

Northwest Autism Foundation

ADDRESSING THE LIFESPAN OF A PERSON WITH AUTISM

Our mission is improving lives affected by Autism Spectrum Disorders through mobilization of resources and championing innovative solutions. Founded in 1997, NWAf is committed to providing valuable and accurate information and educational resources about autism to medical professionals, parents, family, friends, educators and caregivers. Working with parent groups and experienced professionals, NWAf has attempted to identify families' greatest needs at this critical time.

NWAf feels strongly about cooperating with other groups to bring the autism community closer together. Although there are other autism organizations, none have the same mission as the Northwest Autism Foundation. NWAf is an organization in which all activities are funded by donation only. Northwest Autism Foundation is a non-profit 501(c)(3) organization.

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The Medical Advisory Committee provides a managed effort to coordinate, educate and communicate information on early diagnosis and treatment protocols of Autism Spectrum Disorders to pediatricians, primary care physicians and nurse practitioners in the Portland metropolitan and Southwest Washington areas. The Medical Advisory Committee represents the following medical providers: Kaiser Permanente, Legacy Health Systems, Northwest Early Childhood Institute, Oregon Health Sciences University, Providence Health Systems and The Children's Program.

For further information & assistance contact:

Northwest Autism Foundation – Joseph H. Taylor, Executive Director – email: director@autismnwaf.org

Website: www.autismnwaf.org – Phone: 503.557.2111 – Fax: 503.557.2156

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 occur in 1.5 million individuals nationally, CDC estimated in 2007 to be 1 in 150 births and estimated to be 1 in 122 births in Oregon. 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 autisms occurrence.

Source: Centers for Disease Control and Prevention

www.cdc.gov

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 and 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.

Source: The Autism Society of America

www.autism-society.org

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. Autism is NOT a mental illness, children with autism are NOT unruly kids who chose 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.

Source: The Swindells Resource Center for Children and Families

www.providence.org/childcenter

Another resource for early identification is the *Help Autism Now Society (HANS)*

www.helpautismnow.com

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Early Diagnosis and Treatment

Early Diagnosis & Treatment

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.

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, and 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.

Early Identification

Research indicates that early diagnosis is associated with dramatically better outcomes for individuals with autism. The earlier a child is diagnosed, the earlier the child can begin benefiting from one of the many specialized intervention approaches.

The characteristic behaviors of autism spectrum disorders may or may not be apparent in infancy (18 to 24 months), but usually become obvious during early childhood (24 months to 6 years).

As part of a well-baby/well-child visit, your child's doctor should do a "developmental screening" asking specific questions about your baby's progress. The National Institute of Child Health and Human Development (NICHD) www.nichd.nih.gov/autism/ lists these five behaviors that signal evaluation is warranted:

- Does not babble or coo by 12 months
- Does not gesture (point, wave, grasp) by 12 months
- Does not say single words by 16 months
- Does not say two-word phrases on his or her own by 24 months
- Has any loss of any language or social skill at any age

Having any of these five "red flags" does not mean your child has autism, but because the characteristics of the disorder vary so much, a child should have further evaluations by a multidisciplinary team that may include a neurologist, psychologist, developmental pediatrician, speech/language therapist, learning consultant, or other professionals knowledgeable about autism. www.providence.org/childcenter or www.helpautismnow.com

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Medical
Home

Early Diagnosis & Treatment *continued*

Behavior
Treatment

Please contact your insurance company to determine which center is covered by your health plan. If your insurance provider or Medical Assistance does not cover the cost of the initial evaluation, you will be responsible for those costs.

Oregon Resources for A Diagnostic Evaluation Include:

Oregon Health & Science University (OHSU)

www.ohsu.edu/outreach/cdrc/clinical/portland/autism.html or phone 503/494-8095

Providence Health & Services, Providence Neurodevelopmental Center for Children (PNCC)

www.providence.org/childcenter or phone 503/215-2400

Kaiser Permanente, Developmental Assessment Clinic (members only through referring physician)

www.kaiserpermanente.org or phone 503/813-4820

Legacy Health System, Pediatric Development & Rehabilitation

www.legacyhealth.org/body.cfm?id=299 or phone 503/413-4505

Adventist Medical Center, Adult Psychiatric Program

Joint venture with Legacy CareMark Behavioral Health Services

www.legacyhealth.org/body_AH.cfm?id=932 or phone 503/257-2500

Northwest Early Childhood Institute

www.nweci.org or phone 503/228-6479

The Children's Program

www.childrensprogram.com or phone 503/452-8002

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General
Services

Where to Start

Job
Training

For an excellent overview of autism and a free guide to Oregon's human service system (DHS), we recommend that you obtain a copy of *Autism An Introduction for Parents*, from the Oregon Technical Assistance Corporation (OTAC)
www.otac.org or phone 503/364-9943.

The Department of Human Services (DHS), State and Local Developmental Disability Services, is another partner in support of autism spectrum disorders (ASD). When contacting the Department of Human Services, inquire about obtaining a case manager who will be very helpful in making families aware of important resources and in getting through the necessary channels to ensure that their child receives the services he/she needs.
www.oregon.gov/DHS/index.shtml or phone 503/945-5944

DHS in collaboration with Oregon Advocacy Center and Oregon Council on Developmental Disabilities has published a helpful free guide to lifespan support services, *A Roadmap to Support Services (2nd Edition)*.
www.ocdd.org or phone 503/945-9941

The Oregon Parent and Information Center (ORPTI) provides information and supports parents in building partnerships in the education, medical and human resources fields.
www.orpti.org or phone 503/581-8156

The Oregon Department of Education (ODE) is your link to an education evaluation and services.
www.ode.state.or.us, search for special education or autism services, or early intervention/early childhood special education or services or phone 503/947-5600.

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Parent Education And Coaching

Helpful Websites

American Academy of Pediatrics: Pediatrician's Role in the Diagnosis and Management of Autistic Spectrum Disorder in Children: www.aap.org

Center for Disease Control & Prevention (CDC) Autism Information Center: www.cdc.gov

National Institute of Child Health & Human Development (NIH) Autism Website: www.nichd.nih.gov/autism

Autism Research Institute (ARI): www.autism.com

Help Autism Now Society (CHAT Screening Tool). This site helps families explain autism to others: www.helpautismnow.com

ARC of the United States: www.thearc.org

Autism Society of America: www.autism-society.org

Autism Society of Oregon: www.oregonautism.com

The Swindells Resource Center for Children and Families: www.providence.org/childcenter

Easter Seals Oregon: http://or.easterseals.com/site/PageServer?pagename=ORDR_homepage

Oregon Families Information Referral Services and Training (OrFirst): www.orfirst.org/

Parents of Autistic Children (POAC) advocates early behavioral intervention: www.poac-or.org

Autism Research & Resources of Oregon (ARRO): www.arroautism.org

Autism Speaks: www.autismspeaks.org

The Oregon Parent Training and Information Center (OrPTI): www.orpti.org

Oregon Technical Assistance Corporation (OTAC). We highly recommend reading the OTAC guide for general information for family issues, support and resources: www.otac.org

National Dissemination Center for Children with Disabilities: www.nichcy.org

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Oregon University Autism Education Programs

Oregon University programs offer specialized coursework to prepare persons working with individuals with Autism Spectrum Disorder.

Western Oregon University, ASD Program: www.wou.edu/education/sped

Portland State University: www.ceed.pdx.edu/autism

University of Oregon: www.education.uoregon.edu/projectPASS

Visit the NWAFF website for updates of resource guide information and direct links. Resources often change names, web links or phone numbers. Many of our previous listings can be found on the main links that we have provided. We highly recommend links to current information from partners of Northwest Autism Foundation (NWAFF) www.autismnwaf.org

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Other Northwest States

Autism Society of America

www.autism-society.org search for Alaska

Disability Law Center of Alaska

www.dlcak.org

Governor's Council on Disabilities and Special Education

www.hss.state.ak.us/ocs

The National Dissemination Center for Children with Disabilities provides information about each state's resources including Parent Training and Information (PTI) and Children's Health Insurance Program (CHIP)

www.nichcy.org

Support for Families

www.stonesoupgroup.org

University of Alaska Anchorage Center for Human Development

www.alaskachd.org

For an excellent overview of autism and a free guide, we recommend that you obtain a copy of *Autism an Introduction for Parents*

www.otac.org

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Autism Society of America

www.autism-society.org search for Idaho

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www.nichcy.org

Support for Families

www.ipulidaho.org

Programs for People with Developmental Disabilities

www.healthandwelfare.idaho.gov

Idaho Council on Developmental Disabilities

www.state.id.us/icdd (support for families)

University of Idaho Center on Disabilities and Human Development

www.idahocdhhd.org/dnn

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Autism Society of America

www.autism-society.org search for Montana

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www.nichcy.org

Support for Families

www.pluk.org

Montana Protection and Advocacy System

www.disabilityrightsmt.org

Programs for People with Developmental Disabilities

www.dphhs.mt.gov

Montana University Affiliated Rural Institute on Disabilities

www.ruralinstitute.umt.edu

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Autism Society of America

www.autism-society.org search for Washington

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www.nichcy.org

Support for Families

www.washingtonpave.org

Washington Protection and Advocacy System

www.disabilityrightswa.org

University of Washington Center on Human Development & Disabilities

www.depts.washington.edu/chdd search for autism

Department of Social & Health Services/ State Developmental Disabilities Program

www.dshs.wa.gov/ddd/autism.shtml

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