What is Autism?

A Resource on: Autism, Asperger’s Syndrome, Pervasive Developmental Disorder – NOS, Rett’s Disorder, and Childhood Disintegrative Disorder
Aloha and e kono mai! This brochure is being provided by the Autism Interagency Collaboration Workgroup to provide information concerning autism and to assist your family in navigating Hawai‘i’s services for children with special needs. The following telephone numbers and web sites are provided to assist you in accessing services for your family.

For services for infants and toddlers between birth and age three:
HKISS (Hawai‘i Keiki Information Service System)
Oahu – 973-9633
Neighbor Islands – 1(800)235-5477

For services for school-age children from birth – 21:
Department of Education: 735-8250, Ext. 229
http://sssb.k12.hi.us (click on autism)

For services for individuals with developmental disabilities:
Division of Developmental Disabilities
733-9172

Sources for parent information:
Special Parent Information Network (SPIN)
Oahu: 586-8126
For neighbor islands:
Dial your island number, and then Ext. 6-8126
Kaua‘i: 274-5141
Hawai‘i: 974-4000
Maui: 984-2400
Moloka‘i: 1(800)468-4644
Lana‘i: 1(800)468-4644
http://www.spinhawaii.org
AWARE Parent Training and Information Project
536-9684; Ext. 26
1(800)533-9684 (Neighbor Islands)
Hawai‘i Families as Allies 487-8785
Military Family Support Group 433-6205
or 577-7643

For national resources on autism and information about the Autism Society of Hawai‘i (ASH):
Autism Society of America
7910 Woodmont Avenue, Suite 300
Bethesda, MD 20814-3015
1(800)3AUTISM
1(301)657-0881
1(301)657-0869
http://www.autism-society.org/
What is Autism?

Autism is a complex developmental disability that typically appears during the first three years of life. The result of a neurological disorder that affects the functioning of the brain, autism and its associated behaviors have been estimated to occur in as many as 1 in 500 individuals (Centers for Disease Control and Prevention 1997). Autism is four times more prevalent in boys than girls and knows no racial, ethnic, or social boundaries. Family income, lifestyle, and educational levels do not affect the chance of autism’s occurrence.

Autism impacts the normal development of the brain in the areas of social interaction and communication skills. Children and adults with autism typically have difficulties in verbal and non-verbal communication, social interactions, and leisure or play activities. The disorder makes it hard for them to communicate with others and relate to the outside world. In some cases, aggressive and/or self-injurious behavior may be present. Persons with autism may exhibit repeated body movements (hand flapping, rocking), unusual responses to people or attachments to objects and resistance to changes in routines. Individuals may also experience sensitivities in the five senses of sight, hearing, touch, smell, and taste.

Over one half million people in the U.S. today have autism or some form of pervasive developmental disorder. Its prevalence rate makes autism one of the most common developmental disabilities. Yet most of the public, including many professionals in the medical, educational, and vocational fields, are still unaware of how autism affects people and how they can effectively work with individuals with autism.
What is the Autism Society of America?

Founded in 1965 by a small group of parents, the Autism Society of America (ASA) continues to be the leading source of information and referral on autism and the largest collective voice representing the autism community for more than 33 years. Today, more than 24,000 members are connected through a volunteer network of over 240 chapters in 50 states.

The mission of the Autism Society of America is to promote lifelong access and opportunities for persons within the autism spectrum and their families, to be fully included, participating members of their communities through advocacy, public awareness, education, and research related to autism.

In addition to its volunteer Board of Directors, composed primarily of parents of individuals with autism, the ASA has a Panel of Professional Advisors, comprised of nationally known and respected professionals who provide expertise and guidance to the Society on a volunteer basis.

The ASA is dedicated to increasing public awareness about autism and the day-to-day issues faced by individuals with autism, their families, and the professionals with whom they interact. The Society and its chapters share common goals of providing information and education, supporting research, and advocating for programs and services for the autism community.
Several related disorders are grouped under the broad heading "Pervasive Developmental Disorder" or PDD—a general category of disorders which are characterized by severe and pervasive impairment in several areas of development (American Psychiatric Association 1994). A standard reference is the Diagnostic and Statistical Manual (DSM), a diagnostic handbook now in its fourth edition. The DSM-IV lists criteria to be met for a specific diagnosis under the category of Pervasive Developmental Disorder. Diagnosis is made when a specified number of characteristics listed in the DSM-IV are present. Diagnostic evaluations are based on the presence of specific behaviors indicated by observation and through parent consultation, and should be made by an experienced, highly trained team. Thus, when professionals or parents are referring to different types of autism, often they are distinguishing autism from one of the other pervasive developmental disorders.

Individuals who fall under the Pervasive Developmental Disorder category in the DSM-IV exhibit commonalties in communication and social deficits, but differ in terms of severity. We have outlined some major points that help distinguish the differences between the specific diagnoses used:

- **Autistic Disorder** - impairments in social interaction, communication, and imaginative play prior to age 3 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 PDD-NOS 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** - 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** - normal development for at least the first 2 years, significant loss of previously acquired skills.

(American Psychiatric Association 1994)

Autism is a spectrum disorder. In other words, the symptoms and characteristics of autism can present themselves in a wide variety of combinations, from mild to severe. Although autism is defined by a certain set of behaviors, children and adults can exhibit any combination of the behaviors in any degree of severity. Two children, both with the same diagnosis, can act very differently from one another and have varying skills.

Therefore, there is no standard "type" or "typical" person with autism. Parents may hear different terms used to describe children within this spectrum, such as: autistic-like, autistic tendencies, autism spectrum, high-functioning or low-functioning autism, more-abled or less-abled. More important to understand is, whatever the diagnosis, children can learn and function productively and show gains from appropriate education and treatment. The Autism Society of America provides information to serve the needs of all individuals within the spectrum.
Diagnostic categories have changed over the years as research progresses and as new editions of the DSM have been issued. For that reason, we will use the term "autism" to refer to the above disorders.

**What Causes Autism?**

Researchers from all over the world are devoting considerable time and energy into finding the answer to this critical question. Medical researchers are exploring different explanations for the various forms of autism. Although a single specific cause of autism is not known, current research links autism to biological or neurological differences in the brain. In many families there appears to be a pattern of autism or related disabilities – which suggests there is a genetic basis to the disorder – although at this time no gene has been directly linked to autism. The genetic basis is believed by researchers to be highly complex, probably involving several genes in combination.

Several outdated theories about the cause of autism have been proven to be false. Autism is not a mental illness. Children with autism are not unruly kids who choose not to behave. Autism is not caused by bad parenting. Furthermore, no known psychological factors in the development of the child have been shown to cause autism.

**How is Autism Diagnosed?**

There are no medical tests for diagnosing autism. An accurate diagnosis must be based on observation of the individual’s communication, behavior, and developmental levels. 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.
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 other professionals knowledgeable about autism. Diagnosis is difficult for a practitioner with limited training or exposure to autism. Sometimes, autism has been misdiagnosed by well-meaning professionals. Difficulties in the recognition and acknowledgment of autism often lead to a lack of services to meet the complex needs of individuals with autism.

A brief observation in a single setting cannot present a true picture of an individual’s abilities and behaviors. Parental (and other caregivers’) input and developmental history are very important components of making an accurate diagnosis. At first glance, some persons with autism may appear to have mental retardation, a behavior disorder, problems with hearing, or even odd and eccentric behavior. To complicate matters further, these conditions can co-occur with autism. However, it is important to distinguish autism from other conditions, since an accurate diagnosis and early identification can provide the basis for building an appropriate and effective educational and treatment program. Sometimes professionals who are not knowledgeable about the needs for and opportunities for early intervention in autism do not offer an autism diagnosis even if it is appropriate. This hesitation may be due to a misguided wish to spare the family. Unfortunately, this too can lead to failure to obtain appropriate services for the child.
**What are People with Autism Like?**

Children within the pervasive developmental disorder spectrum often appear relatively normal in their development until the age of 24-30 months, when parents may notice delays in language, play or social interaction. Any of the following delays, by themselves, would not result in a diagnosis of a pervasive developmental disorder. Autism is a combination of several developmental challenges.

The following areas are among those that may be affected by autism:

- **Communication:** language develops slowly or not at all; uses words without attaching the usual meaning to them; communicates with gestures instead of words; short attention span;

- **Social Interaction:** spends time alone rather than with others; shows little interest in making friends; less responsive to social cues such as eye contact or smiles;

- **Sensory Impairment:** may have sensitivities in the area of sight, hearing, touch, smell, and taste to a greater or lesser degree;

- **Play:** lack of spontaneous or imaginative play; does not imitate others' actions; does not initiate pretend games;

- **Behaviors:** may be overactive or very passive; throws tantrums for no apparent reason; perseverate (shows an obsessive interest in a single item, idea, activity or person); apparent lack of common sense; may show aggression to others or self; often has difficulty with changes in routine.

Some individuals with autism may also have other disorders which affect the functioning of the brain such as: Epilepsy, Mental Retardation, Down Syndrome, or genetic
disorders such as: Fragile X Syndrome, Landau-Kleffner Syndrome, William's Syndrome or Tourette's Syndrome. Many of those diagnosed with autism will test in the range of mental retardation. Approximately 25-30 percent may develop a seizure pattern at some period during life.

Every person with autism is an individual, and like all individuals, has a unique personality and combination of characteristics. There are great differences among people with autism. Some individuals mildly affected may exhibit only slight delays in language and greater challenges with social interactions. The person may have difficulty initiating and/or maintaining a conversation, or keeping a conversation going. Communication is often described as talking at others (for example, monologue on a favorite subject that continues despite attempts of others to interject comments). People with autism process and respond to information in unique ways.

Educators and other service providers must consider the unique pattern of learning strengths and difficulties in the individual with autism when assessing learning and behavior to ensure effective intervention. Individuals with autism can learn when information about their unique styles of receiving and expressing information is addressed and implemented in their programs. The abilities of an individual with autism may fluctuate from day to day due to difficulties in concentration, processing, or anxiety. The child may show evidence of learning one day, but not the next. Changes in external stimuli and anxiety can affect learning. They may have average or, above average verbal, memory or spatial skills but find it difficult to be imaginative or join in activities with others. Individuals with more severe challenges may require intensive support to
Contrary to popular understanding, many children and adults with autism may make eye contact, show affection, smile and laugh, and demonstrate a variety of other emotions, although in varying degrees. Like other children, they respond to their environment in both positive and negative ways. Autism may affect their range of responses and make it more difficult to control how their bodies and minds react. Sometimes visual, motor, and/or processing problems make it difficult to maintain eye contact with others. Some individuals with autism use peripheral vision rather than looking directly at others. Sometimes the touch or closeness of others may be painful to a person with autism, resulting in withdrawal even from family members. Anxiety, fear and confusion may result from being unable to “make sense” of the world in a routine way. With appropriate treatment, some behaviors associated with autism may change or diminish over time. The communication and social deficits continue in some form throughout life, but difficulties in other areas may fade or change with age, education, or level of stress. Often, the person begins to use skills in natural situations and to participate in a broader range of interests and activities. Many individuals with autism enjoy their lives and contribute to their community in a meaningful way. People with autism can learn to compensate for and cope with their disability, often quite well.

While no one can predict the future, it is known that some adults with autism live and work independently in the community (drive a car, earn a college degree, get married); some may be fairly independent in the community and only need some support for daily pressures;
while others depend on much support from family and professionals. Adults with autism can benefit from vocational training to provide them with the skills needed for obtaining jobs, in addition to social and recreational programs. Adults with autism may live in a variety of residential settings, ranging from an independent home or apartment to group homes, supervised apartment settings, living with other family members or more structured residential care. An increasing number of support groups for adults with autism are emerging around the country. Many self-advocates are forming networks to share information, support each other, and speak for themselves in the public arena. More frequently, people with autism are attending and/or speaking at conferences and workshops on autism. Individuals with autism are providing valuable insight into the challenges of this disability by publishing articles and books and appearing in television specials about themselves and their disabilities.

**Autism Check List**

Individuals with autism usually exhibit at least half of the traits listed below. These symptoms can range from mild to severe and vary in intensity from symptom to symptom. In addition, the behavior usually occurs across many different situations and is consistently inappropriate for their age.

- Insistence on sameness; resists changes in routine
- Severe language deficits
- Difficulty in expressing needs; uses gestures or pointing instead of words
- Echolalia (repeating words or phrases in place of normal, responsive language)
- Laughing, crying, or showing distress for reasons not apparent to others
- Prefers to be alone; aloof manner
- Tantrums-displays extreme distress for no apparent reason
- Difficulty in mixing with others
- May not want cuddling or act cuddly
- Little or no eye contact
- Unresponsive to normal teaching methods
- Sustained odd play
- Spins objects
- Inappropriate attachment to objects
- Apparent oversensitivity or undersensitivity to pain
- No real fear of dangers
- Noticeable physical overactivity or extreme underactivity
- Not responsive to verbal cues; acts as if deaf although hearing tests in normal range
- Uneven gross/fine motor skills (may not kick a ball but can stack blocks)

Please note this symptom list is not a substitute for a full-scale diagnostic assessment.

Consult your health care provider to obtain a complete diagnostic evaluation.

What are the Most Effective Approaches?
Evidence shows that early intervention results in dramatically positive outcomes for young children with autism. While various preschool models emphasize different program components, all share an emphasis on early, appropriate, and intensive educational interventions for young children. Other common factors may be: some degree of inclusion, mostly behaviorally-based interventions, programs which build on the interests of the child, extensive use of visuals to accompany instruction, highly structured schedule of activities, parent and staff training, transition planning and follow-up. Because of the spectrum nature of autism and the many
behavior combinations which can occur, no one approach is effective in alleviating symptoms of autism in all cases. Various types of therapies are available, including (but not limited to) applied behavior analysis, discrete trial instruction, floor time, medications, occupational therapy, parent support/education, physical therapy, social skills training and speech/language therapy.

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. Learning to cross a street safely, to make a simple purchase or to ask assistance when needed are critical skills, and may be difficult, even for those with average intelligence levels. Tasks that enhance the person’s independence and give more opportunity for personal choice and freedom in the community are important.

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.

Rarely can a family, classroom teacher or other caregiver provide effective habilitation for a person with autism unless offered consultation or in-service training by an experienced specialist who is knowledgeable about the disability.

A generation ago, the vast majority of the people with autism were eventually placed in institutions. Professionals were much less educated about autism than they are today; autism specific supports and services were largely non-existent. Today the picture is brighter. With appropriate services, training, and information, most families are able to support their son or daughter at home. Group homes, assisted apartment living arrangements, or residential facilities offer more options for out of home support. Autism-specific programs and services provide the opportunity for individuals to be taught skills which allow them to reach their fullest potential.

Families of people with autism can experience high levels of stress. As a result of the challenging behaviors of their children, relationships with service providers, attempting to secure appropriate services, resulting financial hardships, or very busy schedules, families often have difficulty participating in typical community activities. This results in isolation and difficulty in developing needed community supports.
The Autism Society of America is here for you.

Members of the ASA represent all walks of life from rural to metropolitan communities. Embracing the diversity of our group, the ASA seeks to provide an open forum for the exchange of ideas. At the very core of the ASA's philosophy is the belief that no single program or treatment will benefit all individuals with autism. Furthermore, the recommendation of what is "best" or "most effective" for a person with autism should be determined by those people directly involved - the individual with autism, to the extent possible, and the parents or family members.

The ASA provides information and education (including results of empirically-based scientific research on effective strategies) to assist parents, education, and other in the decision-making process. Providing information on available intervention options, rather than advocating for any particular theory or philosophy, is the focus at the ASA.

Is There a Cure?

Understanding of autism has grown tremendously since it was first described by Dr. Leo Kanner in 1943. Some of the earlier searches for "cures" now seem unrealistic in terms of today's understanding of brain-based disorders. To cure means "to restore to health, sound-ness, or normality." In the medical sense, there is no cure for the differences in the brain which result in autism.

However, better understanding of the disorder has led to the development of better coping mechanisms and strategies for the various manifestations of the disability. Some of these symptoms may lessen as the child ages; others may disappear altogether.
With appropriate intervention, many of the associated behaviors can be positively changed, even to the point in some cases, that the child or adult may appear to the untrained person to no longer have autism. The majority of children and adults will, however, continue to exhibit some manifestations of autism to some degree throughout their entire lives.

The Autism Society of America Foundation (ASAF) was founded with the primary mission to raise and allocate funds for research to address the many unanswered questions about autism. We are still far from fully understanding autism and knowing how to prevent it.

The ASAF has implemented action on several pressing autism research priorities as areas of initial focus: developing and publicizing up-to-date prevalence statistics; quantifying the societal and family economic consequences of autism; developing a national registry of individuals and families with autism who are willing to participate in research studies; and implementing a system to identify potential donors of autism brain tissue for research purposes and facilitating the donation process. In addition, the Foundation is contributing substantial funds for applied and biomedical research in the causes of and treatment approaches to autism.

References:
Dr. Christopher Gillberg, Center for Disease Control and Prevention Conference. Autism; Emerging Issues in Prevalence and Etiology. 1997
Where Can I Get More Information?

Educating yourself and others about autism is a critical way to assist with the education and development of the individual with autism and to help society understand the nature of this common developmental disorder. Information packages on a variety of autism-related topics are available from the Autism Society of America. To request additional information or to find answers to other questions on autism, please call or write ASA. We are here to help.

Autism Society of America Services and Benefits

The Autism Society of America prides itself on being a vital source of current information and support for parents, educators, service providers, and medical professionals.

The Advocate Newsletter

Frequently referred to as the "best" benefit of membership in the Society, the ASA publishes the largest, most comprehensive national newsletter devoted to autism. Six issues each year present the latest developments in the field. Articles written by respected autism professionals sit side by side with stories from parents sharing the triumphs and challenges of life with autism.

Information and Referral

Staff at the ASA national office respond to requests from more than 1,500 callers each month and distribute information on a variety of autism-related topics.

- The ASA provides a toll-free line for information, 800-3AUTISM, Extension 130
- ASA’s award-winning World Wide Web Site allows access to vital autism and ASA information http://www.autism-society.org/
• Responding to the needs of approximately 300 members outside the U.S., ASA has expanded the range of materials available about autism and other related disorders in English, Spanish, French, Chinese, and Vietnamese.

• Two ASA Chapter operated mail-order bookstores offer over 160 titles covering both classic and contemporary publications.

**Autism Society of America Foundation**
The latest step in ASAs long-term commitment to autism research was made with the formation of the ASA Foundation (ASAF) in 1996. The ASAF is committed to advancing research that will yield new information about autism, lead to better treatments, and ease the challenges that autism presents us with every day. ASAF projects include the Autism Research Registry, to enhance research capabilities by giving researchers controlled access to potential research participants; the Autism Tissue Program, to make available brain tissue for biomedical research; Applied Autism Research Projects, designed to advance research into the social, cognitive, educational, and behavioral issues associated with autism; and Biomedical Research Projects, to advance better understanding and treatment of autism. For more information on the ASA Foundation, please call 800-328-8476.

**Government Advocacy**
Through ASAs lobbyist on Capitol Hill and participation in various Washington-based disability coalitions, ASA keeps a finger on the pulse of Congress and legislation affecting the disability community. In addition, ASA furnishes national legislators and government agencies with information about the needs of people with autism and their families and promotes medical research in the
field. ASAs constituency has brought about effective change by responding to the Society’s Action Alerts, ensuring that the needs of individuals with autism are heard in the House and Senate.

**Public Relations**
The ASAs Public Relations initiative helps to ensure that issues important to the ASA and the autism community are addressed through the media. The ASA generates appropriate, timely responses to various autism-related issues that appear in the news and takes a proactive approach to issues important to ASA’s membership. The ASA has reached many individuals through its annual National Autism Awareness Month efforts.

**Annual National Conference on Autism**
Each summer the ASA holds a Conference on Autism, a national forum for the presentation of important field studies, intense educational sessions, structured networking opportunities, information exchanges, and interaction between individuals interested in the well-being of children and adults with autism. Each Annual ASA National Conference has an average of 2,000 attendees, and is the largest single source of groundbreaking information for parents, professionals, service providers, and individuals with autism. Features include nationally recognized keynote presentations and seminars covering a range of autism and disability issues.

**ASA Chapter Network**
More than 240 chapters in 50 states provide support services on a local and state level. ASA chapters are a critical resource to help families find trained professionals and service
providers in their community. ASA Chapters are invaluable for parents of recently diagnosed children and a comfort and companion to families managing the years of growth and change. Some chapters arrange seminars and educational programs for parents, hold statewide conferences, maintain lending libraries, publish local newsletters, hold regular parent support meetings, and provide other community activities. Through this extensive network the Autism Society is able to advocate for appropriate services in individual communities and states.

JOIN US!
We invite you to become part of the growing network of parents, family members and professionals working together to bring about positive changes within the world of autism. Join us today and begin receiving the benefits of membership immediately.

AUTISM SOCIETY OF AMERICA
MEMBERSHIP APPLICATION
Yes, Please enroll me in the following membership category:

☐ Student $15.00 ☐ Outside USA $40.00
☐ Individual $25.00 ☐ Agency $200.00
☐ Family $35.00 ☐ Life $500.00
☐ New ☐ Renewal

Name:__________________________________
Address:_________________________________
City:______________State:________Zip:______
Office Phone: (___)___________________
Home Phone: (___)___________________

☐ I am joining through ASA’s local chapter named:____________________________
☐ I am joining At-Large. Please put me in touch with a local chapter.
Please check the category which best describes you:

- Parent
- Educator
- Family Member
- Individual with Autism
- Medical Professional
- Service Provider
- Other (describe)___________________

- Yes, sign me up for a subscription to the journal of Autism and Developmental Disorders (JADD), at the special ASA member rate of $30 per calendar year (subscribers receive the 6 bimonthly issues starting with February of current calendar year).

- Yes, sign me up for a subscription of Focus on Autism and Other Developmental Disabilities at the special ASA member rate of $30 per year (subscribers receive 4 quarterly issues).

Payment:

- Check (US funds drawn on a US Bank only)
- Credit Card:    - Mastercard
- Visa

Card #:____________________________
Expiration Date:_____________________
Signature:____________________________

Membership Fee: $_____________
JAPD Subscription: $_____________
Focus Subscription: $_____________
Additional Donation: $_____________
Total Amount Enclosed: $_____________

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