

HELP FOR FAMILIES

A Directory of Advocacy and Support Groups
for
Youth with Emotional, Developmental and Behavioral Disorders

Compiled by: American Psychiatric Association
Committee on
Chronically Ill and Emotionally Handicapped Children and Adolescents
1994-1998

updated January, 2001

INTRODUCTION

This resource book was created by the members of the American Psychiatric Association's Committee on Chronically Ill and Emotionally Handicapped Children and Adolescents from 1994 to 1998. Cynthia Pfeffer, M.D. was instrumental in the development of this book when she was the chairperson of this committee.

This directory is to help clinicians who evaluate, treat, and provide services to children and adolescents who are behaviorally and emotionally handicapped by offering a brief directory of national groups that advocate for children and their families. It is suggested that collaboration among clinicians, families, and such advocacy groups may expand support available for children who have complex emotional problems.

These advocacy groups have vast experience with individuals who have chronic emotional problems and, as a result, have developed insights into the needs of such individuals. The main aims of these advocacy groups are to identify effective intervention approaches and services to support families of chronically ill children and adolescents, and to raise funds to assist development of research and service delivery. The information in this book includes the name, address, telephone, fax number, and website, where appropriate, of such groups and a brief description of their purpose. This information may be useful to parents and families who have children with specific mental health problems.

Organizations which provide advocacy and support services for this population who wish to be included in this book may contact the Office of Children's Affairs at the American Psychiatric Association (APA) at (202) 682-6857(phone) or e-mail, kids@psych.org.

*The inclusion of an organization in this resource book does not imply endorsement by the American Psychiatric Association.

AL-ANON and ALATEEN

TEL: 1-800-245-4656 - for closest meeting
1-800-992-9239 - drug and alcohol hotline
900-344-26666 - world wide Al-Anon information or
consult phone book for local chapter.

This is a nationwide support service for relatives of active or recovering alcoholics, including adult children of alcoholics, and is run by fellow relatives of alcoholics. It is an official branch of Alcoholics Anonymous (AA) and follows the 12 step principles of AA. This group disseminates information and runs 24-hour drug and alcohol hotlines.

Alateen is a branch of Al-Anon for children aged 10 through adolescence. Some towns have Alateen groups for younger children (e.g., 5-13 years, 8-10 years).

AMERICAN ACADEMY OF CHILD AND ADOLESCENT PSYCHIATRY
3615 Wisconsin Avenue, NW
Washington, DC 20016

Tel: 202-966-7300 Fax: 202-966-2891
Website: www.aacap.org

The American Academy of Child and Adolescent Psychiatry (AACAP) is the leading national professional medical association dedicated to treating and improving the quality of life for children, adolescents, and families affected by mental, behavioral, and developmental disorders.

Membership: 6,500

How to become a member: Members of AACAP are physicians with five years training in general and child and adolescent psychiatry beyond medical school.

Newsletter and other publications: *AACAP News,*
Journal of the American Academy of Child and Adolescent Psychiatry,
Facts for Families

Meetings: Annual Meeting, Mid-Year Institute

AACAP provides information to aid in the understanding and treatment of the developmental, behavioral, and mental disorders which affect children, adolescents, and their families. Of special interest is a series of informational pamphlets called "Facts for Families" which may be seen and printed out from the website cited above.

AMERICAN ASSOCIATION OF SUICIDOLOGY
Suite 408
4201 Connecticut Ave., NW
Washington, D.C. 20008

TEL: 202-237-2280 FAX: 202-237-2282
Website: www.suicidology.org

This nonprofit organization is comprised of mental health professionals, suicide prevention center volunteers, and survivors of suicide. Its purposes are to provide education to the public about methods of suicide prevention. It assists suicidal individuals through a national network of certified suicide prevention centers and hot lines and offers support to families and friends of individuals who committed suicide. It holds an annual national conference in which current research, treatment, and other services are discussed. It disseminates literature, newsletters and other materials pertinent to suicide prevention.

ANXIETY DISORDERS ASSOCIATION OF AMERICA (ADAA)
11900 Parklawn Drive, Suite 100
Rockville, Maryland 20852-2624

Tel: 301-231-9350 Fax: 301-231-7392

E-mail: anxdis@adaa.org

Website: www.adaa.org

ADAA receives more than 75,000 calls and letters each year from people seeking information on anxiety disorders and to contact treatment providers. A subscription to ADAA's bimonthly newsletter, the REPORTER, costs \$30 (includes listing of treatment providers in your state who are ADAA professional members and specialize in treating anxiety disorders). ADAA professional membership costs \$150 a year, and student membership is \$25.

ADAA's annual conference is held each March. The 2001 meeting will be held in Atlanta, GA, March 22-25 at the Grand Hyatt Atlanta Buckhead Hotel.

Lists of anxiety support groups in every state are available from ADAA. An on-line bookstore features more than 100 consumer and professional titles available at substantial discounts to ADAA subscribers/ supporters and professional and student members. Materials are available on anxiety disorders in children, adolescents and young adults. Contact ADAA today for a wide variety of useful information on anxiety disorders.

The ARC of the United States

1010 Wayne Ave., Suite 650
Silver Spring, MD 20910

TEL: 301-565-3842

FAX: 301-565-5342

There are many local chapters throughout the country. In some districts, a list of the chapters can be found in the white pages of the phone book under the Arc.

The Arc is the nation's largest organization solely devoted to improving the welfare of children and adults with mental retardation and related developmental disabilities and their families. The Association also provides services to parents and other individuals, organizations, and communities for jointly meeting the needs of people with mental retardation. The Arc is essentially a grass-roots organization formed in 1950 by a small group of parents and other concerned individuals. Today it has 140,000 members and 1,000 state and local chapters across the nation.

The Arc conducts an annual nationwide television, radio, and print media campaign to educate the public about people with mental retardation. The National Employment and Training Program of the Arc, through a nationwide network of job placement personnel, is helping workers with mental retardation obtain and retain jobs in competitive employment.

The Arc's Research Fund supports activities aimed at reducing the effects of mental retardation. The Arc continuously works with the nation's policymakers to protect the rights of children and adults with mental retardation and to create and expand programs for them.

Local chapters of the Arc differ in their services and interests, offering a diverse array of activities and opportunities for retarded persons and their families. There are many successful parent support groups. Citizen advocacy and self-advocacy programs, recreational activities, public education efforts and employment programs also are available through many local chapters.

Asperger Syndrome Coalition of the United States, Inc. (ASC-US)
P.O. Box 49267
Jacksonville Beach, FL 32240-9267

Website :www.asperger.org

ASC-US is a national, non-profit organization that provides current, comprehensive information on Asperger Syndrome and related conditions including pervasive developmental disorder not otherwise specified, high-functioning autism, nonverbal learning disability, semantic-pragmatic disorder, and hyperlexia.

Asperger Syndrome Education Network, Inc. (ASPEN)
Tel: 737-321-0800

e-mail: info@aspennj.org
website: www.aspennj.org

ASPEN is a volunteer, non-profit organization providing support, advocacy, and information to individuals and families whose lives are affected by Asperger Syndrome, pervasive developmental disorder not otherwise specified (PDD-NOS), and high-functioning autism. As an approved New Jersey Department of Education Professional Development Provider, ASPEN® conferences and workshops offer continuing education credits to its attendees.

The 11 New Jersey chapters hold monthly meetings, alternating parent support/information sharing with speaker presentations on those topics most relevant to the individuals and families served. Educators and medical/health professionals are welcome to attend those meetings featuring speakers. ASPEN maintains a comprehensive website, publishes a resource directory and quarterly newsletter, hosts statewide conferences and workshops, and performs in-service training for school districts. Each local chapter provides members with a lending library of the most current and useful materials on AS, PDD-NOS, and HFA.

Annual dues are \$25 for families and professionals.

AUTISM RESEARCH INSTITUTE
4182 Adams Avenue
San Diego, CA 92116

Tel: 619-281-7165 Fax: 619-563-6840
Website: www.autism.com/ari/

The Autism Research Institute (ARI) conducts research and disseminates information on autism, pervasive developmental disorder (PDD), and related severe behavioral disorders in children.

ARI provides information on request to parents, to professionals, to other groups, and to the media. Its newsletter is *Autism Research Review International*. An educational conference, Defeat Autism Now!, is held annually for physicians and parents.

For a free information package, including a sample copy of the newsletter, contact the above address/phone and indicate whether requester is a parent or a professional.

AUTISM SOCIETY OF AMERICA

Suite 650

7910 Woodmont Avenue

Bethesda, MD 20814-3015

TEL: 301-657-0881 FAX: 301-657-0869

1-800-3AUTISM

There are many local state and city chapters. Phone numbers are listed in the white pages of the phone book.

The purposes of the Autism Society of America are:

- a) to promote and advocate for the general welfare of people with autism,
- b) to further the advancement of all ameliorative and preventative study, research, therapy, care and cure of persons with autism,
- c) to develop a better understanding of the problems of persons with autism by the public throughout the country and the world,
- d) to promote the establishment of adequate diagnostic, therapeutic, education and recreational facilities for persons with autism,
- e) to encourage the formation of local chapters, to advise and aid parents in helping their family members with autism, and to coordinate the efforts and activities of these chapters, and
- f) to serve as a clearinghouse for gathering and disseminating information regarding persons with autism.

The Autism Society has more than 10,000 members. More than 20 percent of the members are professionals in the field of autism and other disabilities. The majority of the members are family members, guardians, and friends of people with autism. In 1989 there were 174 local chapters and 47 state chapters of the Society.

C.H.A.D.D.
Children and Adults with Attention-Deficit/Hyperactivity Disorder
Suite 201
8181 Professional Plaza
Landover, MD 20785-7221

Tel: 301-306-7070 Fax: 301-306-7090

Website : www.chadd.org

CHADD, founded in 1987, is a support network run by and for parents of children with attention-deficit/hyperactivity disorder. This disorder affects as many as three to five percent of all children and approximately two to four percent of adults. It has support groups throughout the country, disseminates information, and sponsors conferences and workshops.

For more information about CHADD, consult its website listed above.

Childhelp USA
15757 N. 78th Street
Scottsdale, AZ 85260

Tel: 602-922-8212 Fax: 602-922-7061
1-800-4-A-CHILD (hotline)
1-800-2-A-CHILD (TDD/hearing impaired)
Website: www.childhelpusa.org

Childhelp USA is one of the oldest national organizations dedicated to the prevention, treatment, and research of child abuse. The National Child Abuse Hotline operates 24 hours a day, seven days a week and provides crisis intervention, information, and referral to agencies and services which range from adult survivor treatment to domestic violence shelters, child abuse evaluations to substance abuse rehabilitation programs, local health services to national prevention resources.

The hotline is anonymous and toll-free. The language line answers calls in 140 different languages. Counselors are all degreed professionals.

COUNCIL FOR CHILDREN WITH BEHAVIORAL DISORDERS
Council for Exceptional Children
1110 N. Glebe Road
Arlington, VA 22201-5704

Tel: 703-620-3660 Fax: 703-264-9494
1-888-232-7733
TTY 1-703-264-9446
Website: www.cec.sped.org

The Council for Children with Behavioral Disorders (CCBD) is the official division of The Council for Exceptional Children (CEC) committed to promoting and facilitating the education and general welfare of children and youth with behavioral and emotional disorders. CCBD members include educators, parents, mental health personnel, as well as a variety of other professionals and related service providers.

The goals of CCBD include:

- Promoting quality educational services and program alternatives for persons with behavioral disorders.
- Advocating for the needs of children and youth with behavioral disorders and their families.
- Encouraging research and professional growth as vehicles for better understanding behavioral disorders.
- Disseminating relevant and timely information through professional meetings, training programs, and publications.
- Providing professional support for persons who are involved with and serve children and youth with behavioral disorders.
- Supporting the activities, policies, and procedures of CEC and other CEC divisions.

CCBD has 8,400 members. For a membership application, call CEC's Constituent Services Center at (toll-free) 888/232-7733; or, see our Website (www.cec.sped.org).

CCBD members enjoy many opportunities for achieving professional growth and networking with others who share their interests. CCBD members receive the division's journals and newsletter. As members of CEC, CCBD members also receive CEC's journals, discounts on professional materials, services, conferences and conventions plus group rates in a variety of insurance plans including professional liability, medical, automobile and other insurance.

The CCBD journal *Behavioral Disorders* (published quarterly), provides professionals with a means to exchange information and share ideas related to research, empirically tested educational innovations, and issues and concerns relevant to students with behavioral disorders. CCBD also has a practitioner-oriented journal, *Beyond Behavior* (published three times a year), that focuses on issues faced by direct service providers in the field. The *CCBD Newsletter* (published six times per year) is designed to keep members informed about the organization and its activities.

CCBD sponsors sessions focusing on behavioral and emotional disorders at the CEC Annual International Convention. CCBD also sponsors an annual conference as well as forums and intensive training institutes throughout the year on topics of interest to persons who work with children and youth with behavioral and emotional disorders.

Cure Autism Now
5455 Wilshire Blvd. #715
Los Angeles, CA 90036

888-8AUTISM
E-mail: info@cureautismnow.org
Website: www.cureautismnow.org

Cure Autism Now is an organization of parents, leading scientists and clinicians dedicated to finding effective treatments and a cure for autism. Through funding and commitments of over \$5.7 million in just five years, Cure Autism Now is the largest private funder of autism research and resources in the country.

Cure Autism Now has also established the Autism Genetic Resource Exchange (AGRE), the largest genetic resource of families with more than one child with autism in the country. Since its development, the number of institutions investigating the genetics of autism has quadrupled.

EASTER SEALS, Inc.
Suite 1800
230 W. Monroe Street
Chicago, IL 60606-4802

Tel: 312-726-6200 Fax: 312-726-1494
312-726-4258 (TDD)
E-mail: info@easter-seals.org
Website: www.easter-seals.org

Easter Seal's mission is to create solutions that change lives for children and adults with disabilities, their families, and their communities. We work to identify the needs of people with disabilities and to provide appropriate developmental and rehabilitation services. Our Easter Seals operate 407 sites that provide services to children and adults with disabilities and their families. Each site provides different services. Call to inquire about Easter Seals in your community. The on-line director lists sites by state: www.easter-seals.org

Major services include:

- Services for children: early intervention, child development centers, part day after school programs, preschool, tutoring
- Medical rehabilitation for children and adults, including physical, occupation and speech therapies, wellness programs, movement and mobility
- Vocational services: employment services for adults and transition for school to work
- Adult and senior day services: respite, in-home programs
- Camping and recreation: day camps, residential camps for children and adults
- Residential housing services
- Support services: support groups, transportation, equipment loan, information and referral to local disability community services
- Disability Help Line: information and referral service through Easter Seals national office.

LEARNING DISABILITIES ASSOCIATION, INC. (LDA)
4156 Library Road
Pittsburgh, PA 15234

Tel: 412-341-1515

There are 50 state affiliates and over 775 local chapters.

The goals of the association are:

To encourage research in neuro-physiological and psychological aspects of learning disabilities,

To stimulate development of early detection programs,

To create a climate of public awareness and acceptance,

To disseminate information widely,

To provide advocacy information,

To develop and promote legislative assistance,

To improve regular and special education, and

To establish career opportunities.

The national office and local chapters provide free information and packets about referral services. They also provide a written list of publications and a resource text.

LDA and state affiliates may work directly with local school systems in the development of programs.

The LDA Public Affairs Committee provides information on pending legislation which may affect children with learning disabilities and/or their families.

NAMI *The Nation's Voice on Mental Illness*
(Formerly the National Alliance for the Mentally Ill)
2107 Wilson Blvd., Suite 300
Arlington, VA 22201-30442

Tel: 703-524-7600 Fax: 703-524-9094
Helpline: (800) 950-6264
Website: www.NAMI.org

Since its first meeting in 1979, NAMI has become the nation's leading grassroots, self-help and family advocacy organization solely dedicated to improving the lives of people with severe mental illnesses such as schizophrenia, bipolar disorder (manic depression), major depression, obsessive-compulsive disorder, and panic disorder.

NAMI has built its organization on four cornerstones: support, education, advocacy and research. With more than 200,000 members and 1,200 state and local affiliates in all 50 states, the District of Columbia, Puerto Rico, American Samoa, and Canada, NAMI's members work to bring hope and progress to thousands of people with severe mental illnesses. *Mental Illness Awareness Week* is observed each year during the first week of October. NAMI affiliates work jointly with members of the American Psychiatric Association to mount this educational campaign.

NAMI's Campaign to End Discrimination, now in its fourth year, is seeing results. National and local legislators are helping to lead the fight for equal access to treatment. Media are educating the public about brain disorders through fair and accurate reporting. And increasingly, Hollywood is recognizing its responsibility to end sensational portrayals of people with mental illness.

Children with mental illness have long been overlooked by the medical community. As few as one in five children with mental illness actually receives treatment. The quarterly newsletter, *Because Kids Grow Up: NAMI News* is a free resource to parents and educators that focuses on early onset mental illness. Through a reading list NAMI offers parents a collection of books and videos on mental illness, including titles specifically dedicated to child and adolescent brain disorders. The website features a youth section where local contacts, factsheets, and newsletter articles are available to read or print.

NATIONAL DEPRESSIVE AND MANIC-DEPRESSIVE ASSOCIATION

Suite 501
730 N. Franklin St.
Chicago, IL 60610

Tel: 312-642-7243
1-800-826-3632

The national headquarters provides referrals to 275 local chapters and to chapters in eight foreign countries. These chapters offer:

- support groups,
- educational activities,
- referrals to MD's, and
- informational referrals to other mental health professionals.

A bookstore catalogue offers books, audio- and videotapes, including material on child and adolescent affective disorders.

The national convention alternates with regional conferences every other year.

Three categories of membership are national members, professional members, and family members.

Membership in the Depressive and Manic Depressive Association includes discounts when ordering through our bookstore and when registering for the national conventions, receipt of a quarterly newsletter, and important updates concerning the illness.

NATIONAL INFORMATION CENTER FOR CHILDREN AND YOUTH WITH
DISABILITIES
P.O. Box 1492
Washington, DC 20013-1492

TEL: 800-695-0285 FAX: 202-884-8441
202-884-8200

This information center gathers and disseminates information regarding children and youth to the age of 21 with a wide range of disabilities. This center produces an updated publication list.

There is an extensive library of information, and staff can research questions or topics and provide written information. The service is available to professionals and lay people. There are small fees for some publications.

OBSESSIVE COMPULSIVE FOUNDATION (OCF)
337 Notch Hill Road
North Branford, Connecticut 064710

Tel: 203-315-2190 FAX: 203-315-2196
E-mail: info@ocfoundation.org
Website: www.ocfoundation.org

The OC Foundation is a voluntary non-profit organization composed of people with obsessive compulsive disorder (OCD), their families, friends, professionals and other concerned individuals. The Foundation is dedicated to early intervention in controlling and finding better treatments for OCD, and for improving the welfare of people with this disorder.

Foundation programs include:

<u>Education</u>	of the public and professionals so that people with OCD can be more easily identified and helped.
<u>Research</u>	into causes, new treatments, and ultimately cure of OCD.
<u>Service</u>	is provided to families and professionals to insure that people with OCD can obtain the information they need to reach their potential. The foundation provides lists of important publications which it makes available to its members, and all members receive, on joining, the book, <u>Learning to Live with OCD</u> (written especially for family members)

OCF also publishes a bi-monthly newsletter, OCD Newsletter. Kidscope is a semi-annual newsletter for children and teens with OCD and related disorders.

Regular membership is \$45 per year or whatever an individual can afford to pay.

THE TOURETTE SYNDROME ASSOCIATION, INC.
42-40 Bell Boulevard
Bayside, New York 11361

Tel: 718-224-2999

E-mail: tse@tse-usa.org

Website: www.tse-usa.org

There are many local/state chapters. The national office can provide the phone numbers.

The Tourette Syndrome Association, Inc. is a voluntary, nonprofit organization of patients, their families and friends, and health care professionals. The goals of the association are:

To educate physicians and the general public about Tourette Syndrome with a view toward promoting more accurate diagnosis and better treatment.

To stimulate and support research on Tourette syndrome, especially through the Tourette Research Brain Bank at Mt. Sinai Hospital in New York City.

To be of service to patients and their families.

The Association maintains a library of information and provides written material to professionals and families. The Association serves as a clearing house for gathering and disseminating information regarding Tourette Syndrome. The Association stimulates the development of state/local chapters and hopes to coordinate the activities of these chapters.

