therapy Group Therapy Behavioral Therapies Skills Development Family Therapy Multisystemic Therapy Individual Psychotherapy Medical detoxification		The use of medication should only be pursued as a last resort in the dually-diagnosed population, as there is potential for misuse and overdose.

<b>Disorders/Behavior</b>	<b>Support for Treatment</b>	<b>Positive Effects -- Consistent Evidence</b>	<b>Inconsistent Evidence – Unproven</b>	<b>Comments</b>
Suicide Prevention	Evidence-based Treatments	<i>Psychosocial</i> Training of Emergency Room professionals for follow up and treatment <i>Pharmacological Treatments</i> Lithium Clozapine SSRIs (comorbid disorders)	Tricyclic antidepressants Closely monitor medications that may increase disinhibition or impulsivity	All medications prescribed to the suicidal child or must be carefully monitored by a third party and any change of behavior or side-effects immediately reported. Education regarding benefits of follow-up treatment to reduce the reoccurrence of attempted suicide should be emphasized.
Tourette's Disorder	Evidence-based treatments	<i>Psychosocial</i> Habit Covariance Habit Reversal <i>Pharmacological Treatments</i> Neuroleptics	Plasma exchange or intravenous immunoglobulin (IVIG)	When tics interfere with functioning and/or there are other disorders also present, medication may be helpful.

## EVIDENCE-BASED CHILDREN’S MENTAL HEALTH Findings by Service Setting

<b>Disorders</b>	<b>Support for Treatment</b>	<b>Positive Effects -- Consistent Evidence</b>	<b>Inconsistent Evidence – Unproven</b>	<b>Comments</b>
Juvenile Justice – Multi Modal Interventions	Evidence-based treatments	Multisystemic Therapy (MST) Wraparound Integrated Systems of Care Functional Family Therapy Cognitive Behavioral Therapy Multidimensional Treatment Foster Care		Multisystemic therapy is the most effective treatment for delinquent adolescents and MST shares strengths with other systemic family approaches.
School Setting Interventions	Promising Approaches	Integration of Mental Health Professionals into the School Environment Creation of a “System of Care” Within the School Environment Engagement of Families in Educational Planning and Services Consistent Program Implementation Other Environmental and Community Factors		Classroom contingency management methods are effective in controlling the behavior of children with conduct problems, parent administered reinforcements enhance classroom contingency management.

# MENTAL RETARDATION

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## **Introduction**

### **Etiology**

### **Comorbidity**

### **Treatment**

*Developmental and Educational Services*

*Treatment of Comorbid Conditions*

*Pharmacological Treatment*

### **Unproven Treatments**

### **Other Important Treatment Elements**

*Cultural Considerations*

*Family Involvement*

*Availability of Community Services and Supports*

## **Introduction**

Mental retardation is not a single, isolated disorder. It is a term used to describe a condition affecting individuals who are limited in mental functioning to a level that affects many aspects of life, including basic skills such as communicating, taking care of personal needs, and social interaction. The national prevalence rate for mental retardation has been cited at approximately one percent (Developmental Disabilities Act, 1994). In Fiscal Year 1999-2000, there were 15,947 children in Virginia ages 3 to 22 in special education who had received a mental retardation diagnosis (Virginia Department of Mental Health, Mental Retardation and Substance Abuse Services, 2001).

The first signs of mental retardation are usually displayed in early childhood, often within the first or second year of a child's life. The child tends to lag behind his peers in milestones such as sitting up, walking, and talking. He also demonstrates lower than normal levels of interest in his environment and responsiveness to others (*Gale Encyclopedia of Childhood and Adolescence*, 1998). It is important that parents, pediatricians, and service providers are familiar with and recognize these signs, as early intervention serves as a crucial component to ensure that the development and quality of life of these children are maximized.

*The Diagnostic and Statistical Manual of Mental Disorders - 4th Edition (DSM-IV)*, published by the American Psychiatric Association, provides the standard criteria for a diagnosis of mental retardation which are used in the diagnosis of children, as well as adults. The disorder is characterized by "significantly subaverage intellectual functioning," which must be supported by three factors: intellectual impairment, significant difficulty in adaptive functioning, and onset before the age of 18 (APA, 1994).

The first required element of the diagnosis—intellectual impairment—is typically measured by cognitive testing instruments. Normal IQ measurements on standardized, individually administered tests such as the Wechsler Intelligence Scale or the Stanford-Binet test generally fall between 80 and 135 and, for this diagnosis, the child must have an intelligence quotient (IQ) that falls below 70 or 75 (Szymanski & King, 1999). The threshold for mental retardation is typically set at 70, and experts

generally agree that scores of 71-75 are only consistent with mental retardation when significant deficits in adaptive behavior are present (Szymanski & King). Normal IQ measurements on these tests generally fall between 80 and 135.

In addition, all children receiving the diagnosis must also demonstrate significant impairment in two or more of the following adaptive skill areas: communication, self-care, home living, social skills, community use, self-direction, health and safety, functional academics, leisure, and work (*DSM-IV*). There are standardized scales to measure these behaviors, but they often do not capture all of the functional domains, and therefore this element of diagnosis is typically measured after a clinical assessment of the child (Szymanski & King, 1999).

The *DSM-IV* also requires that the onset of symptoms occur prior to the age of 18. It is important to note, however, that experts warn that children under the age of two should not be given a diagnosis of mental retardation unless the deficits are relatively severe and/or the child has a condition that is highly correlated with mental retardation, such as Down's Syndrome. Instead, service providers should acknowledge the cognitive or behavioral deficit as a form of developmental disability and leave room for further diagnosis as the child gets older (Biasini et al., in press; Sattler, 1992). "Mental retardation" should not be used interchangeably with the term "developmental disability." A developmental disability is not a medical term, but is instead a legislative concept referring to a broad spectrum of disorders, including mental retardation, epilepsy, and autism.

A diagnosis of mental retardation has been further classified based on the child's level of impairment. The four categories adopted by the *DSM-IV* are: mild (IQ between 50/55 and 70), moderate (IQ between 35 and 50), severe (IQ between 20 and 35), and profound (IQ below 20). Studies have found that 80 to 85 percent of those with the diagnosis fall within the mild mental retardation range, while less than six percent are diagnosed with severe or profound mental retardation (Szymanski & King, 1999).

## **Etiology**

There are numerous causes for mental retardation. Those most frequently cited include external factors such as infections, trauma, toxins, premature births and delivery problems. Genetic disorders have also been cited as a frequent cause of mental retardation, accounting for approximately one third of cases (Szymanski & King, 1999). It is important for the causes of retardation to be identified if possible, in order to clarify the prognosis and tailor treatment efforts (Szymanski & King). Furthermore, the identification of causation may be valuable in alerting the clinician to possible medical and behavioral complications that occur more frequently in certain conditions (Szymanski & King). However, research has shown that in 58 to 78 percent of the cases of mild retardation and in 23 to 43 percent of severe cases, no official cause has been determined (Szymanski & King).

A multidisciplinary team that may include psychologists, psychiatrists, pediatricians, and clinical geneticists typically conducts the assessment for mental retardation. All assessments should be comprehensive, and should include standardized intelligence testing, evaluation of adaptive skills through testing or clinical evaluation, biomedical and family history evaluation, and psychological and behavioral testing (Szymanski & King, 1999).

## **Comorbidity**

Individuals who receive a diagnosis of mental retardation frequently suffer from additional mental disorders as well (Masi, 1998). Clinicians and researchers have explained this high prevalence of comorbidity as the result of the psychological vulnerability of children with mental retardation. This can have a significant impact on a child's coping skills and mental health, and it may be one of the

primary factors limiting the functioning, quality of life, and adaptation of mental retardation to community life (Masi).

The prevalence of comorbidity of mental illnesses has been found to range from 27 to 71 percent in children with mental retardation (Bregman, 1991). There is a substantial range of variation in the prevalence rates found in prior studies due to differences in methodology, diagnostic definitions, and population sampling strategies among the different studies. The most common comorbid conditions are described in more detail below:

- *General Medical Conditions* – Seizure disorders are present in 15 to 30 percent of individuals with severe or greater mental retardation, and motor handicaps (20 to 30 percent) and sensory impairments (10 to 20 percent) are also frequently reported (Szymanski & King, 1999).
- *Pervasive Developmental Disorders* – Mental retardation is extremely common in children with pervasive developmental disorders. Approximately 75 percent of autistic children are also diagnosed with mental retardation (Fombonne, 1997). However, a reciprocal relationship has not been reported; the majority of children with mental retardation do not display significant impairments in reciprocal social interaction that are typically present in pervasive developmental disorders such as autism.
- *Attention Deficit Disorders (ADD and ADHD)* – The incidence of Attention Deficit Disorder (ADD) is more frequent in persons with mental retardation (18 percent) than in the general population (9 percent) (*DSM-IV*). Attention Deficit Hyperactivity Disorder (ADHD) is also particularly frequent, with a range of 4 to 11 percent of persons with mental retardation affected by this disorder (Feinstein & Reiss, 1996). Experts have attributed the frequency of these diagnoses in the mentally retarded to the fact that inattention is often a component of intellectual impairment.
- *Conduct Disorder* – It has been reported that approximately one third of children and adolescents with mental retardation display the characteristics of conduct disorder (Richardson et al., 1985). However, experts caution that it is important to consider the child's circumstances, ability to understand social rules, and possession of sufficient skills to communicate opposition when proposing such a diagnosis (Szymanski & King, 1999).
- *Behavior Disorders* – Children with greater degrees of mental retardation have been found to display increased aggressiveness, feeding disorders, stereotyped movements and self-injurious behavior (Masi, 1998). Self-injurious behavior is particularly common, with approximately 10 to 15 percent of persons with mental retardation displaying these characteristics (Oliver et al., 1987). The tendency to self injury is particularly common in certain mental retardation syndromes, such as Lesch-Nyhan, Prader-Willi, as well as in patients with mental retardation who experience mood disorders (depressive and manic), schizophrenia, personality disorders, and anxiety disorders (especially obsessive-compulsive disorder) (Masi).
- *Mood Disorders* – Mood disorders, especially of the depressive nature, are quite common in persons having mental retardation and are believed to be significantly underdiagnosed (Szymanski & King, 1999). Social isolation, stigmatization, and poor social skills put children with mental retardation at increased risk for depression (Reiss & Benson, 1985). The symptoms are often triggered by external stressful events, but ordinary life changes can also be responsible (Masi, 1998). Bipolar mood disorders are also present in the mentally retarded, but are more difficult to recognize. They have been found to involve dysphoria coupled with periods of irritability, aggressiveness, or self-injury, rather than the more typical manic episode (Masi).
- *Anxiety Disorders* – While it is likely that these disorders are highly prevalent in persons with mental retardation, they are believed to be underreported due to the difficulty diagnosing persons of limited intelligence (Masi, 1998). Research indicates that the most frequent manifestations of anxiety disorders in this population include acute episodes of anger, flight, and crying or

compulsions (repetitive, ritualistic behaviors) (Masi). Clinicians have found that psychosocial stress factors, including fragile self-esteem, fears of failing, and loss of caregivers are likely contributors to the psychological difficulties of this population (Szymanski & King, 1999).

- *Posttraumatic Stress Disorder (PTSD)* – PTSD is also believed to be significantly under-diagnosed in this population (Szymanski & King, 1999). Mentally retarded children are particularly vulnerable to abuse given their high level of dependency and their tendency to want to please others, as well as lack of understanding of their rights. They may also be targeted because of their lack of communication skills, which may prevent reporting.
- *Schizophrenia* – The incidence of schizophrenic disorders has been found to be higher in children diagnosed with mental retardation than in the general population (Heaton-Ward, 1977). All forms of psychotic disorders have been identified in mentally retarded persons (Masi, 1998).

The diagnostic evaluation for psychiatric disorders is principally the same for patients with mental retardation, child and adult, as it is in the general population (Szymanski & King, 1999). It is important to recognize, however, that the psychiatric diagnostic assessment of children with mental retardation must be comprehensive and consider biological, psychological, and social contexts, rather than being merely a “medication evaluation” focused only on the choice of drug to suppress a disruptive behavior. Furthermore, any additional mental health diagnosis should be formal and specific, rather than a nonspecific description of “behavior disorder” or “challenging behavior.” It is important that the child’s assessment and resulting diagnosis demonstrate that he is ill, rather than merely “bad” or “noncompliant.”

There are certain specific limitations that affect the reliability of the dual diagnosis in children and adolescents with mental retardation. First of all, the level of communication skills that the child or adolescent exhibits is strongly related to the reliability of the diagnosis (Szymanski & King, 1999). Individuals with more severe cognitive limitations are less likely to be given a dual diagnosis than children with lower levels of impairment due to their inability to communicate their symptoms and distress (Borthwick-Duffy & Eyman, 1990). Evaluation of significantly impaired children requires the mental health assessor to depend on information provided by the caregivers familiar with the child and direct behavioral observations, which tend to be less informative and reliable.

The reliability of the diagnosis is also highly reliant on the availability of information regarding the biological, psychological, and social history of the child or adolescent (Biasini et al., in press). The child’s history of behavior and symptoms are often crucial in making a diagnosis and, in the absence of this information, the evaluator is placed in the difficult position of making a diagnosis strictly on current symptoms and behavior without being fully informed of a child’s treatment history. This information is particularly crucial in the evaluation of children with profound and severe mental retardation. Many psychologists and psychiatrists rely heavily on biological markers, observable signs, and patterns of family psychopathology to diagnose these severely impaired children (Sturmeay, 1995).

The strength and accuracy of a diagnosis is also directly affected by the experience and training of the clinician conducting the evaluation (Szymanski & King, 1999). It is crucial that the assessment be conducted by an individual specially trained in the evaluation and treatment of children with mental retardation. Furthermore, clinicians must recognize that there are often mismatches between the behaviors scripted in the *DSM-IV* for certain diagnoses and the symptoms presented in children with mental retardation (Biasini et al., in press). These differences can lead to under-diagnosis; therefore evaluators must be comprehensive in their approach and think outside the usual formulas when diagnosing mentally retarded children (Sturmeay, 1995).

## Treatment

The treatment of children with mental retardation is based on two guiding principles: normalization and community-based care (Szymanski & King, 1999). Normalization requires that children with mental retardation live under patterns and conditions of everyday life that are as close as possible to mainstream society. The concept of community-based care flows directly from this principle, calling for the treatment and integration of mentally retarded children within the community to the maximum extent possible. No more than 10 percent of persons with mental retardation in this country have ever lived in institutional settings, and most can be found either living with their families or in community-based out-of-home placements such as foster care, group homes, and independent living programs (Szymanski & King). Service providers have found that, with proper services, the majority of children with mental retardation do well in the community. Those children with mental retardation who are admitted to an institutional setting typically display symptoms of severe mental disorder or intensive or massive medical needs in conjunction with mental retardation.

The primary goal of service providers specializing in mental retardation is prevention, as there is no cure for the condition once the damage has occurred (Szymanski & King, 1999). Whenever possible, providers hope to prevent conditions that may result in mental retardation in children by educating women and families about the need for behaviors such as abstinence from alcohol during pregnancy and frequent child immunizations. Moreover, if an underlying condition that may lead to mental retardation has been identified in a child, providers focus on the treatment of that specific disorder in order to minimize potential brain injuries that could increase the risk of mental impairment.

However, once a child has been diagnosed with mental retardation, providers begin to pursue early intervention, education, and ancillary treatments, such as physical, occupational, and language therapies (Szymanski & King, 1999). In addition, family support and other services are typically put into place to ensure that the child is receiving comprehensive care in the home, school, and community.

The methods and intensity of treatment are adapted as the child progresses in age. In infants, exercises and special types of play are used to provide sensory and motor stimulation and enhance development (*Gale Encyclopedia of Childhood and Adolescence*, 1998). All states are required by law to offer early intervention programs for mentally retarded children from the time they are born. Once the child reaches the age of three, federal law requires that special education programs be made available for the child and family. These services concentrate on self-care, such as feeding, dressing, and toilet training, and also provide assistance with language and communication difficulties and physical difficulties. As the child gets older, the emphasis of special education programs changes to training in daily living skills as well as academic subjects. Treatment efforts will also include medical care for any comorbid physical conditions, such as seizure disorders, motor handicaps, and sensory impairments, as well as treatment of any psychosocial dysfunction and comorbid mental disorders.

Several factors may impact the choice of treatment method in children with mental retardation. First, the child's level of cognitive and communication skills may cause a service provider to adapt the method of treatment. For example, a child who lacks communication skills would be unable to benefit from verbally-based treatments such as psychotherapy; consequently, behavioral modification and educational accommodations would be more effective. Another consideration is the impact of any concurrent general medical disorders. An effective treatment plan requires that the service provider recognize the child's physical limitations and synthesize physical, developmental, and psychological needs and interventions (Szymanski & King, 1999).

Furthermore, the site of treatment may impact the methodology used. In most cases, outpatient settings are appropriate if the necessary services can be secured in the community. However, providers must be more cautious when placing mentally retarded children in inpatient treatment facilities. Clinicians have reported that not all of these facilities are familiar with needs of children with mental retardation and many are not equipped to provide these children with appropriate therapy, habilitative or recreational programs and other necessary services (Szymanski & King, 1999). Consequently, placements must be carefully made after the provider has gained a wealth of knowledge regarding the services offered and the methods used by the facility.

An additional factor that can have a significant impact on treatment efforts is the willingness of the child and family members to participate and comply with the therapeutic plan. Education and ongoing support are essential, and detailed explanations must be given to family members to ensure that they understand all of the behavioral and pharmacological interventions that are being used to treat the child.

## **Developmental and Educational Services**

All states are required by law to offer early intervention programs for children with mental retardation from the time they are born. Infant/toddler services can be home-based, center-based, or some combination of these two methods. The nature of the services is determined based on an assessment of the child and the family priorities. Under federal law, these considerations must be used to develop an Individual Family Service Plan (IFSP) for the child, which should include input from all parties participating in the intervention. This plan is usually developed and coordinated by a case manager who is available and acceptable to the family. The services that are provided in response to this plan may include assistive technology, intervention for sensory impairments, family counseling, parent training, health services, language services, nursing intervention, nutrition counseling, occupational therapy, physical therapy, case management, and transportation to services (Biasini et al., in press).

As the child gets older, psychoeducational services must be provided. The Individuals with Disabilities in Education Act (IDEA) (Public Law 94-142, Public Law 99-457, and Public Law 102-119) requires that children with mental retardation or related developmental disorders receive a free and appropriate education. Interventions are based on the needs of the child as determined by a team of professionals. They should address the priorities and concerns of the family and should be provided in the least restrictive and most inclusive setting, allowing them to have every opportunity to interact with nondisabled peers and to have access to the community resources available to all other children.

The services provided to preschool children and school-aged children can be home-based, but are more frequently center-based. As in the case of infants and toddlers, an Individualized Education Plan (IEP) is developed through team evaluation and parent input. This plan describes the objectives for improving the child's skills and may include family or parent-focused activities. It may include special education services, child counseling, occupational therapy, physical therapy, language therapy, recreational activities, school health services, transportation services, and parent training or counseling. These services must also be provided in the least restrictive setting possible, such as a regular preschool program, Head Start Center, or the child's home (Biasini et al., in press).

## **Treatment of Comorbid Conditions**

The general principles of treatment are the same as those for children with other mental disorders. However, treatment techniques may need to be modified in order to adapt to the individual's developmental level, particularly with regards to communication skills.

There are two elements that have a significant impact on the effectiveness of psychotherapy in children with mental retardation. First, the child must exhibit a sufficient level of communication skills in order for this type of therapy to be appropriate. Second, in order to maximize results, treatment must be implemented across settings (classroom, home, and other environments); and the therapist must collaborate with the other interested parties in the child's life, such as teachers, family members, and other service providers (Szymanski & King, 1999).

The most effective forms of psychotherapy are:

- *Individual therapy* – This type of intervention has been found to be beneficial for mentally retarded children with higher cognitive skills (Harris, 1995). It is best conducted by a therapist specifically trained in developmental disorders. Techniques and activities should be adapted to the child's chronological age and level of development (Szymanski & King, 1999).
- *Family therapy* – Research supports the benefits of family therapy for children with mental retardation (Harris, 1995). It typically focuses on the caregiver's identification and support of the child's strengths and independence, and the provision of opportunities for success. It may also include educational and emotional support components. The family should be seen as treatment team members, as they are essential to recognizing the child's strengths, avoiding guilt feelings and overprotection, supporting the child's pathways to independence, and providing opportunities for success. This form of therapy has also been found to be beneficial in assisting in locating resources, identifying entitlement for services and providing advocacy, empathy, and concrete advice in management of the child's disability (Szymanski & King, 1999).
- *Group therapy* – Therapeutic efforts in a group environment have been found to be particularly useful with adolescents who have relatively good verbal skills, as they often benefit from peer interaction and support (Szymanski & King, 1999; Harris, 1995). Multiple family group therapy has also been found to be beneficial, as it provides the family and child with support in a context similar to society at large (Szymanski & Kiernan, 1983).
- *Behavior modification* – Behavioral modification has been reported to be beneficial to children with mental retardation that lack social skills or demonstrate problem behaviors such as self-injury (Reiss, 1985). This intervention provides a consistent and structured framework for teaching appropriate behavioral patterns, as well as adaptive life skills. It should be generalized and consistent in all settings, such as home and school, and should focus on teaching appropriate skills and behaviors to replace maladaptive behaviors, rather than merely suppressing them (Szymanski & King, 1999).
- *Social skills training* – Social skills training has also been found to improve the integration of mentally retarded children into the community (Hollins et al., 1994). Those who receive social skills training are taught effective social interactions and appropriate social behavior.
- *Cognitive therapy* – This form of therapy teaches children with mild retardation to recognize situations in which they get into trouble and to adopt alternative behaviors and solutions. It has only recently been adapted for use with mentally retarded children, and therefore research regarding its effectiveness is limited (Benson, 1992).

## **Pharmacological Treatment**

The effects of medication are not generally different in mentally retarded children than in the general population (Szymanski & King, 1999). However, certain issues related to pharmacology have been recognized exclusively in the mentally retarded population. For example, clinicians have found that medication is often prescribed to mentally retarded children for symptom suppression without being integrated into the overall treatment plan (Szymanski & King, 1999). The literature repeatedly

advises that medication should not be used for the convenience of caregivers or as a substitute for appropriate services. An additional concern is that follow-up behavioral data is infrequently collected and providers often fail to monitor for side effects. This is especially important in mentally retarded populations, because these patients may be unable to report symptoms adequately.

While psychotropic drugs are not often used with mentally retarded children, they are most often prescribed in patients who exhibit disruptive behavior, including self-injury, stereo-typed behaviors (such as hand or finger twisting, or complex whole body movements), and aggression (Szymanski & King, 1999).

## **Unproven Treatments**

The effectiveness of diet restrictions in mentally retarded patients generally is not supported by research (Szymanski & King, 1999). These types of treatments include vitamin and mineral supplements and various dietary restrictions, such as yeast and gluten-free regimens.

## **Other Important Treatment Elements**

### ***Cultural Considerations***

Any assessment of adaptive behavior focuses on how well children can function and maintain themselves independently and how well they meet the personal and social demands imposed on them by their cultures. Because various cultures may hold their own views regarding the level of functioning/skills expected in children of certain ages, clinicians must be culturally sensitive in diagnosing children with developmental delays and retardation. In addition, the sociocultural background and native language of the child should be considered in assessing intelligence and level of impairment (Szymanski & King, 1999).

### ***Family Involvement***

Service providers must make every effort to include the family in all aspects of treatment and planning. They must consider the level of knowledge and understanding of the family regarding the disability of the child, and must also be sure that the family is sufficiently informed of all service and treatment options. If professionals fail to acknowledge parents as partners in the process, they run the risk of alienating them in the process. This can result in a lack of interest or participation in necessary services.

### ***Availability of Community Services and Supports***

The Arc, a non-profit organization that supports the mentally retarded, has reported that approximately 200,000 individuals nationwide are on waiting lists for such essential supports and services as service coordination, housing, employment, in-home supports, early intervention, transportation, and respite care (The Arc, 1999). A report by the Virginia's Department of Mental Health, Mental Retardation, and Substance Abuse Services (DMHMRSAS) shows that service availability for mentally retarded children is also a serious concern in Virginia. In its Comprehensive State Plan, the DMHMRSAS reported that 1,858 children and adolescents were on the waiting list for mental retardation services (DMHMRSAS, 2001).

Research indicates that lack of services can exacerbate the problems of children with mental retardation, as it may allow for an increase in the severity of the disability or learning delays (The Arc, 1999). Furthermore, the lack of services may also lead to greater dependence, isolation, and a decrease in self-esteem and productivity. Consequently, providers and policy makers must make every effort to identify these children and provide them with necessary services to ensure that they become productive members of society.

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### **Additional Resources/Organizations**

American Association on Mental Retardation  
 4444 North Capitol Street, NW, Suite 846, Washington, DC 2001-1512  
 Website: <http://aamr.org>.  
 Also, *Mental retardation: Definition, classification, and systems of supports* (1992)

National Information Center for Children and Youth with Disabilities (NICHCY)  
 P.O. Box 1492, Washington, D.C. 20013  
 1-800-695-0285 (Voice/TTY)  
 Email: [NICHCY@aed.org](mailto:NICHCY@aed.org); website: <http://www.nichcy.org>

The Arc (formerly Association for Retarded Citizens), website: <http://www.thearc.org>.

IDEA 1997 Statute on Implementing Regulations: contact the United States Department of Education at (202) 205-5465 or (202) 205-5507, or website: <http://www.ed.gov/offices/OSERS/IDEA>.

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# ERVASIVE DEVELOPMENTAL DISORDERS

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## **Introduction**

### **Etiology**

### **Categories of Pervasive Developmental Disorders**

#### **Autistic Disorder**

*Diagnosis*

*Comorbidity*

*General Treatment Principles*

*Treatment Guidelines*

*Promising Treatments*

*Unproven Treatments*

#### **Asperger's Disorder**

*Diagnosis*

*Comorbidity*

*General Treatment Principles*

*Promising Treatments*

*Unproven Treatments*

## **Conclusion**

## **Introduction**

Pervasive Developmental Disorders (PDDs) is a classification used to describe disorders arising during the first years of life which disrupt various developmental processes (National Information Center for Children and Youth with Disabilities, 2001). The diverse expression of symptoms that accompany PDDs may challenge clinicians in diagnosis and treatment. Although children with these conditions may present for evaluation and treatment at any point in the life cycle, parents usually note symptoms as early as infancy and typically onset is prior to three years of age (National Institute of Neurological Disorders and Stroke). PDDs vary from the majority of recognized mental disorders which generally appear in late adolescence or early adulthood (Volkmar, 1999).

Symptoms of PDD include communication problems such as using and understanding language; difficulty relating to people, objects, and events; unusual play with toys and other objects; difficulty with changes in routine or familiar surroundings, and repetitive body movements or behavior patterns (National Institute of Neurological Disorders and Stroke, 2001). Table 1 presents the most common characteristics of PDDs.

*Table 1*

### **Characteristics of Pervasive Development Disorders**

Impairment in social interaction skills; Impairment in communication skills; or Presence of stereotyped behavior, interests, and activities.
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Source: National Information Center for Children and Youth with Disabilities, January 1998.

Children diagnosed with this class of disorders may also exhibit the following characteristics: impairments in social interaction, imaginative activity, verbal and nonverbal communication skills; and participation in activities that tend to be repetitive, and possession of limited number of interests.

Autism is often referred to as a "spectrum disorder," meaning that the symptoms and characteristics of autism can present themselves in a variety of combinations, ranging from extremely mild to quite severe (Autism Spectrum Disorders, 2002). Table 2 identifies all of the umbrella PDD categories, according to the *Diagnostic and Statistical Manual of Mental Disorders - 4th Edition (DSM-IV)*. Two of these—Autistic Disorder and Asperger's Disorder—are covered in this section. Persons needing information on Childhood Disintegrative Disorder and Rett's Disorder, which have a low incidence in children, should research current literature.

Table 2

### Types of Pervasive Development Disorders

- |   |
|---|
| <ul style="list-style-type: none"><li>• <b>AUTISTIC DISORDER</b></li><li>• <b>ASPERGER'S DISORDER</b></li><li>• <b>RETT'S DISORDER</b></li><li>• <b>CHILDHOOD DISINTEGRATIVE DISORDER</b></li><li>• <b>PERVASIVE DEVELOPMENTAL DISORDER NOT OTHERWISE SPECIFIED</b></li></ul> |
|---|

Source: The National Institute of Neurological Disorders and Stroke, 2001.

## Etiology

PDDs are believed to be caused by neurological differences that have yet to be fully explained (Stanford University School of Medicine, 2002). Currently, researchers are investigating areas such as neurological damage and biochemical imbalance in the brain. It is currently understood that these disorders are not caused by any psychological factors (National Information Center for Children and Youth with Disabilities, 2001). Although a number of different theories have been put forward, none has withstood close scrutiny. Probably several causes and etiological pathways lead to PDD. There is no reason to suppose there is only one pathway.

Ten years ago, commonly accepted incidence rates ranged from 5-15 individuals per 10,000 (Stanford University School of Medicine, 2002). Today, projected incidence rates range anywhere from 7-48 per 10,000 for individuals diagnosed with PDD (Stanford University School of Medicine). There also appears to be a gender difference in autism with 4 times more males than females being diagnosed. Autism affects individuals across all racial, ethnic and social groups. Table 3 illustrates these incidence rates.

Table 3

### Incidence of Pervasive Development Disorders

- |  |
|--|
| <ul style="list-style-type: none"><li>• 1 in 1,000 individuals diagnosed the "classic" autism;</li><li>• 1 in 500 individuals within the autism spectrum, including PDDs; and</li><li>• 1 in 200 individuals within the autism spectrum, including PDD and Asperger's.</li></ul> |
|--|

Source: National Autism Society of America Conference, Dr. Marie Bristol-Powers from the National Institute of Child Health and Human Development, as cited by the Autistic Children's Activity Program, 2002.

## Categories

Each of the PDDs has specific diagnostic criteria as outlined by the American Psychiatric Association in its *DSM-IV*. Although the term *pervasive development disorders* was introduced well over a decade ago, it is unfamiliar to lay people, as well as policy makers and health administrators (Rimland, 1993). Rimland notes that classifying these disorders as PDDs may prove to be confusing due to the fact that autism is a specific, rather than a pervasive, disorder characterized by deficits in social and cognitive functioning. However, there is a need for a classification title for this group due to the fact that most children have some form of this disorder, rather than specifically being diagnosed with autism or Asperger's Disorder (Rimland).

The intent behind the *DSM-IV* is that the diagnostic criteria not be used as a checklist, but rather as guidelines for diagnosing pervasive developmental disorders. There are no clearly established guidelines for measuring the severity of a child's symptoms. In many situations, it is difficult to isolate the characteristics of autism from a PDD not otherwise specified (PDDNOS) [Boyle, as cited in the National Information Center for Children and Youth with Disabilities (NICHCY), 2001]. Accordingly, a child may be diagnosed by one practitioner as having autistic disorder and by another practitioner as having PDDNOS.

Generally, a child is diagnosed as having PDDNOS if he has have some behaviors that are seen in autism, but does not meet the full *DSM-IV* criteria for having autistic disorder (NICHCY, 2001). Furthermore, although the terminology and diagnostic process for these disorders can be confusing, the treatment of the child will be consistently based on his diagnosis.

Table 4 outlines major points that help distinguish the difference between the specific diagnoses.

Table 4

### Distinguishing Characteristics of Pervasive Development Disorders

- **AUTISTIC DISORDER**—Impairments in social interaction, communication, and imaginative play prior to age three years. Stereotyped behaviors, interests and activities.
- **ASPERGER'S DISORDER**—Characterized by impairments in social interactions and the presence of restricted interests and activities, with no clinically significant general delay in language, and testing in the range of average to above average intelligence.
- **PERVASIVE DEVELOPMENTAL DISORDER NOT OTHERWISE SPECIFIED**—(commonly referred to as atypical autism) a diagnosis of PDDNOS may be made when a child does not meet the criteria for a specific diagnosis, but there is a severe and pervasive impairment in specified behaviors.
- **RETT'S DISORDER**—A progressive disorder which, to date, has occurred only in girls. Period of normal development and then loss of previously acquired skills, loss of purposeful use of the hands replaced with repetitive hand movements beginning at the age of 1-4 years.
- **CHILDHOOD DISINTEGRATIVE DISORDER**—Characterized by normal development for at least the first two years, significant loss of previously acquired skills.

Source: American Psychiatric Association, as cited by the Autism Society of America, 2002.

## AUTISTIC DISORDER

Autistic disorder is the most common of the PDDs. Manifestations of the disorder vary greatly depending on the developmental level and chronological age of the individual (NICHCY, 1998).

By definition, the onset of autistic disorder is prior to age three years and it follows a continuous course (NICHCY, 1998). In school-age children and adolescents, developmental gains in some areas are common (e.g., increased interest in social functioning as the child reaches school age). Some individuals deteriorate behaviorally during adolescence, whereas others improve (NICHCY).

The essential features of Autistic Disorder are the presence of markedly abnormal or impaired development in social interaction (Murphy, 2001). Older children may fail to develop nonverbal forms of communication and do not have interest in forming friendships. There may be a lack of sharing, enjoyment, interests, or achievements with other people (NICHCY, 1998).

There is an increased risk of autistic disorder among siblings of individuals with the disorder. Rates of the disorder are four to five times higher in males than in females (*DSM-IV*, as cited in the PDD Support Page, 2000). Females with the disorder are more likely, however, to exhibit more severe mental retardation (NICHCY, 1998).

### ***Diagnosis***

There are no medical tests for diagnosing autism, thus an accurate diagnosis must be based on observation of the child's communication, behavior, and developmental levels (Autism Society, 2002). However, because many of the behaviors associated with autism are shared by other disorders, various medical tests may be ordered to rule out or identify other possible causes of the symptoms being exhibited (Murphy, 2001).

Since the characteristics of the disorder vary so much, ideally a child should be evaluated by a multidisciplinary team, which may include a neurologist, psychologist, developmental pediatrician, speech/language therapist, learning consultant, or another professional knowledgeable about autism (Autism Society of America, 2002).

Table 5 outlines the diagnostic criteria for autistic disorder.

### ***Comorbidity***

Research has revealed that autism has familial links with other mental disorders, notably depression, obsessive-compulsive disorder and motor tics [The Chemical, Industrial & Pharmaceutical Laboratories (CIPLA), 2000]. Depression is more frequent in immediate relatives and pre-dates the arrival of the child with autism. However, its occurrence is linked to the development of depression in the child with autism. It may appear that some children with autism appear to have mental retardation, language disorders or even congenital deafness or blindness and these conditions do co-occur with autism (Murphy, 2001). Epilepsy occurs in up to 30 percent of those with autism and can amplify their symptoms. Research has been conducted which suggests that epilepsy might cause or mimic autism (CIPLA).

Table 5

### Diagnostic Criteria for Autistic Disorder

- A. A total of six (or more) items from (1), (2), and (3), with at least two from (1), and one each from (2) and (3):
1. Qualitative impairment in social interaction, as manifested by at least two of the following:
    - (a) marked impairment in the use of multiple nonverbal behaviors such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction;
    - (b) failure to develop peer relationships appropriate to developmental level;
    - (c) a lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g., by a lack of showing, bringing, or pointing out objects of interest);
    - (d) lack of social or emotional reciprocity;
  2. Qualitative impairments in communication as manifested by at least one of the following:
    - (a) delay in or total lack of development of spoken language (not accompanied by an attempt to compensate through alternative modes of communication such as gesture or mime);
    - (b) in individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others;
    - (c) stereotyped and repetitive use of language or idiosyncratic language
    - (d) lack of varied, spontaneous make-believe play or social imitative play appropriate to developmental level;
  3. Restricted repetitive and stereotyped patterns of behavior, interests, and activities, as manifested by at least one of the following:
    - (a) encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus;
    - (b) apparently inflexible adherence to specific, nonfunctional routines or rituals;
    - (c) stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping or twisting, or complex whole-body movements);
    - (d) persistent preoccupation with parts of objects;
- B. Delays or abnormal functioning in at least one of the following areas, with onset prior to age 3 years: (1) social interaction, (2) language as used in social communication, or (3) symbolic or imaginative play.
- C. The disturbance is not better accounted for by Rett's Disorder or Childhood Disintegrative Disorder.

Source: American Psychiatric Association, 1994, as cited in NICHCY.

### **General Treatment Principles**

Due to the severity of autistic disorder, the need for a high level of service, and corresponding high costs, there has been a continuing search for effective treatments. The goal of treatment for autistic disorder is to promote the child's social and language development and minimize behaviors that interfere with the child's functioning and learning (U.S. Department of Health and Human Services, 1999). Intensive special education programs that are sustained over time and behavior therapy implemented early in life can aid the autistic child to acquire language and the ability to learn. Special education programs in highly structured environments also aid the patient in gaining social and job skills. Only recently have studies shown positive outcomes for very young children with autism (U.S. Department of Health and Human Services).

## ***Treatments Guidelines***

Although there is no proven treatment for autism, research has demonstrated the efficacy of applied behavioral methods in reducing inappropriate behavior and in increasing communication, learning, and appropriate social behavior (U.S. Department of Health and Human Services, 1999). Because of the spectrum nature of autism and the many behavioral combinations which can occur, no one approach is effective in alleviating symptoms of autism in all cases.

The treatment information discussed in the following paragraphs has been compiled and analyzed by the Autism Society of America.

Studies show that individuals with autism respond well to a highly structured, specialized education program, tailored to their individual needs. A well-designed intervention approach may include some elements of communication therapy, social skill development, sensory integration therapy and applied behavior analysis, delivered by trained professionals in a consistent, comprehensive and coordinated manner. The more severe challenges of some children with autism may be best addressed by a structured education and behavior program which contains a one-on-one teacher to student ratio or small group environment. However, many other children with autism may be successful in a fully inclusive general education environment with appropriate support. In addition to appropriate educational supports in the area of academics, students with autism should have training in functional living skills at the earliest possible age.

To be effective, any approach should be flexible in nature, rely on positive reinforcement, be re-evaluated on a regular basis and provide a smooth transition from home to school to community environments. A good program will also incorporate training and support systems for parents and caregivers, with generalization of skills to all settings.

## ***Promising Treatments***

The following section is a summary of the treatments highlighted by Families for Early Autism Treatment, Inc. that show promising results in the treatment of autistic disorder in children.

### **Educational and Communication Focused Interventions**

The Treatment and Education of Autistic and Related Communication Handicapped Children (TEACCH) approach recognizes differences in the rate and nature of development among children. Teaching objectives are based on individual developmental patterns. The guiding principles of the TEACCH program are to provide strategies that support the person throughout the lifespan; facilitate autonomy at all levels of functioning; and can be accommodated to fit individual needs.

### **Natural Language Methods**

Significant gains for teaching language, including speech intelligibility, have occurred in the past few years. Speech and language pathologists often integrate communication training with the child's behavior program to provide a coordinated opportunity for structured and naturalistic language learning. The chief focus of skill development for children with autism is communication, because it is the most pervasive area of developmental delay. Instruction in communication is designed to provide a generative tool that will serve many immediate needs throughout the child's life.

### **Picture Exchange Communication System**

The Picture Exchange Communication System (PECS) is a communication training program which helps children with autism acquire functional communication skills. Children using PECS are taught to give a picture of a desired item to a communicative partner in exchange for the item, thus initiating a communicative act for an actual outcome.

### **Behavior Intervention**

Effective treatment for severe behavioral disorders requires early intervention during all or most of the child's waking hours, addressing all significant behaviors in all of the child's environments by all significant persons for many years (Lovaas, as cited by the Autism Society of America, 2002). This best describes the basic idea of intensive behavior intervention. The goal is to teach the child how to learn by focusing on developing skills in attending, imitation, receptive/expressive language, pre-academics, and self-help. However, this method has been controversial and the research findings have been considered by some to be difficult to replicate (Mudford et al., as cited by Elder, 2002).

### **Educational Implications**

Early diagnosis and appropriate educational programs are important to children with autism or PDD (NICHCY, 1998). From the age of three, children with autism and PDD are eligible for an educational program appropriate to their individual needs. Behavior and communication problems that interfere with learning frequently require the assistance of a knowledgeable professional in the autism field who develops and helps to implement a plan which can be carried out at home and school (Autism Society of America, 2002).

### **Pharmacological Treatments**

Antipsychotic medications are often used to treat severe aggression exhibited by children with autism. Numerous controlled clinical trials cited by Elder (2002) and referred to in this section have shown that various types of antipsychotics are efficacious in treating hyperactivity, excitability, and stereotyped behaviors. Psychostimulants have also been used for years to treat the hyperactivity and inattention common in autism. Of all pharmacological information reviewed, the findings associated with psychostimulant trials and the reports of clinicians and families are mixed. However, studies have shown that many children with autism who present with extreme hyperactivity do benefit from psychostimulants. However, individual reactions vary greatly, and many families oppose using these medications.

Serotonin-affecting medications have been shown to be effective in treating symptoms of autistic disorder and have shown to be effective in reducing self-injury, increasing socialization, and decreasing anxiety. It has been estimated that 80 percent of the psychopharmacological interventions used to treat children have unfortunately not been empirically tested on children (Riddle, Kastelic, & Frosch, as cited by Elder). It is not surprising that there are questions about the use of these pharmacologic interventions.

## ***Unproven Treatments***

The following are treatments where there is conflicting data regarding effectiveness.

Auditory integration training	Steroids
Facilitated communication	Antifungal medications
Hyperbaric oxygen	Detoxication; chelation
Secretin	Dietary manipulations (elimination of gluten, casein, etc.)
Vitamin B6 and magnesium	Hippotherapy; dolphin therapy
Dimethylglycine (DMG)	Sensory integration therapy
Intravenous immunoglobulin (IVIG)	Craniosacral therapy
AZT (zidovudine, Retrovir)	Behavioral optometry

Source: Kallen, R. J., M.D. , 2000.

The understanding of autism has grown tremendously since it was first discovered. Although there is no cure, increased knowledge about the disorder has led to the development of better treatments. Because of the rising prevalence of autism, more research is needed to increase knowledge about effective treatment interventions.

## **ASPERGER'S DISORDER**

Asperger's Disorder is a type of PDD which is characterized by problems in development of social skills and behavior (American Academy of Child & Adolescent Psychiatry, 1999). Asperger's is commonly recognized after the age of three (National Institute of Neurological Disorders and Stroke, 2001). In the past, many children with Asperger's Disorder were diagnosed as having autism or other disorders. While autism and Asperger's have certain similarities, there are also several important differences (American Academy of Child & Adolescent Psychiatry).

Clinically, the difference between autism and Asperger's Disorder is based upon the severity and in the qualitative expression of the criteria (Bloch-Rosen, 1999). Both syndromes are characterized by social interaction deficits, impaired communication skills, and unusual or bizarre behaviors (Frith 1991, as cited in Bloch-Rosen). However, motor deficits are more pronounced in Asperger's Disorder and its onset is later, with the child exhibiting social skill deficiencies without grossly impaired language skills (Frith 1991, as cited in Bloch-Rosen). Additionally, children with Asperger's Disorder may exhibit a variety of characteristics and the disorder can range from mild to severe. Children may also have difficulties with change and prefer sameness (Kirby, 2001). Other symptoms include sensitivity to sounds, tastes, smells, and sights, and a preference for soft clothing, certain foods, and intolerance to certain sounds or lights (Kirby).

Asperger's Disorder was not added to the *DSM-IV* until 1994 and only in the past few years has it been recognized by both professionals and parents (Kirby, 2001). Of all of the PDDs included in the *DSM-IV*, Asperger's Disorder has been the most debated (Journal of the American Academy of Child & Adolescent Psychiatry, 1999). Today, children who are diagnosed with Asperger's would have been diagnosed with autism prior to its addition in the *DSM-IV*. The *DSM-IV* classification defines Asperger's on the basis of the presence of qualitative impairments in social interaction like those observed in autism, but without the significant delay in language or cognitive behavior (Journal of the American Academy of Child and Adolescent Psychiatry).

## ***Diagnosis***

Diagnosis of Asperger's Disorder requires the participation of professionals with different areas of expertise. Klin & Volkmar (1995) have stated that this is particularly true with overall developmental functioning, neuropsychological features, and behavioral status. Accordingly, clinical assessment is most effectively conducted by an experienced interdisciplinary team. In the majority of cases, a comprehensive assessment will involve the following components: history; psychological assessment; communication and psychiatric assessments; further consultation as needed; parental conferences; and recommendations. Also, due to the lack of awareness many service providers may have about Asperger's Disorder, it is beneficial for evaluators assessing the child to maintain contact with the professionals who are responsible for obtaining and employing the treatment interventions.

It is important to encourage parental participation in the evaluation of the child. One reason is to demystify the assessment procedures and to make parents an integral part of the assessment and treatment planning. At this time, parents can be informed and educated about the lack of knowledge about Asperger's Disorder and the confusion surrounding the disorder.

## ***Comorbidity***

There are few studies regarding comorbid psychiatric disorders with children diagnosed with Asperger's Disorder. However, research has shown an association between Asperger's Disorder and Tourette's Syndrome (Bloch-Rosen, 1999). Other disorders which may co-occur with Asperger's Disorder include obsessive-compulsive disorder, depression and ADHD (Bloch-Rosen). Comorbidity of certain conditions may vary according to the child's developmental level. For example, ADHD appears to be more common in younger children diagnosed with Asperger's Disorder, while depression may be more apt to emerge in adolescence (Bloch-Rosen). Children with Asperger's Disorder are also at risk for other psychiatric problems, including schizophrenia (Journal of the American Academy of Child & Adolescent Psychiatry, 1999). Mental retardation is not usually observed in children diagnosed with Asperger's Disorder (Journal of the American Academy of Child and Adolescent Psychiatry).

## ***General Treatment Principles***

Because of the scarcity of research on interventions, there are no evidence-based practices available for treating children with Asperger's Disorder. However, there are guiding principles which may be offered, based on informal observations made by experienced clinicians, intervention strategies used with individuals with high-functioning autism, and suggested interventions for individuals with Nonverbal Learning Disabilities syndrome (Klin & Volkmar, 1995).

Treatment for Asperger's, as with all PDDs, should be focused and individualized in order to appropriately relate to the full range of impairments (Journal of the American Academy of Child and Adolescent Psychiatry, 1999). Treatment planning should include provisions for structured opportunities for learning, along with appropriate generalization of what is being learned in order to ensure comprehension (Journal of the American Academy of Child and Adolescent Psychiatry).

Specific intervention, including teaching practices and approaches, behavioral management techniques, strategies for emotional support, and activities intended to foster social and communication competence, should be conceived and implemented in a thoughtful, consistent and individualized manner (Klin & Volkmar, 1995).

### ***Promising Treatments***

The following is a summary of the treatments indicated to have promising results for children having Asperger's Disorder.

### **Educational Interventions**

Educational interventions are necessary in treating a child with Asperger's Disorder. Moreover, because securing educational and related services may be difficult due to lack of knowledge about Asperger's, it is important for the parents and clinician to work closely together to supply the child and school personnel with the necessary information and help.

Because these children generally do well with memory tasks, teaching in a rote fashion may help the child to retain the information presented (NAMI, 2002).

The most important component of the educational curriculum and treatment strategy involves enhancing communication and social competence (Klin & Volkmar, 1995). Accordingly, the curriculum content for the child should be decided based on long-term goals, so that the utility of each element is evaluated in terms of its long-term benefits for the child's socialization skills, vocational potential, and quality of life.

### **Behavior Management**

Children with Asperger's exhibit various challenging behaviors. Therapeutic and educational strategies can be beneficial, and training is favorable for assisting the child in recognizing troublesome behaviors (Klin & Volkmar, 1995). Setting appropriate limits in dealing with problematic behaviors such as obsessive-behavior, excessive interrupting, or any other disruptive behaviors can also be very effective. Moreover, because a child with Asperger's Disorder may require assistance with making safe and appropriate choices, behavior management techniques teach the child how to consider alternatives or the actions of their choices (Klin & Volkmar).

As children diagnosed with Asperger's Disorder age, they may demonstrate symptoms of despondency, negativism, and clinical depression due to their feelings of inadequacy in social situations and failures in maintaining relationships (Klin & Volkmar, 1995). Practicing communication and social skills prepares the child to deal with social and interpersonal expectations. This, in turn, enhances the possibility of establishing friendships (Klin & Volkmar).

### **Psychotherapy**

Although insight-oriented psychotherapy has not been shown to be very helpful, it does appear that fairly focused and structured counseling can be useful for individuals with Asperger's, particularly when the child is experiencing overwhelming sadness or negativism, anxiety, family functioning, frustration about vocational goals and placement, and ongoing social adjustment.

### ***Unproven Treatments***

No drugs are used routinely to treat Asperger's Disorder. Because little information about pharmacological interventions with individuals with Asperger's is available, pharmacological interventions with young children are probably best avoided (Klin & Volkmar, 1995). Specific medication might be indicated if Asperger's is accompanied by debilitating depressive symptoms, severe obsessions and compulsions, or a thought disorder. Pharmacologic interventions are used to treat comorbid disorders, including attention problems, mood disorders, dysthymia, bipolar disorder, and obsessive-compulsive disorder (Klin & Volkmar).

Recent studies suggest Serotonin Selective Reuptake Inhibitors (SSRIs) help treat repetitive behaviors, impulsivity, irritability, and aggression (Brasic, 2002). Controlled clinical trials, based on well-diagnosed populations, are needed to confirm the impression that SSRIs and atypical neuroleptics may alleviate core symptoms of Asperger's syndrome and related conditions (Brasic).

## Conclusion

Early intervention and treatment is the single most important effort a parent can make to influence the outcomes for a child with PDD. Proper assessment is crucial in the diagnosis and treatment of PDD. With appropriate intervention, many associated behaviors can be modified and effective strategies can be instilled to allow the child to cope with PDD.

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### **Additional Resources/Organizations**

National Information Center for Children and Youth with Disabilities  
P.O. Box 1492, Washington, DC 20013-1492  
nichcy@aed.org - www.nichcy.org  
Tel: 202-884-8200 or 800-695-0285 - Fax: 202-884-8441

National Institute of Mental Health (NIMH)  
6001 Executive Blvd., Rm. 8184, MSC 9663, Bethesda, MD 20892-9663  
nimhinfo@nih.gov - www.nimh.nih.gov  
Tel: 301-443-4513 TTY: 301-443-8431 Depression Info: 800-421-4211;  
Anxiety Info: 88-88-ANXIETY (269-4389); Panic Info: 888-64-PANIC (64-72642)  
Fax: 301-443-4279

National Institute on Deafness and Other Communication Disorders Information Clearinghouse  
Communication Avenue, Bethesda, MD 20892-3456  
nidcdinfo@nidcd.nih.gov - www.nidcd.nih.gov  
Tel: 800-241-1044 TTD/TTY: 241-1055

National Institute of Child Health and Human Development Clearinghouse  
PO Box 3006, Rockville, MD 20847  
NICHDClearinghouse@mail.nih.gov  
www.nichd.nih.gov - Tel: 800-370-2943

MAAP Services (For Autism, Asperger's Syndrome, and PDD)  
P.O. Box 524, Crown Point, IN 46308  
chart@netnitco.net; www.maapservices.org/index.html  
Tel: 219-662-1311, Fax: 219-662-0638

Autism Research Institute (ARI)  
4182 Adams Avenue, San Diego, CA 92116  
www.Autismresearchinstitute.com  
Tel: 619-281-7165, Fax: 619-563-6840

Virginia Resource Page  
PADD (People with Attention and Developmental Disabilities Association)  
Contact: Mr. Mark Jacob - Executive Director  
11048 Warwick Boulevard, Newport News, Virginia 23601  
1-888-33PADD or (757) 591-9119  
Fax 757/591-8990, Website: www.padda.org

PEATC (Parent Educational Advocacy Training Center )  
6320 Augusta Drive, Suite 1200, Springfield, Virginia 22150  
Phone: (703) 923-0010 or in VA only 1-800-869-6782; Fax: (703) 923-0030;  
Latino Outreach: (703) 569-6200  
Email: partners@peatc.org; Website: www.peatc.org

Assessment Clinic for Children with Developmental Disorders  
VCU/MCV Department of Psychiatry  
Virginia Treatment Center for Children  
515 N. 10<sup>th</sup> Street, Richmond, Virginia 23219  
Phone (804) 828-4725

Autism Society of America  
7910 Woodmont Avenue, Suite 650, Bethesda, Maryland 20814-3015  
Phone: (301) 657-0881 or 1-800-3-AUTISM; Fax: (301) 657-0869  
Web site: <http://www.Autism-society.org>  
Asperger Syndrome and High Functioning Autism Parents Support Group, Fairfax, Virginia  
Contact: Barry Loss: 703-866-2121; [bloss@erols.com](mailto:bloss@erols.com)

# ADJUSTMENT DISORDERS

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## **Introduction**

## **Classifications**

## **Etiology**

## **Diagnosis**

## **Comorbidity**

## **Promising Treatments**

*Psychotherapy*

*Pharmacological Treatment*

## **Introduction**

An adjustment disorder is a behavioral response to a stressful event or variation in a child or adolescent's life that is not a healthy response to the event or change (The Medical Center Online, 2002). Youth who experience distress in excess of what is expected as a response to a stressor may even experience significant impairment in normal daily functioning and activities (Institute for Health, Health Care Policy and Aging Research, 2002).

Adjustment disorders in children are created by factors similar to those found in adults. Four factors which may contribute to the development of adjustment disorders are the nature of the stressor, vulnerabilities of the child, intrinsic factors, and extrinsic factors (Benton & Lynch, 2002).

In order to be considered and diagnosed as an adjustment disorder, the child's reaction must occur within three months of the identified event (The Medical Center Online, 2002). Typically, the symptoms do not last more than six months, and the majority of the children quickly return to normal functioning (United Behavioral Health, 2002). Adjustment disorders differ from post-traumatic stress disorder (PTSD) in that PTSD usually occurs in reaction to a life-threatening event and may be longer-lasting (Access Med Health Library, 2002).

In 1997, the U.S. Department of Health and Human Services, the Substance Abuse and Mental Health Service Administration and Center for Mental Health Services conducted a Client/Patient sample survey of 8,000 children in mental health facilities. These children were randomly selected and surveyed in order to calculate national estimates regarding mental health services. The findings of the study indicated that 16 percent of these children who were admitted had an adjustment disorder (Institute for Health, Health Care Policy and Aging Research, 2002).

## **Classifications**

The following six types of adjustment disorders are listed in the *Diagnostic and Statistic Manual, IV Edition (DSM-IV)*:

- Adjustment disorder with depressed mood: Symptoms are that of a minor depression.
- Adjustment disorder with anxious mood: Symptoms of anxiety are dominant.
- Adjustment disorder with mixed anxiety and depressed mood: Symptoms are a combination of depression and anxiety.
- Adjustment disorder with disturbance of conduct: Symptoms are demonstrated in behaviors that break societal norms or violate the rights of others.

- Adjustment disorder with mixed disturbance of emotions and conduct: Symptoms include combined affective and behavioral characteristics with mixed emotional features and with disturbance of conduct.
- Adjustment disorder not otherwise specified: This residual diagnosis is used when a maladaptive reaction that is not classified under other adjustment disorders but occurs in response to stress.

Source: Benton & Lynch, 2002.

## Etiology

Adjustment disorders are a behavioral or emotional reaction to an outside stressor and, accordingly, there is no single trigger between the stressor and the child’s reaction to it (The Medical Center Online, 2002). Furthermore, because children possess varying dispositions, as well as different vulnerabilities and coping skills, it is impossible to attribute a single cause to this mental disorder. Thus, the developmental stage of the child and the strength of their support system may influence their reaction to a stressor (The Medical Center Online). There is no evidence to indicate that biological factors influence the cause of adjustment disorders. The common thread in the cause of anxiety disorders is stress as the precipitating factor (Benton and Lynch, 2002).

According to Benton and Lynch (2002), the most important factor in the development of an adjustment disorder is the vulnerability of the child. Vulnerability depends on the characteristics of both the child and the child’s environment. A reliable assessment is not available to assess this variable.

## Diagnosis

Children with adjustment disorder may have a wide variety of symptoms. Symptoms normally include several of the symptoms shown in Table 1.

Table 1

### Symptoms of Adjustment Disorders

Hopelessness	Withdrawal
Sadness	Inhibition
Crying	Truancy
Anxiety	Vandalism
Worry	Reckless driving
Headaches or stomachaches	Fighting
	Other destructive acts

Source: Turkington, 1995.

Because most features of adjustment disorders are subjective (e.g. the stressor, the maladaptive reaction, the accompanying mood and feature, and the time and relationship between the stressor and the response), these disorders can be very difficult to diagnose (Benton and Lynch, 2002). A qualified mental health professional should assess the child for an adjustment disorder following a comprehensive psychiatric evaluation and interview with the child and the family (The Medical Center Online, 2002). Specifically, a personal history appraising development, life events, emotions, behaviors, and the identified stressful event is performed during the assessment process in order to correctly diagnosis the adjustment disorder (The Medical Center Online).

Table 2

## Characteristics of Adjustment Disorders

- Adjustment disorders occur equally in males and females.
- Adjustment disorder stressors and symptoms may vary based on cultural influences.
- The characteristics of adjustment disorder in children differ from those in adults.
- Adolescent symptoms are more behavioral.
- Adult symptoms are more depressive.

Source: The Medical Center Online, 2002.

### **Comorbidity**

Benton & Lynch (2002) indicate that adjustment disorders are most likely to occur with personality disorders, anxiety disorders, affective disorders, and psychoactive substance abuse disorder. More studies that focus on the association between adjustment disorders and other mental disorders, including substance abuse disorders, are needed.

### **Promising Treatments**

There have been no significant studies conducted to assess the effectiveness of treatment for adjustment disorders. However, research has been conducted regarding the age of the child and its impact upon treatment results. Andreasen and Hoenk, as cited by Benton and Lynch (2002), reported that, in children and adolescents, more serious mental illnesses were present at five years following treatment for adjustment disorders.

However, the consensus on treating adjustment disorders is that because an adjustment disorder is a psychological reaction to a stressor, the stressor must be identified and communicated by the child (Benton and Lynch, 2002). If the stressor is "eliminated, reduced or accommodated" (Strain, as cited by Benton and Lynch), the child's maladaptive response can also be reduced or eliminated. Accordingly, treatment of adjustment disorder usually involves psychotherapy that seeks to reduce the stressor, remove the stressor, or improve coping ability.

Treatments for adjustment disorders must be customized to the needs of the child based on the child's age, health and medical history (The Medical Center Online, 2002). Other determining factors include the extent of the symptoms and the subtype of the adjustment disorder.

### **Psychotherapy**

Psychotherapy is the treatment of choice for adjustment disorders, since the symptoms are a direct reaction to a specific stress (Turkington, 1995). However, the type of therapy depends on the needs of the child, with the focus being on addressing the stressors and resolving the problem.

Brief treatment using cognitive-behavioral strategies is the preferred practice (United Behavioral Health, 2002). Cognitive-behavioral approaches are used to improve age-appropriate problem solving skills, communication skills, impulse control, anger management skills, and stress management skills (The Medical Center Online, 2002). Additionally, therapy assists with formatting an emotional state and support systems to enhance adaptation and coping (Benton and Lynch, 2002).

Research conducted by Strain, as cited by Benton and Lynch (2002), suggest that the goals of psychotherapy should include the following:

- Analyze the stressors that are affecting the child, and determine whether they can be eliminated or minimized;
- Clarify and interpret the meaning of the stressor for the child;
- Reframe the meaning of the stressor;
- Illuminate the concerns and conflicts the child experiences;
- Identify a means to reduce the stressor;
- Maximize coping skills; and
- Assist the child to gain perspective on the stressor and manage themselves and the stressor.

Stress management and group therapy are particularly beneficial in cases of high work/family stress. Family therapy is frequently utilized, with the focus being on making needed changes within the family system. These changes may include improving communication skills and family interactions and increasing support among family members (The Medical Center Online, 2002).

### ***Pharmacological Treatment***

Medication is seldom used as a singular treatment for adjustment disorders due to the fact that the child requires assistance in coping with the stressor that is causing the maladaptive behavior. However, targeted symptomatic treatment of the anxiety, depression, and insomnia that occur with adjustment disorders may effectively augment therapy, but is not recommended as the primary treatment for adjustment disorders. As cited in Benton and Lynch (2002) in a retrospective study of 72 adolescents having adjustment disorder, the researchers (Ansari & Matar) found that disappointment in relationships was the primary stressor causing the disorder. Accordingly, such issues must be addressed through psychotherapy, rather than pharmacology, to address the symptoms of the disorder.

If a clinician determines that pharmacotherapy is necessary, short-term use of anxiolytics and hypnotics may be beneficial.

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Turkington, C. (1995). Gale Encyclopedia of Medicine. Adjustment disorders.

United Behavioral Health. (2002). Preferred Practice Treatment Guidelines. Adjustment Disorders. [Online] Available: <http://www.Ubhone.com/html/Guidelines/Preferredpracticeguidelines/Index.html>. [November 2002].

**Additional Resources/Organizations**

Horowitz, Mardi Jon Stress Response Syndromes: PTSD, Grief, and Adjustment Disorders (Hardcover - August 1997).

Noshpitz, Joseph D., Coddington, R. Dean (Editor). Stressors and the Adjustment Disorders (Wiley Series in General and Clinical Psychiatry) Paperback. 1990.

# BEHAVIOR DISORDERS

## ATTENTION DEFICIT HYPERACTIVITY DISORDER

### Introduction

### Etiology

### Comorbidity

### Treatment

#### *Pharmacological Treatments*

### Unproven Treatments

### Other Important Treatment Elements

### Introduction

Attention Deficit Hyperactivity Disorder (ADHD) is one of several childhood disorders brought into the public arena in recent years. ADHD is the current term for a specific developmental disorder describing specific behavioral difficulties. Children with ADHD experience an inability to sit still and pay attention in class. ADHD is also characterized by multiple symptoms of persistent and dysfunctional patterns of overactivity, impulsiveness, inattention, and distractibility (Murphy, Cowan & Sederer, 2001).

*Table 1*

### Facts About Attention Deficit Hyperactivity Disorder

- ADHD affects an estimated 4.1% of youths age 9 to 17 in a six-month period.
- About 2 to 3 times more boys than girls have ADHD.
- Children with untreated ADHD have higher than normal rates of injury.
- ADHD often co-occurs with other problems, such as depressive and anxiety disorders, conduct disorder, drug abuse, or antisocial behavior.
- Symptoms of ADHD usually become evident in preschool or early elementary years.
- The disorder frequently persists into adolescence and into adulthood.
- Treatment may be required throughout life.

Source: National Institute of Mental Health, 2000.

Children with ADHD experience harmful consequences as a result of their behavior. They frequently experience peer rejection and academic and social difficulties which may have long-term effects. According to the National Institute of Mental Health (NIMH) these children may have conduct disorders, experience drug abuse, exhibit antisocial behavior, and incur injuries of all sorts. For many individuals, the impact of ADHD continues into adulthood (NIMH, 2000).

ADHD has been given numerous names since it was first documented. Some of these names include Minimal Brain Dysfunction, Hyperkinetic Reaction of Childhood, and Attention-Deficit Disorder With or Without Hyperactivity (CHADD, 2001). According to the organization Children and Adults with Attention Deficit Disorders (CHADD), with the *Diagnostic and Statistical Manual, 4th Edition (DSM-IV)* classification system, the disorder has been renamed Attention Deficit Hyperactivity Disorder. The current name reflects the importance of the inattention characteristics of the disorder, as well as hyperactivity and impulsivity (CHADD).

## **Etiology**

ADHD is one of the best researched disorders in medicine. Studies over the past 20 years involving twins, adoptions, and molecular investigations have revealed that there is a genetic basis for the disorder (MediFocus, 2002). Recent imaging studies have documented the factual etiology of ADHD within specific areas of the brain.

Since ADHD runs in families, inheritance appears to be an important factor. Families with a child diagnosed with ADHD are more likely than those without ADHD offspring to have family members with the disorder. The heritability of ADHD averages approximately 80 percent, rivaling the heritability factor for the trait of height (Barkley, 2001). Several other developmental characteristics are associated with ADHD. Perinatal injury, malnutrition and substance exposure have also been linked to ADHD (Murphy et al., 2001).

Although a diagnostic test for ADHD is not available, (CHADD, 2001) there is insurmountable evidence supporting the validity of the disorder.

## **Comorbidity**

According to the National Institute of Mental Health (NIMH), ADHD is not usually an isolated disorder and comorbidities may complicate research studies. Specifically, ADHD can occur with learning disabilities (15-25 percent), language disorders (30-35 percent), conduct disorder (15-20 percent), oppositional defiant disorder (up to 40 percent), mood disorders (15-20 percent), and anxiety disorders (20-25 percent). Up to 60 percent of children with tic disorders also have ADHD.

Difficulties with memory, cognitive processing, sequencing, motor skills, social skills, modulation of emotional response, and response to discipline are commonly associated with ADHD (NIMH, 2000). Sleep disorders are also more prevalent in children who suffer from ADHD.

## **Treatment**

There is no treatment available to cure this disorder but many treatments are available that effectively assist with its management. A wide variety of treatments have been used to treat ADHD. Foremost is education of the family and school staff about ADHD and its management.

Among the treatments that result in the greatest degree of improvement in the symptoms, research strongly supports the use of stimulant medications. Methylphenidate is the first-line agent followed by d-amphetamine (Murphy et al., 2001).

Studies on the efficacy of medication and psychosocial treatments for ADHD support the effectiveness of the combination of stimulants and psychosocial treatments for ADHD. Studies also reveal the superiority of stimulants compared to psychosocial treatments (NIMH, 2000).

A Consensus Statement published by the National Institute of Mental Health (1998) maintains that psychosocial treatment for ADHD has included a number of behavioral strategies such as contingency management (e.g., point/token reward systems, and timeout) that typically are conducted in the classroom, parent training (where the parent is taught child management skills), clinical behavior therapy (parent, teacher, or both are taught to use contingency management procedures), and cognitive-behavioral treatment (e.g., self-monitoring, verbal self-instruction, problem-solving strategies, self-reinforcement). Clinical behavior therapy, parent training, and contingency management have also produced beneficial effects. Intensive direct interventions in children with ADHD have produced improvements in key areas of functioning. However, no studies have been conducted on some of these intensive interventions or on how these interventions work with medications prescribed for ADHD.

Studies did reveal that the combination of medication and behavioral treatments usually were not much more effective than just medication alone. However, combined treatment did result in more improved social skills and accordingly, parents and teachers judged this treatment more favorably. Both medications and combined treatment was superior to routine community care, which often involved the use of stimulants.

Treatment of ADHD requires behavioral, psychological and education components. Education of the child and family regarding the nature of the disorder and the methods proven to manage the disorder is crucial in its management. Treatment must be provided over long periods to assist those with ADHD in the ongoing management of their disorder.

### ***Pharmacological Treatment***

The following is based on information from the National Institute of Health (1998). Stimulants are generally considered to be first line treatment for ADHD and are often prescribed by pediatricians, family physicians, specialized psychiatrists or child psychiatrists.

Short-term trials of stimulants have supported the effectiveness of methylphenidate dextroamphetamine (MPH). Few differences have been found among these stimulants. However, MPH is the most studied and the most often used of the stimulants. For a variety of reasons including side effects, incomplete responses or other circumstances, other medications are often recommended in combination with or following unsuccessful trials of stimulants.

Trials have found beneficial effects on the defining symptoms of ADHD and associated aggressiveness for as long as medication is taken. However, stimulant treatments may not regulate the entire range of behavior problems, and children under treatment may still show a higher level of behavioral problems than children without ADHD. The findings also show that there is little improvement in academic achievement or social skills.

It is critical that all involved with the use of these powerful medications in children be clear as to what the treatment targets are for a particular medication so that it can be maintained if it is successful and stopped if it is not effective.

### **Unproven Treatments**

There is a long history of a number of other interventions for ADHD. These include: dietary replacement, exclusion, or supplementation; various vitamin, mineral, or herbal regimens; biofeedback; perceptual stimulation; and a host of others. Some of the dietary elimination strategies showed intriguing results, suggesting the need for future research. Although these treatments have generated considerable interest and there are some controlled and uncontrolled studies using various

treatment strategies, the research regarding these interventions is disproportionate, ranging from no data to well-controlled trials.

## **Other Important Treatment Elements**

It is important to realize that simple inattention or hyperactivity by itself is not sufficient for diagnosis. ADHD has been misdiagnosed in both children and adults by parents, teachers, and even by patients themselves. Misbehavior by children or teens has been inappropriately diagnosed and treated by persons looking for a simple solution to personality difficulties in hopes of avoiding psychotherapy.

While no treatment can cure ADHD, caregivers and parents must educate themselves about this disorder so they can understand it and design an effective treatment plan. It is up to the caregiver to become an informed consumer and learn to distinguish the accurate information from the inaccurate. Relatives, teachers and caretakers need to understand that ADHD is neurobiological and a child's brain works a bit differently. ADHD is not the result of too much sugar or too little discipline.

Effective treatment involves the use of a multimodal approach that includes an appropriate educational program; behavior modification; parent, child and teacher education; and sometimes counseling and medication (CHADD, 2001). Caregivers need to advocate for their children in academic settings as well as in their home environment. Children with ADHD are now eligible for special educational services in the public schools under both the Individuals with Disabilities in Education Act (IDEA: Public Law 101-476) and Section 504 of the Rehabilitation Act of 1973 (Public Law 93-112) (Barkley, 2001). Maximizing positive outcomes under these laws is possible with caregiver involvement.

Effective parent training teach strategies to modify behaviors and improve outcomes. Because ADHD is highly hereditary, many parents of children with ADHD discover that they too have ADHD when their child is diagnosed (CHADD, 2001). Parents with ADHD may need the same types of evaluation and treatment that they seek for their children.

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### **Additional Resources/Organizations**

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Children and Adults with Attention Deficit Disorders (CHADD)  
8181 Professional Place, Suite 201, Landover, MD 20785  
CHADD National Call Center (800) 233•4050; Business (301) 306•7070 FAX (301) 306•7090  
<http://www.chadd.org>

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### **Suggested reading for parents recommended by CHADD:**

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