

# Frequently Asked Questions (FAQ) and Resources on Autism Spectrum Disorders

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## EARLY

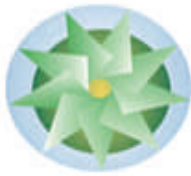
Early Autism Research  
and Learning for the  
Young Child

### WHAT'S INSIDE

- EARLY Mission and Contacts
- Definitions of Diagnosis
- Finding Support for Your Child
- And More!

[http://ucedd.uoregon.edu/?page\\_id=39](http://ucedd.uoregon.edu/?page_id=39)





The University of Oregon  
**Center for Excellence in  
 Developmental Disabilities**  
 Education, Research, and Service



**Early Autism Research and Learning for the Young Child (EARLY)** is a unit within the University Center of Excellence on Developmental Disabilities at the University of Oregon (UCEDD). **Our mission** is to improve the quality of life

of young children with Autism Spectrum Disorders (ASD) and their families. The Institute works with the programs of the UCEDD on projects and goals benefiting young children with ASD and their families. The **primary goals of EARLY** are to provide evidence-based research, training, and service to children, families, and the community.

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**Other Publications Available from EARLY**

*All publications are available for free download.*

- **EARLY Brochure**– Learn more about EARLY Staff, goals, projects and services. <http://ucedd.uoregon.edu/wp-content/products/EARLY/EARLYBrochure.pdf>
- **Treatment Tips Flier**– Tips for parents seeking treatment for children. <http://ucedd.uoregon.edu/wp-content/products/EARLY/Treatments.pdf>
- **Poster: Frequently Asked Questions on Autism**– The companion full color, large format poster to this brochure. Designed to print at 22”x34”. <http://ucedd.uoregon.edu/wp-content/products/EARLY/NewBrochures/AutismFAQposter.pdf>
- **Poster: Oregon Resources on Autism**- secondary companion to this brochure showcasing Oregon-specific resources for children and families living with Autism. Full color and designed to print at printer standard size A2. <http://ucedd.uoregon.edu/wp-content/products/EARLY/NewBrochures/AutismFAQoregonPoster.pdf>



Visit the UCEDD Website

<http://ucedd.uoregon.edu/> to find these publications as well as additional resources to support your child and family from birth through adulthood.





3. The **Jefferson Education Service District** provides the name and number of the Special Programs Director.

<http://www.jcesd.k12.or.us/education/dept/dept.php?sectionid=13>

5. **Douglas Education Service District** lists the services they provide to students with special needs

<http://www.douglasesd.k12.or.us/Educators/SpecialPrograms/tabid/349/Default.aspx>

6. **South Coast Education Service District** for Coos County provides Adaptive Life Skills, Early Intervention, Speech and Language, and Special Education services. Clicking on the links on the box on the right will show the specific services and contact information. [http://www.scesd.k12.or.us//index.php?option=com\\_content&task=section&id=6&Itemid=27](http://www.scesd.k12.or.us//index.php?option=com_content&task=section&id=6&Itemid=27)

7. **Lane Education Service District** lists the services to students with special needs. <http://www.lesd.k12.or.us/se/>

8. Early Intervention contact information in all the counties. <http://www.oregon.gov/DHS/ph/ch/docs/guide/guide75.pdf>



## What are Autism Spectrum Disorders?

Autism Spectrum Disorders (ASD) are neurobiological disorders defined by a set of behaviors that can range from very mild to severe. All children with ASD show deficits in social interaction, verbal and nonverbal communication and repetitive behaviors and interests. ASD occurs in all racial, ethnic and social groups. Currently, the autism spectrum category includes:

- Autistic disorder (“classic” autism)
- Asperger syndrome
- Pervasive Developmental Disorder Not Otherwise Specified (atypical autism)
- Childhood Disintegrative Disorder (extremely rare)

## How do I know if my child is showing signs of autism?

- The **Center for Disease Control and Prevention's Act Early Campaign** provides important developmental milestones and information on what to do if you have concerns. <http://www.cdc.gov/ncbddd/actearly/index.html>
- **Autism Speaks** provides videos of typical and delayed development and red flags suggestive of autism. It is free to register and view the videos. <http://www.autismspeaks.org/video/glossary.php> They also offer developmental milestones by age and an interactive “Learn the Signs” quiz. <http://www.autismspeaks.org/whatisit/learnsigns.php#redflags>
- **First Signs** is dedicated to educating parents and professionals about the early warning signs of autism and related disorders. <http://www.firstsigns.org/about/index.htm>



# Is there an autism epidemic?

The **Center for Disease Control and Prevention** provides information on the prevalence of autism and discusses this question. The CDC states that the prevalence of autism spectrum disorders has risen and constitutes an urgent public health concern.

<http://www.cdc.gov/ncbddd/autism/index.html>

## My child was just diagnosed with autism, what should I do?

**Autism Speaks** created a **free 100 Day Kit** ([http://www.autismspeaks.org/community/family\\_services/100\\_day\\_kit.php](http://www.autismspeaks.org/community/family_services/100_day_kit.php))

helping newly diagnosed families to make best possible use of the first 100 days following the diagnosis of autism. It provides information on autism, families, accessing services, treatment, an action plan, safety kit, forms and local resources. You may request a free kit or download the information at [http://www.autismspeaks.org/community/family\\_services/100\\_day\\_kit.php](http://www.autismspeaks.org/community/family_services/100_day_kit.php)

### **ADEPT:Autism Distance Education Parent Training**

A **free online training program** for parents of children with ASD who want to learn to apply the techniques of Applied Behavior Analysis (ABA) to increase their parenting skills. <http://media.mindinstitute.org/education/ADEPT/Module1Menu.html>



3. **Child Development and Rehabilitation Center** specializes in diagnosis, assessment and intervention related to disorders affecting development.

<http://www.ohsu.edu/cdrc/clinical/eugene/index.html>

4. **Bridgeway House** offers a variety of therapeutic services to children and families of all income levels with autism and related disabilities. <http://www.bridgewayhouse.org/>

5. **Autism Society of Oregon**, Lane County Chapter works closely with local organizations catering to people with autism. They currently have a program called “take a BREAK on ASO” that provides caregivers with respite care and an outing for two. <http://asolanecounty.org/index.html>

6. The **ARC of Lane County** provides educational and recreational opportunities for people with developmental disabilities. Their lifespan respite care program provides several regularly scheduled respite programs to fit the needs to families. <http://www.arclane.org/index.html>

## Where can I find out about early intervention/ education services in Oregon?

1. Select your County and it will direct you to their site. <http://www.osba.org/edlinks/esds.asp>

2. The **Linn Benton and Lincoln Education Service District** website explains the referral process, services available and resources in the area. It is located in the Special Education box of the Parents tab. <http://www.lblesd.k12.or.us/parents/>



5. **Autism Society of Oregon** is a statewide support group and state chapter of **Autism Society of America**. <http://www.oregonautism.com/>

6. **The ARC** provides services to children and families with developmental disabilities. Each local ARC Chapter varies in its programs and events. <http://www.thearc.org/NetCommunity/Page.aspx?pid=326>

7. **The Swindells Center** allows you to browse and borrow from their lending library, search resources in your area and view their events calendar.

You can also download or order a Care Notebook to help you organize your child's medical files.

<http://www.childdisabilityconnection.org/>



## What services (parent training, parent

## support, advocacy, legal support, child care) are available in Lane County?

1. **Direction Service** is a non-profit multi-program family support agency located in Eugene, Oregon. They offer Family Support & Service Coordination, Information Services, Counseling Center and Center for Appropriate Dispute Resolution in Special Education. <http://www.directionservice.org/>

2. **Early Childhood CARES** provides early intervention and early childhood special education services to infants, toddlers and preschool age children in Lane County. <http://eccares.uoregon.edu>



## I'm New to Autism...

### What websites should I visit?

- **The Department of Health and Human Services, Center for Disease Control and Prevention's** website provides an overview of autism, symptoms, information about vaccines, diagnosis and treatment. <http://www.cdc.gov/ncbddd/autism/index.htm>
- The **National Dissemination Center for Children with Disabilities**—provides information about children with disabilities organized according to age group. <http://www.nichcy.org/Pages/Home.aspx>
- **Autism Speaks** is an advocacy group that aims to fund research in the field of autism. Information on the site can be read in English or Spanish. The **Be Informed** presents five sections: What is autism, What to do about it, How to cope, How to Grow With It, Navigating the Spectrum. Each section contains information, expert interviews, resources and their video series. [http://www.autismspeaks.org/whatisit/index.php?WT.svl=Top\\_Nav](http://www.autismspeaks.org/whatisit/index.php?WT.svl=Top_Nav)
- The **Organization for Autism Research** focuses solely on applied research. They also provide an overview of autism, diagnosis, intervention and research. Emphasis is placed on providing tools for understanding, evaluating and applying research findings to decision making. They provide **free online publications** under the **Resources** tab. <http://www.researchautism.org/default.asp>
- The **Autism Society of America website** lists state and local autism societies and provides resources for parents, including legislative information and answers to frequently asked questions from parents about autism spectrum disorders. <http://www.autism-society.org/site/PageServer>





## Definitions of Diagnosis

### What are the best sources of information about autism diagnosis?

The **Organization for Autism Research** explains the two step process of diagnosis: screening and a comprehensive diagnostic evaluation.

<http://www.researchautism.org/family/diagnosis/index.asp>

### What is PDD-NOS?

**Pervasive Developmental Disorder - Not Otherwise Specified (PDD-NOS)** is under the autism spectrum disorders. People with PDD-NOS exhibit some, but not all, of the symptoms associated with classic autism. It can include difficulty socializing with others, repetitive behaviors, and heightened sensitivities to certain stimuli. While they may exhibit some symptoms of other conditions in the spectrum, they don't fit the bill closely enough to fully satisfy all criteria set by the experts.

[http://www.autismspeaks.org/navigating/pdd\\_nos.php](http://www.autismspeaks.org/navigating/pdd_nos.php)

### What is High Functioning Autism?

**High functioning autism** is not an official diagnostic term, although it is sometimes used as such. It usually describes people who have symptoms of autism and average or above average intelligence.



[index.html](#)

**Understanding Early Childhood Transition: A Guide for Families and Professionals** <http://dpi.state.nd.us/speced/early/guide.pdf>  
Includes timelines and worksheets to make the transition process understandable and smooth for your child and family.

### Where can I find out about other services (parent training, parent support, advocacy, legal support, child care) in Oregon?

1. **Oregon Parent Training and Information Center** provides parent training and information for parents of children with disabilities. They have a lending library, a special education help line, and trainings on a variety of topics related to children with disabilities. <http://www.orpti.org/>

2. **Disability Rights Oregon (DRO)** provides information and tools for successful self-advocacy, provides legal representation and promotes policies that benefit all Oregonians with disabilities. DRO is the state's Protection & Advocacy System.

<http://www.disabilityrightsoregon.org/>

3. **Oregon Child Care Resource and Referral Network** provides child care referrals (not recommendations) and parenting information to parents. [http://www.oregonchildcare.net/findcc/prov\\_search.htm](http://www.oregonchildcare.net/findcc/prov_search.htm)

4. A list of **State Resources for Children and Families** <http://www.ode.state.or.us/search/page/?=1387>





**Zero to Three** answers common questions around social emotional development. It provides tips on how to develop specific social emotional skills such as cooperation, self control and how to address challenging behaviors.

[http://www.zerotothree.org/site/PageServer?pagename=key\\_social](http://www.zerotothree.org/site/PageServer?pagename=key_social)

## Where can I find respite care (short, temporary care)?

1. **The Arc** provides a quick reference guide on respite care.

[www.thearc.org/NetCommunity/Document.Doc?&id=160](http://www.thearc.org/NetCommunity/Document.Doc?&id=160)

2. <http://chtop.org/Search-For-Respite.html> allows you to search for a respite care provider anywhere in the United States.

## How can I help my child make the transition from Early Intervention to public school?

To find out more about special education in Lane County, school choices, contact persons, etc. visit <http://www.lesd.k12.or.us/se/>



## What is Asperger Syndrome?

**Asperger Syndrome (AS)** is a neurobiological disorder on the higher-functioning end of the autism spectrum. An individual's symptoms can range from mild to severe. Individuals with AS and related disorders exhibit serious deficiencies in social and communication skills. Their IQ's are typically in the average to superior range.

**Asperger Syndrome Education Network** is a non-profit organization that provides education, support, and advocacy.

<http://aspennj.org/aspergers-syndrome.asp>

## What is the difference between Asperger Syndrome and High Functioning Autism?

There is no definitive answer for this question. Currently, there is no formal diagnosis called "high functioning" autism and there is no agreed definition of "high functioning." On the other hand, **Asperger Syndrome** is a specific diagnosis, with specific diagnostic criteria. The difference is determined based on whether a person developed speech typically as a toddler. Those who developed speech typically as a toddler were considered to have Asperger syndrome while those who did not were diagnosed with autism. Experts are currently debating whether speech development is the best way to distinguish between autism and Asperger syndrome or if there even is a difference. [http://www.sacramentoasis.com/docs/8-22-03/as\\_&\\_hfa.pdf](http://www.sacramentoasis.com/docs/8-22-03/as_&_hfa.pdf)

## What is an autism eligibility?

**Autism eligibility** is governed by law and is used to determine special education services. The criteria used to determine



eligibility in Oregon can be found at <http://www.ode.state.or.us/search/page/?id=299>. Each state determines its own eligibility criteria.

## How is eligibility different from a diagnosis?

A web-based article discusses the differences in meaning and purpose of autism eligibility and autism diagnosis.

<http://www.behavior-consultant.com/diagnosiseligibility.htm>

## Finding Support for Your Child



What treatments/therapies work? What are some evidence-based practices?

The **Autism Spectrum Institute** at Illinois State University has compiled a list of evidence-based practices that have convincing empirical efficacy and support. They also provide a free online workshop called **Basic Level Autism Team Training** for individuals who work and live with children and adolescents with autism. The Online Course tab on the left will open the page.

<http://www.autismspectrum.ilstu.edu/resources/factsheets/evidencebasedpractices.shtml>

**Autism Internet Modules** provides learning modules of evidence-based interventions in several areas (behavior, communication,



social skills, etc.). Modules may take 30 minutes to 2.5 hours to complete. It is free to register and use the modules. Some modules are not yet posted and labeled as “Coming Soon.” If you want to be notified when the modules are posted, select Yes on Email Updates. You can change this preference on the User Profile tab on the left.

<http://www.autisminternetmodules.org/index.php>

## Where can I get more support and training to help my child?

**Oregon Parent Training and Information Center** provides parent training and information for parents of children with disabilities. They have a lending library, a special education help line, and trainings on a variety of topics related to children with disabilities. <http://www.orpti.org/>

**Ohio Center for Autism and Low Incidence (OCALI)** is developing a series of 60 online modules on ASD including characteristics, diagnosis, interventions and supports, transition, and employment. <http://www.autisminternetmodules.org/>

## How can I support my child’s social emotional development?

**The Center on the Social and Emotional Foundations for Early Learning (CSEFEL)** provides resources to promote social and emotional competence in infants and young children. The Resources tab provides Practical Strategies such as Scripted Stories, tools for building relationships, a book list and several books and charts that can be downloaded. In the Family Tools section under Resources, families can download modules that address emotional development.

<http://www.vanderbilt.edu/csefel/index.html>

