OHSU

DOERNBECHER
CHILDREN'S
Hospital

Autism Spectrum Disorder Handbook

About this Booklet

We greatly value the opportunity to meet with you and to help you better understand Autism Spectrum Disorder (ASD). This book was written with the help of families as an ongoing resource to answer questions you may have now or in the future. We have included a lot of information on a variety of topics in hopes that you will be able to find some of the information you need to get started.

If you have specific questions about the reports you receive from the Autism Clinic at OHSU Doernbecher's Child Development and Rehabilitation Center (CDRC), please write them down and call any of the clinicians who worked with you. Their names and phone numbers are listed on the written reports you will receive. Please think of us as an ongoing resource for you to provide information, to answer questions, or help you find the supports you need.

Tips for using this booklet:

1. Don't feel like you have to read it all at once.
2. Read what is important to you now and save the rest.
3. Know that your experience and needs may differ from those shared here.
4. Keep your notes and other paperwork in a set place, like a file, so that you can take it with you to your future appointments.

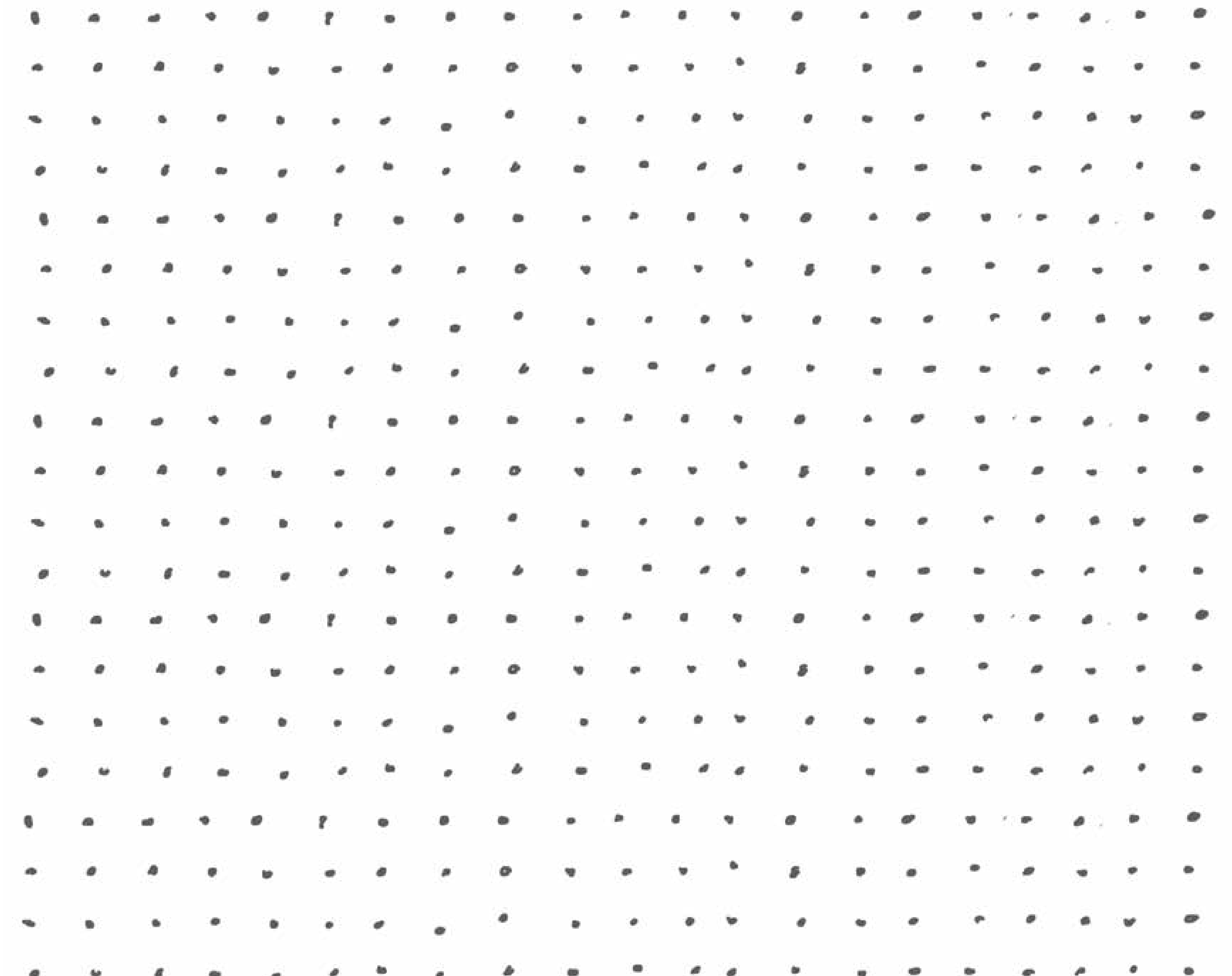
Thank you again for trusting us with your care.

Lark Huang-Storms, Ph.D.
Director, Autism Program at
OHSU Doernbecher Children's Hospital
Assistant Professor of Pediatrics

Table of Contents

What Do I Do Now?

Every individual and family that comes to the OHSU Autism Clinic is unique and comes with their own set of expectations and questions. Some families are relieved to hear about a diagnosis of Autism Spectrum Disorder (ASD), and others need some time to accept the diagnosis. No matter what you feel today, at some point you will be thinking: “What do I do now?” Finding out what resources are available and coming up with a plan to help you and your child be successful is a great place to start.



Getting Started

We have provided (below) a list of things that you can do to get started. Many of them are also listed on the recommendations you were given in the OHSU Autism Clinic.

☐ **Schedule an appointment with your primary care doctor.**

- Bring a copy of the reports you were given after your evaluation with us. Your referring provider should also be receiving the results from Doernbecher.
- Discuss the information you were given and get any referrals for therapies or follow-up appointments if needed.
- Make sure your doctor is comfortable and knowledgeable regarding ASD.

☐ **Contact your local Education Service District (ESD) if your child is under 5 years old.**

- Begin an Early Intervention (EI) program if your child is not already participating in one. These programs are usually free in Oregon and Washington.

☐ **If your child is school-aged, share the information with the teacher or school special education team.**

- Sharing information and coming up with a plan together is helpful for the school, the parents and most of all, the child. Your child may need to have an Individual Education Program (IEP) developed or an existing program changed to support his or her success.

☐ **Talk to another parent of a child with ASD.**

- The Autism Society of Oregon (ASO) can connect you with other families in your area. OHSU and ASO also collaborate on the Welcome Project to help families and individuals connect with each other.
- The Family Involvement Network (FIN) is a free program that is staffed by family members and Spanish language speakers are available. For more information, contact **503-494-0864.**

☐ **Talk to a peer with ASD.**

- If you are a teenager or adult, it may be helpful for you to talk to someone who also been diagnosed with ASD. You may find others at school, or social clubs or events that are specifically for individuals with an ASD. The Autism Society of Oregon and the Welcome Project can also help to connect you to others in your community.

Receiving an ASD Diagnosis

Finding out that you or your child is experiencing ASD can be a very emotional time. All families react in different ways, but many people report struggling on some level.

As a parent, you love your child so much that it can be heartbreaking to think that things will be hard for him or her. Adults receiving a diagnosis for themselves may also have many different emotions. Some may be relieved to finally understand themselves better, while others may feel overwhelmed.

Facing and accepting an ASD diagnosis is not a one-time experience. There may be times when things are going well and parents or individuals feel they have come to accept their diagnoses, and then something will trigger the emotions all over again.

There are emotional stages that many individuals report experiencing, which may include:

Shock or confusion

The day you or your child is diagnosed with ASD can be very overwhelming and confusing. Some people may deal with this by not agreeing with the diagnosis, getting angry or wanting a second opinion. Some people "disconnect" and attempt to ignore the information, while others just feel at a loss for how to communicate about it. It takes time to really process the news you have been given.

Sadness

Some people feel like they are mourning the loss of what they thought they or their child might become. Sometimes the realization of how unfair it will be that they or their child will struggle with some things is hard to accept. It is normal to be sad and upset, and it is healthy to cry. As a parent, it is important to not let the sadness consume you because the thing you and your child need most is you. Starting to come up with a plan for how you are going to move forward to help yourself and/or your child may help you feel more in control, even if it is just one step at a time.


Guilt

Many individuals feel guilt. They wonder if they may have caused their child's ASD, or if they could have done something to prevent it. Even though the causes of ASDs are not completely known, we do know that they are nothing a person could have controlled. Research suggests that ASD is genetically linked and that changes in brain development happen very early. ASD rates are similar across ethnic and racial groups around the world, so it is widely accepted that it is not caused by specific environmental or medical factors.

Anger

It is very hard to watch your child struggle with things that come naturally to other children. Sometimes you might feel angry at others, your spouse, yourself, or anger that is not directed at anyone in particular. This is a natural part of the process. Even years from now, there will be times when things seem so unfair it will make you angry. Many times others do not understand that you are hurting or that you may need support. It can be very helpful to talk to other individuals and parents who have similar experiences.

Loneliness

This can often come and go for individuals and for parents whose child has a disability. It may seem that no one can understand or that others don't have to go through the same struggles. Others who do not experience a disability or have a child with a disability may find it hard to grasp what you are going through. It may be up to you to tell them what it is like so they can support you.

Acceptance

Periods of acceptance may mean that you can appreciate the reality of living with ASD, and are also ready to advocate for what you or your family needs. Acceptance is an ongoing process, not an end stage.

Autism Speaks **(www.autismspeaks.org)** created a number of free downloadable toolkits for family members about topics like sleep, supporting siblings, managing tantrums, and more.

Individuals

Learning that you have autism as a teenager or adult can be a lot to take in. It is important that you find others to talk to about your diagnosis and what it might mean for you. It does not mean that you are all of the sudden limited by your new label. Hopefully it will instead give you tools to better understand what "makes you tick" and will help you thrive. You are still the same person with the same potential. Understanding what works well for you, and seeking out help for things that are hard for you, will be important. Don't be afraid to work with a therapist or mental health professional to help you come up with specific strategies that work for you.

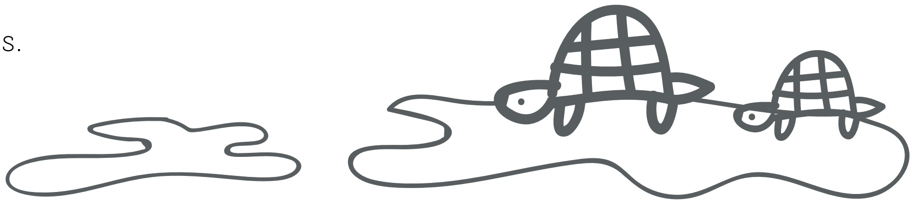
Siblings

Siblings of a child with ASD often have their own set of questions, stressors and challenges. It is important that you attend to their needs too, and take time alone with them. They can easily be overshadowed by the demands of their sibling with ASD and may benefit from their own therapies or special times with you. It can be helpful to find activities that siblings can enjoy together. Autism Speaks had a booklet that you can download that is specifically for siblings **(www.autismspeaks.org).**

Family members

Others in your family will respond to a new diagnosis in different ways, just like every individual deals with ASD differently. They may not have received all of the information that you have. Sometimes parents choose to wait until they are more comfortable with ASD before talking about it with friends or family. Other people who love you and your child may also feel overwhelmed, angry or confused. Encourage them to:

- Be respectful and supportive of the decisions you are making for your child.
- Learn more about ASD.
- Follow the routines and systems that your child is used to.
- Find a support group for themselves.



I was diagnosed with Asperger's Syndrome at age 36. It was a joyful occasion — it helped me finally stop trying to be normal. The more I learned about ASDs (Autism Spectrum Disorders), the better I was able to adapt myself to life in a functional and enjoyable way. It turns out that being weird is not only functional, it's really fun. I researched ASDs in earnest. I interviewed parents, teachers, OTs, and psychologists, neurologists — you name it. What I found is that an awful lot of those well-meaning adults were busily working "against the grain" of AS/Autism. They were frustrated and tired too! In the hope of saving a few parents and teachers some of that time, energy and pain, I have come up with a list of "suggestions" for them. These come from the heart of an Aspie who really likes the strange creatures we call "typical."

— Jennifer McIlwee Myers

Jennifer’s Suggestions

1. Please don’t try to make us “normal.” We’d much rather be functional. It’s hard to be functional when you have to spend all your time and energy focusing on making eye contact and not tapping your feet.

2. Please don’t overprotect, indulge, or cosset us. We already have enough social problems without additionally learning to be spoiled and self-indulgent.

3. Don’t teach us social skills according to how you wish the world was, or even how you think it is. Look carefully at what is really going on and teach us real world rules.

4. Don’t talk and/or act as if your life would be perfect or soooo much easier if you had a “normal” child. We don’t thrive on knowing that we are the children you didn’t want.

5. Don’t make the mistake of thinking that teaching us typical behaviors and successful masking means we are “cured.” Please remember that the more typical our behavior seems, the harder we are working. What is natural, simple behavior to you is a constant intense effort for us.

6. Please don’t punish us with rewards or reward us with punishments. For those of us who find recess to be the most stressful part of school, any action that will keep us in from recess is one we will learn to repeat ad infinitum. Getting rewarded for good behavior with fashionable but really itchy clothing will train us to NOT behave too well!

7. If you assiduously train us to imitate and conform to other children’s behavior, don’t be shocked if we learn to curse, whine for popular toys, dress in ways you don’t like, and eventually drink, smoke, and attempt to seek out sex as teenagers. Those “nice kids” you think so highly of do a lot of things you don’t know about — or don’t you remember high school?

8 Please do give us information about ASD/Asperger's early on at a level we can digest. We need to know what's going on — and we will figure out that something is "wrong" with us whether you tell us or not.

9 Don't avoid a diagnosis or help for us because you are scared of us being labeled. Without that diagnosis and appropriate support, our teachers, family, and fellow students will give us plenty of labels — and we might just believe them if we hear them often enough

10 Don't force us to do things we can't do. A forced social situation won't teach us social skills any more than dumping us in the middle of the Pacific Ocean will teach us to swim.

11 Don't punish us for what other kids do. The fact that other kids tease and torture us for benign "Autistic" behaviors doesn't mean we need to change, it means they do. Needing to bounce or swing for the whole recess is not morally wrong; tormenting someone for having a neurological disability is.

12 Don't attempt to use humiliation or public embarrassment to "teach us a lesson." We get way too much of that from other people, and the only lesson learned is that we can't trust you either.

13 Do punish us (or give us "consequences," heaven help us) when it is necessary to do so – but make the connection between cause and effect very, very clear. We often need visual aids to understand how our behavior can cause an unwanted result for us!

14 Don't cut us too much slack when our behavior is potentially dangerous to us. For example, adolescent pre-stalking behavior should result in serious consequences — because not treating such behavior seriously when we are young can lead to problems involving law enforcement when we're older!

15 Don't trust untrained camp counselors, "typical peers," or youth pastors to be able to deal with Asperger's. Often their answers to our problems involve highly destructive phrases like "try harder," "you could do it if you really wanted to," and "snap out of it."

16 Don't model one thing and teach another. If you yell or hit when you're mad, we will too. If you rage at us, don't be shocked at our "Autistic rages." And DON'T lecture us about our stims while you smoke, tap your foot, pick at your manicure and down your third double latte today.

17 Don't require us to be wildly successful at something because your ego has been wounded by having a "flawed" child. We can't all be Temple Grandin. Remember, all honest work is noble, even if you can't brag about us to your friends.

18 Do spend time with our siblings, even if you need to arrange for respite care to do so. Schedule something special for them without us along, even if it's just lunch at a fast-food joint once a week or so.

19 Do ask for help for yourself as needed. Take advantage of respite care when you can. Get cognitive- behavioral counseling and/or medication when you are depressed. Don't try to do it all alone. Remember: it is much more important that you get a nap and a nourishing meal than that we have a tidy house.

20 Most important: please, please, please don't wait until we're "cured" or "recovered" to love and accept us. You could miss our whole lives that way.

** Please note that since 2013, Asperger's Syndrome is now simply referred to as Autism Spectrum Disorder. However, many people who received an Asperger's Syndrome diagnosis are most comfortable retaining this earlier diagnostic language*

Defining the Spectrum

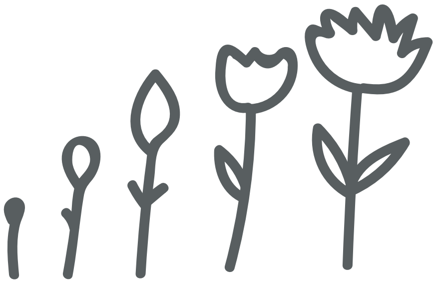
The term "spectrum" simply means that symptoms may look very different for each person. Although there are clear patterns that define the diagnosis of ASD, there is a wide range of how different symptoms affect different people.

Rather than thinking of a number line of increasing intensity, you can think of ASD like a "buffet" — everyone at the table gets the same basic courses, but the portioning and condiments will be unique to the individual.

Because of this, ASD can seem very different in each person and can also shift over the course of a lifetime. For example, one child may have a very hard time with social skills and have very few repetitive behaviors. Another child might be consumed by routines and have an easier time with language. A girl who seems shy in kindergarten may become more verbal in middle school, but also begin to struggle with anxiety or depression.

How is ASD Diagnosed?

There is no medical test that can be done to diagnose ASD, including blood tests or brain imaging. But there are a number of assessments that should be completed as part of an evaluation for an ASD. Most of these tests are known as "standardized" or "validated" tests. They require a well-trained person (a doctor or psychologist) to interact with an individual while looking for some very specific types of behavior patterns. Other assessments help the clinical team rule out other disorders that may look like ASD or that often go along with ASD (like ADHD). Some tests are used to help the team understand an individual's strengths and weaknesses to ensure the right planning for supports, interventions and goal setting.



There will usually be a combination of tests done directly with the individual being assessed, as well as interviews that rely on parent report or input from teachers/caregivers/ employers. Both types of information (direct and indirect) are important for making a diagnosis. This helps the clinical team to get a good behavioral "snapshot," as well as a history of any behaviors they may not get to observe during appointments.

Understanding ASD

ASD is a developmental disability that is caused by the way the brain develops. Symptoms of ASD appear during early childhood (although they may not result in a diagnosis until later), and include significant challenges in a person's ability to relate to and communicate with other people.

The medical criteria for diagnosing Autism Spectrum Disorder (ASD) is based on the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5). A major change from the earlier fourth edition is that ASD is now considered a single spectrum, rather than several sub-types (like PDD-NOS, Asperger's Disorder, and Autistic Disorder). The reason for this change is that research over the past decades has shown that the core symptoms in each subtype were actually similar and shifted in intensity over time.

Because ASD is defined by a common set of core behaviors, it is best represented as a single diagnosis.

It is important to know that anyone diagnosed with any type of ASD before this change should still meet the new criteria for ASD.

The following describes the symptoms a child must demonstrate to be diagnosed with ASD:

1. **Difficulties with social interaction and communication (across settings):**
    - Social-emotional reciprocity (sharing interests or emotions, pointing out objects, initiating social situations, back and forth conversation)
    - Using and understanding nonverbal communication (eye contact, facial expressions, gestures, body-language, combining verbal and nonverbal efforts)
    - Making and keeping age-typical social relationships (showing interest in others, sharing imaginative play, adjusting behavior to match situations)

2. **Restricted and repetitive patterns of behavior, interests, or activities (two or more of these):**
    - Repetitive speech, motor movements, or use of objects (hand flapping, echolalia, non-functional use of objects)
    - Inflexibility about routines, repetitive patterns of behavior, or strong resistance to change (insistence on same driving route, repetitive questioning or extreme distress at small changes)
    - Restricted, fixated interests that are abnormally intense or focused (attachment to objects, excessively narrow or preoccupying interests)
    - Over- or under-reactivity to sensory input or unusual interest in sensory aspects of the environment (pain/heat/cold, specific sounds or textures, smelling or touching of objects, fascination with lights or spinning objects)

3. **These difficulties must be present in early childhood (but may not be fully observed until social demands exceed a person's abilities).**

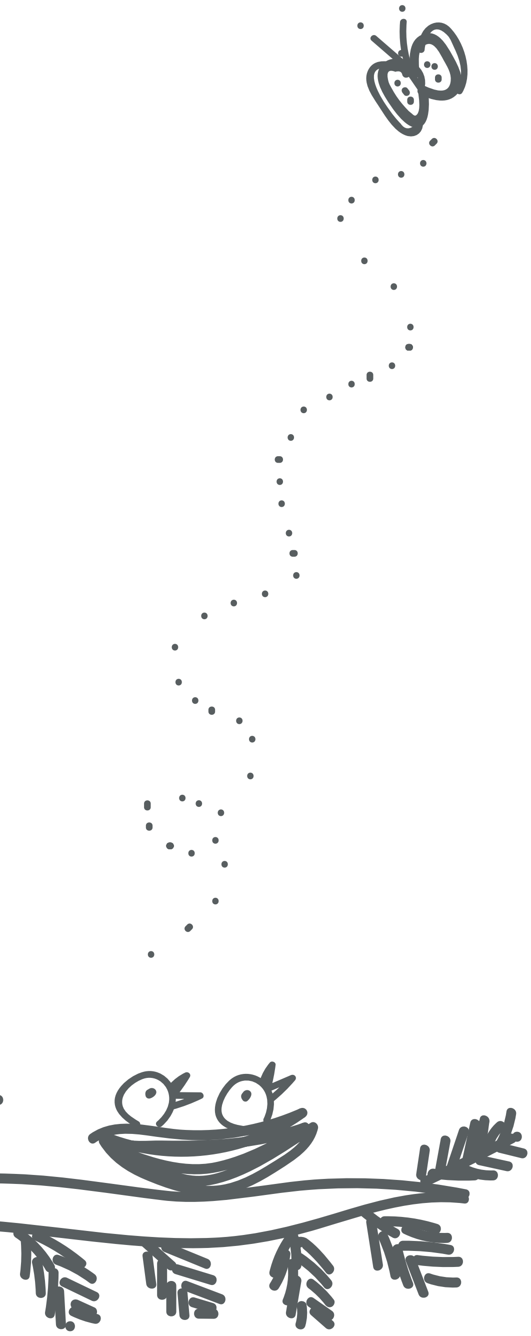
4. **These difficulties limit and impair everyday functioning.**

Other Characteristics of ASD

Advanced thinking

Individuals with an ASD can be very bright and highly motivated by their own internal desire to master a subject. They sometimes have intense interests and can become experts in those areas. Even those who are very strong on cognitive testing may still have a hard time in many areas such as:

- Abstract thinking
- Seeing the whole picture
- Filtering out what is not important
- Organization
- Planning
- Problem solving
- Taking something they have learned and applying it to a different setting.



Global Developmental Delay (GDD)

This diagnosis is provided when young children are delayed across different areas of their lives (such as communication, fine motor skills, or age-typical independence skills). Global simply means that the delay can be seen across most areas of the child's abilities. This diagnosis is for children six years old and under.

Intellectual Disability (ID)

If a person has low IQ (a measure of mental ability) and their "life skills" are significantly delayed after age six, it is called Intellectual Disability. ID must be diagnosed before age 18, and includes people with significant limitations in their ability to carry on everyday life activities (such as self-care and communicating), as well as in their general mental abilities to reason, plan, and solve problems.

Anxiety and depression

Some people with an ASD also suffer from anxiety and/or depression. This is more common as children get older and become more socially aware. Social expectations also increase with age so it can become even more difficult to keep up with peers. The stress of this can accumulate over time and make a person vulnerable to feeling constantly worried or hopeless. Mood and problematic behavior changes over time should be discussed with therapists and primary doctors.

Genetic disorders

Some individuals have ASD as a part of a genetic disorder, such as Fragile X syndrome. Others may have a dual diagnosis of ASD with another syndrome like Down Syndrome. Being tested for a genetic disorder is considered best practice for people with an ASD diagnosis. It will not change the ASD diagnosis, but it may help explain why a person has these difficulties or indicate that other medical conditions should be monitored. It can also help in family planning and understanding if others in the family may be at risk for passing on a syndrome to their children.

Gastrointestinal and feeding disorders

Some people with ASD report gastrointestinal (GI) or stomach problems. Children and adults with ASD are sometimes very picky eaters and may have difficulty swallowing or even tolerating certain food in their mouth. Children with an ASD may have problems such as chronic constipation or diarrhea. These difficulties should be discussed with your medical providers so they can be addressed sooner rather than later. This may include a referral to a GI specialist, feeding/ swallowing clinic or supportive therapies like occupational therapy or speech-language therapy.

Sleeping problems

Many people with ASD have trouble falling asleep and/or staying asleep at night. This can be very hard on the whole family. If you or your child is having trouble with sleep, talk to your doctor about things you can do to help, possibly including behavioral interventions, medical treatment, or a sleep study.

What causes ASD?

Scientists do not know what causes ASD. There is a lot of research being done to answer that question. Let your clinical team know if you would like to get involved. It is likely that within the next 20 years there will be much more information available to explain the diversity and presence of ASD around the world. For now, there are some things that are widely accepted.

- ASD is caused by the way the brain develops, likely beginning very early in development.
- There is not one single cause of ASD. There are likely multiple factors that may make a child more likely to experience ASD.
- Genes are one of the risk factors. ASD often runs in families. A child with a sibling or parent who has ASD is more likely to have ASD, too.

What does not cause ASD?

The causes of ASD have not been determined, but some things have been ruled out.

- There have been many large, high-quality studies done, and no link between vaccines and ASD has been found.
- Bad parenting was once thought to be a cause of ASD. This is not true.
- Some people wonder whether diet during pregnancy is a factor, but there is no research to support this. Many ethnic groups around the world have similar ASD rates and their diets are very different.

Why are there so many children with ASD?

The Centers for Disease Control and Prevention reports that about 1 in 68 children in the United States have ASD. This number has risen drastically in the last decades. Why is this?

- When the Diagnostic and Statistical Manual of Mental Disorders (DSM) was revised in the 1990s, the definition was deliberately broadened to include more people who could benefit from supports. Previously, many people would not have been "severe" enough to qualify for the diagnosis. This is the main reason the numbers have risen.
- There is also much more public awareness of ASD and less social stigma around the diagnosis.
- There have been active efforts in the past decades to screen for and diagnose ASD earlier and to provide interventions and supports.

Public Services

BIRTH–21 YEARS

Special education (0–kindergarten)

Once a child has been identified as having a medical diagnosis of ASD he or she will likely be eligible for special education services. In Oregon, school districts have their own eligibility criteria, which sometimes can be different from medical criteria. This can be confusing so don't be afraid to ask the educational team questions. There are also statewide parent organizations that can help answer questions, such as FACT Oregon. The federal government mandates that all children with a disability receive a "free and appropriate education."

For children birth until kindergarten, most educational services are provided by the child's local Educational Service District (ESD).

- Children under three years old receive Early Intervention (EI) services (often in the home setting).
- Children between the ages of three years and kindergarten receive Early Childhood Special Education (ECSE) services (often in a preschool classroom setting).

For young children who qualify for Early Intervention and/or Early Childhood Special Education (EI/ECSE), a team of professionals and the child's parents work together to come up with an Individual Family Service Plan (IFSP). This is a plan that helps the child learn strategies to be more successful at home and at school. This plan will include how the child is currently performing and the goals they will be working towards. Some of the things that ESDs may provide include:

- Speech therapy (speaking and using language, feeding, etc.)
- Occupational therapy (sensory, self-care, fine motor skills, etc.)
- Physical therapy (mobility or movement, gross motor skills, etc.)
- Behavioral therapy (transitions, play, behavioral regulation, etc.)
- Training for parents and families
- Social play groups

The Early Intervention programs can be very different from region to region. Some of the services will be provided in the home, others may be at a preschool or other location depending on the needs of the child and the resources of the ESD.

Special education services (kindergarten–age 21)

Children between the ages of five and 21 receive special education services through their local public school district. These programs always include an Individualized Education Program (IEP). This is developed by a team of school professionals and the child's parents in order to decide what the child needs to be successful at school. The IEP is a plan that the school is required to have in place, and follow for each child with an eligible disability.

The range of services that may be provided by a school district is very broad, and depends on the needs of the child. Some children may benefit from being in a classroom with children who also have disabilities, while other children may do better if they remain in the regular education classroom (and some may do best with a combination of both).

It is very important that parents are involved in the decisions that affect the education of their child. Parents should be treated as equal partners in the education process. Sometimes parents have to advocate for different placements or interventions for their child that may not be obvious to other educators on the team.

Transition to adulthood

When an individual turns 18, he or she becomes a legal adult regardless of disability. Here are some changes to be aware of:

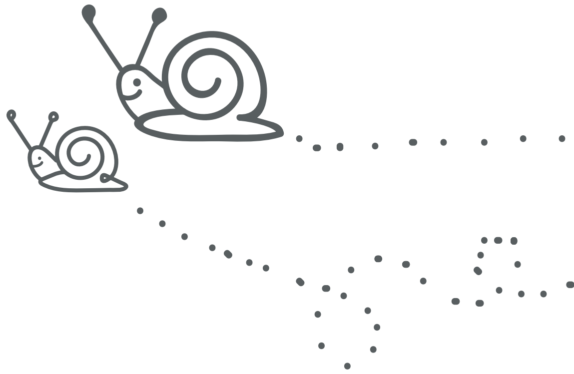
1. **Legal** – Depending on the support needs of the person on the autism spectrum, the parents or guardians may need to obtain legal instruments regarding their adult child such as guardianship, conservatorship and/or powers of attorney. These take time and can be expensive to implement, so start to research these instruments well before your adult child turns 18.

2. **Medical** – At age 18, and sometimes earlier, the disabled person controls access to his or her medical records. To access your adult child's medical records after age 18, parents will need the written consent of their adult child, or a separate legal right to access those records.

3. **Social Security** – At age 18, income and asset eligibility will be based on only the disabled person's income and assets, not the family's income and assets. A parent can be designated as the representative payee although that does not confer separate legal rights such as guardianship. A person receiving SSI or other Social Security program can be employed in specific circumstances. Please contact SSA for more information as there are several programs and the requirements can be complex. For more information on Social Security disability programs, see: **https://www.ssa.gov/disabilityssi/**

4. **Support services for adults** - At age 18, the person on the autism spectrum transitions into adult support services, which can continue to be through the county Developmental Disability (DD) services or be provided through brokerage support services. These services are designed to help a person with a developmental disability live in their own home or with family or friends and fully participate in community life, including work.

    a. To be eligible, the person must have a confirmed DD diagnosis, not be receiving comprehensive services, and be eligible for DD Services. For a list of local DD program offices go to: **www.oregon.gov/DHS/dd/county/county_programs.shtml** or call your local County DD Program Office, or call



1-800-282-8096. If the disabled person does not already have DD Services, try to apply before his or her 22nd birthday, as it's much easier.

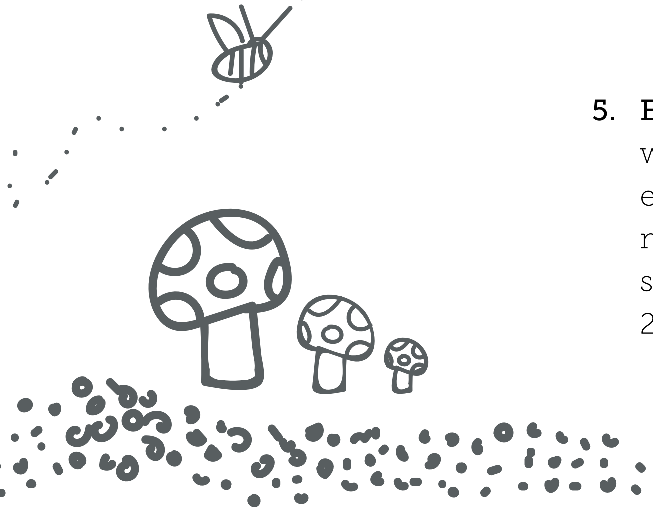
b. Comprehensive Services such as residential services, group homes, and foster homes are different as they provide 24 hour supports. Enrolling in Support Services for Adults will not hurt the chances of accessing Comprehensive Services or any other service a person with ASD may need in the future.

c. Your adult child can receive services through either the county DD Services or through a Support Brokerage. This is a change from years past when services for adults were only through the Support Brokerages. The person receiving services can chose to move from county services to Brokerage services (and back) at any time, although some Brokerages have waitlists.

d. Services through a brokerage are provided by your Personal Agent (PA). Services through the county are provided by your Service Coordinator (SC). Services are provided based on need as determined by an Adult Needs Assessment. From there, an Individual Support Plan (ISP) will be prepared to help the person function as independently as possible at home and in the community. The person receiving services can change their PA or SC at any time.

e. An adult can hire his or her parents as Personal Support Workers, but NOT if the parent is the legal guardian of the disabled person because it's a conflict of interest. Instead, a third party would need to be appointed to make that decision.

5. **Education** – If the person on the autism spectrum graduates with a regular high school diploma, they are no more educational services available. However, graduation with a modified diploma means the person is eligible for transition services until the end of the school year when they turn 21 years old.



6. **Vocational rehabilitation** – This is a state agency that helps people with disabilities find and keep appropriate employment. The person doesn't have to be eligible for DD Services to be eligible for help through Voc Rehab. For a list of Voc Rehab offices, see: **https://www.oregon.gov/DHS/Offices/Pages/Vocational-Rehabilitation.aspx**

Information adapted from: *A Road Map to Support Services for Adults*, 3rd Edition, A collaborative project of DRO, OCDD, Oregon DHS – Seniors and People with Disabilities.

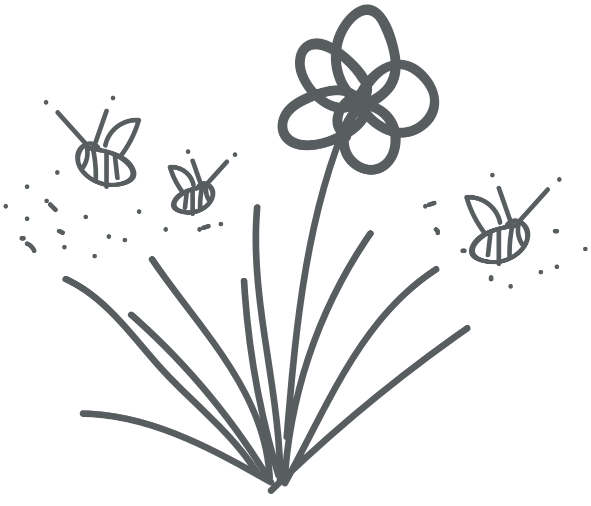
ASD an Introduction for Parents: A Guide to Oregon's Human Services System. Published by: Oregon Technical Assistance Corporation

What types of services are available for children under 18?

Supports for families

Every county in Oregon has a program that can help families with respite, training opportunities and other basic assistance not provided by special education. This support is administered by your County Developmental Disabilities Program. Your child must meet Oregon's definition of "developmentally disabled" to be eligible for help under this program. You'll need school test results and/or doctor's reports that show your child has an ASD. The program is open to families at all income levels.

Case managers can help you think about the type of respite and training you need to care for your child at home. You will play a big part in this — you determine where and when you need help, and what kind. Case managers will coordinate and monitor the assistance you receive. Remember, the program is small and probably can't meet all your needs. But it can get you started.



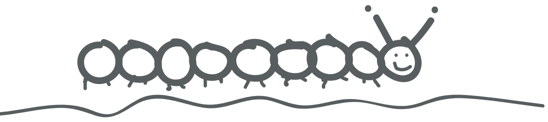
Intensive in-home services (for children under 18 years old)

If your child needs intense supervision or intervention because of dangerous behavior and/or medical problems, your county may refer you to a state program for intensive in-home services. This program is for children who can't remain at home unless their family receives significant help with personal care, safety modifications, training, behavior consultation and similar child-related needs. A checklist that rates the severity of the child's difficult behaviors and/or medical issues determines eligibility. It's not easy to get into this program and there is a limit to the number of children who can be served. But if you think you need it, ask your county developmental disabilities case manager to be considered.

Crisis/out-of-home placement (for children under 18 years old)

If your child is in crisis and can't live at home, county and regional/state placement specialists can work with you to find a temporary foster home or group home for your child. Some children are in a placement setting for a few weeks; others for a longer period of time, depending on the child and the family's situation. There are a limited number of foster and group homes in the state that provides services to children with an ASD and other developmental disabilities. (Oregon has no specific institution or residential public school for children with an ASD). Your county may have some crisis foster homes but probably will refer you to the state program for children's crisis services. Unfortunately, the specialized placements may not be close to the family home.

A legal agreement with the State is required. It is called the Developmental Disabilities Child Placement Agreement. Also, a plan will be written to include ways that families can remain involved with their children during placement. Families are required to authorize the Oregon Program for Seniors and People with Disabilities (SPD) as payee for their children's SSI benefits (see below). If the child does not currently receive SSI, the program will apply for these benefits in the child's name. The cost of the placement is not charged to families; however, this could change in the future. Families are expected to provide clothing and retain health insurance for their child. SPD also will apply for a medical card to supplement the family's health insurance.



Supplemental Security Income (SSI)

SSI is a federal program that provides income and medical insurance through Medicaid to eligible children who are disabled or chronically ill and whose families have little or no income or financial resources. Your child may qualify for SSI payments if your family is eligible for Medicaid. Applying for SSI can be challenging and complex, but it can be done. For more information, contact your county Mental Health and Developmental Disabilities Services Office.

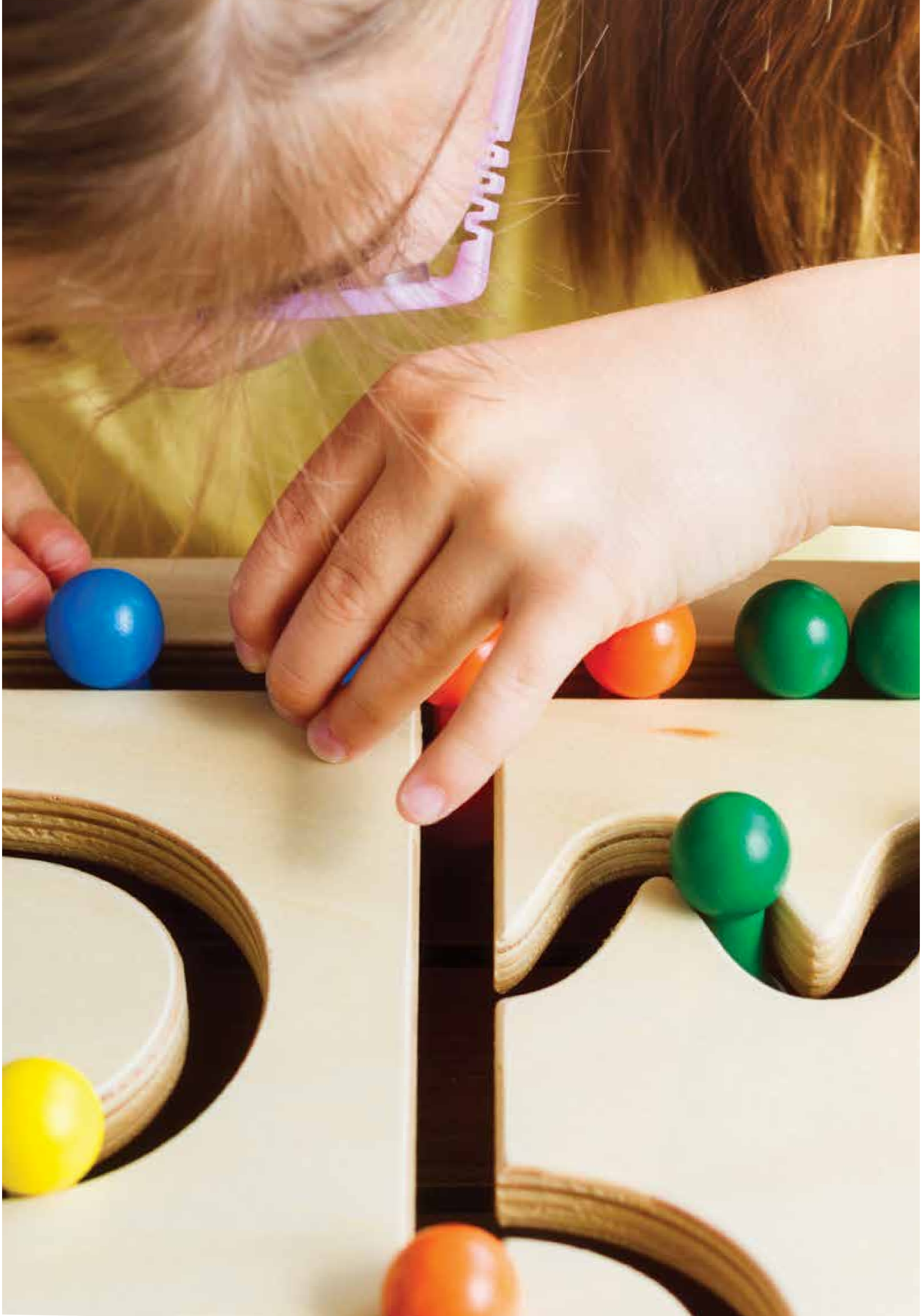
Oregon's Program for Seniors and People with Disabilities offers services ranging from respite care and technical consultation to intensive in-home assistance, crisis intervention and out-of-home placement. There is no separate, specific program for individuals with an ASD. Instead, services are provided through county and state programs that serve people with developmental disabilities.

If your child is under 18, it's important to understand that there is no "entitlement" to services from the Program for Seniors and People with Disabilities. Unlike special education, where children with disabilities have a legal right to public education, there is no law requiring services to children with disabilities — even if eligible.

Services are generally limited to available funds in crisis situations. However, in the past few years, services for children with disabilities who are under 18 years old and their families have been expanded and improved. Now there is more help available for families caring for children with disabilities at home and more dollars going to prevent crisis and "burnout" in families.

No matter your child's age, the "doorway" to services is your local county Developmental Disabilities Program. It's usually located in the county Mental Health Department (see State and Local Developmental Disability Services). Case managers (sometimes called service coordinators) in your county will talk with you to see if your child is eligible for services.

- If your child is younger than 18, the case manager will help decide what help you need and develop service options.
- If your child is 18 or older, the case manager will work with your child and you to identify options and access available services.



Treating ASD: Frequently Recommended Therapies

Communication, speech and language

One of the key components of autism is communication, speech and language development. Some individuals may be preverbal, while others may speak very well but with poor social conversational ability. Regardless of the level at which individuals with autism use language, they all will have some level of social- communication challenge. Speech and language therapy can begin as early as 18 months of age. Some common difficulties in this area are:

- Not speaking at all
- Difficulty answering questions or telling a story
- Lack of reciprocity ("back-and-forth") in conversation
- Unnatural tone of voice ("prosody") or use of unusual vocal sounds
- Repeating what another person says ("echolalia")
- Difficulty understanding abstract meanings or words out of context
- Poor use and understanding of eye contact, body language/ nonverbal cues
- Repeating memorized words or phrases in a rote manner, sometimes in context

A speech language pathologist (SLP) is trained to work on speech, language, and communication, nonverbal communication, and sometimes feeding. They can help with many issues, such as:

- Requesting help and appropriately protesting
- Initiating and maintaining play
- Conversation skills to help build relationships
- Recognizing verbal and nonverbal cues

- Learning appropriate times for specific communications (hello, goodbye, etc.)

- Augmentative and alternative communication (AAC): Ways for a child who does not speak to communicate through a variety of systems including a Picture Exchange Communication System (PECS), computers, letter boards and tablets.

Occupational therapy

Individuals with ASD can often benefit from occupational therapy (OT). An occupational therapist works with people to increase their skills in the "occupation" of living (i.e., playing and school for children). They help to identify things that are keeping the person with ASD from fully participating in the typical activities of daily life (eating, grooming, safety, playing, writing, typing, going to school or work, etc.).

Many people with ASD have trouble processing sensory information or being able to take in information around them in an effective way (touch, smell, sight, sound). For example, they may get overwhelmed by loud noises or the way things feel on their skin. This can make it difficult to regulate their behaviors, attention, and emotions. Sensory integration (SI) Therapy addresses these issues, and OT is usually the primary specialty involved in making treatment plans in this area.

- OT is a common therapy that school age children receive at school.

- It can occur at home, in a clinic, or in the community.

- This therapy is very individualized and based on the needs of each person.

Some examples of what an OT might do:

- Plan games that increase hand-eye coordination

- Adjust sensory input to improve ability to process (wearing headphones if it is too loud)

- Change the environment with technology or different equipment (can be as simple as using a pencil grip for writing, or wearing soft clothes)

- Often OT includes swings, trampolines, and other ways to incorporate physical movement for children

Physical therapy

Motor skills impact the way a person is able to move their body to do a task. Sometimes individuals with autism have less developed motor skills. If this is the case, physical therapy (PT) can help. A physical therapist works on physical limitations to help a person develop the muscles, balance and coordination needed for the day-to-day activities.

Behavioral therapy

Applied Behavior Analysis (ABA)

ABA is the most well supported intervention for ASD and is based on research. ABA is the use of scientifically based behavioral principles in everyday situations ABA Therapy works towards goals that help to increase or decrease different behaviors. For example, a family may want to increase their child's food intake, while also decreasing head banging. Which behaviors are most helpful to target will depend on the specific situation. All ABA programs share similar components, including specialized teaching, parent involvement, and teaching skills that can be used at home, school and other settings. ABA should be playful and motivating for children.

- ABA can help build skills so a person can function at a higher level in everyday life. ABA is often used to increase skills in the area of language, play, behavior, attention and being able to learn.
- People of all ages can benefit from ABA, although some research suggests that the earlier this approach is used, the better.
- ABA is a treatment that is used for all kinds of behavioral needs, not just those experienced by people who have ASD.

The following approaches are also grounded in the science of ABA:

- Early Start Denver Model (ESDM)
- Pivotal Response Treatment (PRT)
- Relationship Development Intervention (RDI)
- Floortime or Developmental Individual Difference Relationship (DIR)
- Treatment and Education of Autistic and Related Communication (TEACCH)
- Discrete Trial Teaching (DTT)

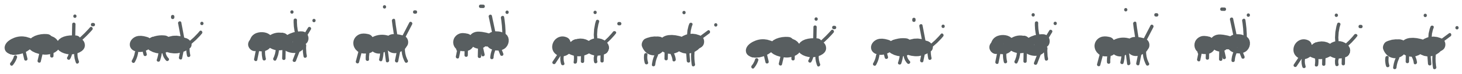
Cognitive Behavioral Therapy (CBT)

CBT refers to a group of well-researched techniques that are effective in treating difficulties experienced by children and adults. CBT works well for treating anxiety and mood disorders, teaching stress and anger management, and improving interpersonal skills. The goal of CBT is to help people learn how emotions, thoughts, and behaviors are related. CBT teaches people how to identify unhelpful beliefs and how to develop more positive patterns of behavior. Treatment is typically skills-based, and involves active family participation for children.

- CBT is helpful for individuals with ASD who have sufficient verbal skills and the ability to think about their thoughts and behavior.
- The use of visual aids and the incorporation an individual's special interests into therapy activities is often helpful.
- Licensed mental health professionals may provide CBT, including psychologists, clinical social workers, psychiatrists, and professional counselors.
- CBT may be done individually or in groups. CBT is often a large part of therapeutic Social Skills Groups aimed at improving social communication and social thinking.

The following treatment approaches effectively incorporate aspects of Cognitive-Behavioral Theory:

- Dialectic Behavior Therapy (DBT)
- Parent-Child Interaction Therapy (PCIT)
- Mindfulness-based CBT



Other supportive therapies and interventions

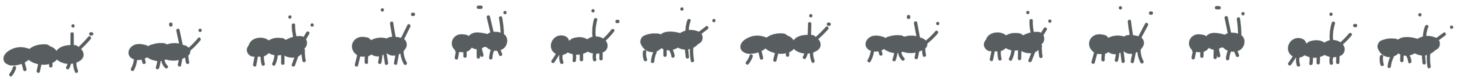
Music, art, adaptive exercise, and animal therapy: There are many therapies that are not yet well researched for the treatment of ASD, but may be helpful. These therapies can support social skills, boost self-esteem and build confidence, help develop motor skills, and improve the overall quality of life for an individual with ASD.

Prescription medications

There is no prescription medication designed to treat ASD, but some medications can effectively treat associated symptoms, such as hyperactivity, inattention, aggression, anxiety, depression, sleep disturbance and mood swings. The goal of including prescription medication as a part of treatment is often to reduce an interfering symptom so a person can respond better to the other types of therapies or educational opportunities. It is important to discuss any behavioral changes with your PCP, and to keep your clinical team informed of all medications (including over-the-counter or vitamin/herbal supplements) in order to monitor any related interaction or side effects.

Dietary interventions

Some people report improvements in functioning after changing their diet. The two most common dietary interventions utilized by families experiencing ASD are gluten and casein-free and yeast-free diets. There are professionals such as naturopathic specialists who can provide guidance in this area, while also seeking the advice of your primary doctor. Together, they can help decide if the potential outcome of the dietary restriction outweighs the potential harm. If there are concerns, specific allergy testing may be recommended.



Glossary of Autism-Related Terms

Americans with Disabilities Act (ADA) is the US law that ensures rights for a person with a disability.

Applied Behavior Analysis (ABA) is a type of therapy that helps individuals change behaviors through a step-by-step process.

Audiologist is a professional who diagnoses and treats individuals with hearing loss or balance problems.

Autism Diagnostic Observation Schedule (ADOS) is an interactive test considered the gold standard for diagnosing ASD. Along with other information (e.g., from interviews and developmental testing), the ADOS is usually incorporated into an autism evaluation.

Chronic constipation is an ongoing condition of having fewer than three bowel movements per week.

Cognitive skills are any mental skills that are used in the process of learning.

Developmental disorder refers to a family of disorders that affect typical development.

Developmental Individual Difference Relationship (DIR) is therapy, known as Floortime.

Developmental milestones skills or behaviors that most children can do by a certain age. These can be found at **www.cdc.gov**

Developmental pediatrician is a medical doctor who has specialty training in developmental-behavioral pediatrics.

Diagnostic and Statistical Manual of Mental Disorders (DSM) is the official system for classification of psychological and psychiatric disorders published by the American Psychiatric Association.

Discrete Trial Teaching (DTT) is a type of behavior therapy.

Dyspraxia is the brain's inability to plan muscle movements and carry them out.

Early Intervention (EI) is a state-funded program designed to identify and treat developmental problems or other disabilities as early as possible. Eligibility for EI is from birth to three years of age.

Echolalia is repeating words or phrases.

Expressive language is communication of intentions, desires, or ideas to others. It includes speech, writing, gestures, signing, use of a communication board and other forms of expression.

Free Appropriate Public Education (FAPE) means that education must be provided to all children ages three to twenty-one at public expense.

Floortime is a developmental intervention for children with an ASD.

Fragile X is a genetic disorder that sometimes shares characteristics of ASD. It is generally recommended that individuals receiving a diagnosis of ASD be tested for Fragile X.

Gastroenterologist doctors specialize in disorders of the GI tract, including esophagus, stomach, small intestine, large intestine, pancreas, liver, gallbladder and biliary system.

General education is a series of "regular education" courses in multiple subjects taught to the same grade level.

Geneticist refers to a medical doctor who specializes in genetic problems.

Gestures are hand and head movements, used to signal communication non-verbally to someone else (such as a give, reach, wave, point, or head shake).

Global Developmental Delay (GDD) is diagnosis in children younger than 6. It means the development is delayed in several areas.

Hyperlexia is the ability to read at an early age. To be hyperlexic, a child does not need to understand what he or she is reading.

Hypotonia is a term that means low muscle tone.

Incidental teaching teaches a child new skills while in their home or community "in the moment," to help make sense of what they learn during formal teaching.

Individual Family Service Plan (IFSP) is developed by a team including family as primary participant. It is a plan that helps identify goals and a process to meet those goals.

Individualized Education Program (IEP) identifies student's specific learning needs, how school will meet them, and methods to review progress. For students 14 & older, the IEP must contain a plan to transition to postsecondary education or the workplace, or to help the student live as independently as possible in the community.

Individuals with Disabilities Education Act (IDEA) is the US law mandating the "Free and Public Education" of all persons with disabilities between ages 3 and 21.

Inclusion involves educating all children in regular classrooms with typically developing peers, regardless of disability.

Intellectual Disability describes limitations in mental functioning that cause an individual to develop more slowly. They may take longer to learn to speak, walk, and take care of personal needs such as dressing or eating, and are likely to have trouble learning in school. May be mild to severe and was previously referred to as mental retardation.

Joint attention is the process of sharing an experience with another person, often observable by following gaze or pointing gestures. Impairment in joint attention is a core deficit of ASD.

Least Restrictive Environment (LRE) a setting that least restricts opportunities for child with disabilities to be with peers without disabilities. The law mandates that every child with a disability be educated in a Least Restrictive Environment.

Mainstreaming means students are expected to participate in existing regular education classess. It may be a gradual, partial, or part-time process (e.g., student may attend separate classes within regular school, or participate in regular gym and lunch only).

Modified Checklist of Autism in Toddlers (MCHAT) is a screening tool for identifying toddlers who may be referred to specialist for further testing.

Motor deficits are physical skills that a person cannot perform or has difficulty performing.

Neurologist refers to a doctor specializing in medical problems associated with the nervous system, specifically the brain and spinal cord.

Nonverbal behaviors convey information or express emotions without words, including eye gaze, facial expressions, body postures, and gestures.

Occupational therapy (OT) assists development of motor skills that aid in daily living. OT may focus on sensory issues, coordination of movement, balance, and self-help skills such as dressing, eating with a fork, grooming, etc. May address visual perception and hand-eye coordination.

Pervasive Developmental Disorder (PDD) used to be considered a subtype of autism, but is no longer used in the medical setting.

Physical therapy helps patients regain or improve their physical abilities.

Pica is persistent eating or mouthing of non-food substances for at least 1 month (older than 18–24 months). Substances may include items such as clay, dirt, pebbles, hair, plastic, etc.

Picture Exchange Communication System (PECS) is a communication system using picture symbols. Individuals learn to use picture symbols to construct complete sentences, initiate communication, and answer questions.

Pivotal Response Treatment (PRT) is a therapy that helps change unwanted behaviors.

Receptive language is the ability to comprehend words and sentences.

Reinforcement or reinforcer is a reward given after a desired behavior.

Relationship Development Intervention (RDI) is a therapy based on building positive behaviors through social connection that normally develop in infancy and early childhood.

Respite care is temporary, short-term care provided to individuals with disabilities. Respite care allows caregivers to take a break in order to relieve stress and fatigue.

Self-regulation refers to self-control. Self-regulation helps individuals manage their emotions and behaviors, and to allow us to participate successfully in society, work, and family life.

Sensory defensiveness is a tendency to over-react negatively to sensory input. Also called hypersensitivity.

Sensory integration is the way the brain processes sensory stimulation or sensation from the body and then translates that information into specific, planned, coordinated motor activity.

Sensory integration dysfunction is a neurological difference causing difficulties processing information rom the senses and positional sense (proprioception). Sensory information may be sensed normally, but perceived abnormally.

Sensory integration therapy is used to improve ability to use incoming sensory information.

Sleep hygiene refers to habits and environmental factors important for sound sleep, such as adjusting noise, light and temperature, avoiding naps and caffeine.

Social reciprocity is the back-and-forth flow of social interaction between people.

Social stories are simple stories that describe situations that may be difficult for a person with ASD to understand. For example, a social story might be written about birthday parties if a child appears to have a difficult time understanding what is expected of him or how he is supposed to behave there.

Social worker is a trained specialist in the social, emotional and socioeconomic needs of families. Social workers often help families find the services they need.

Special education is a public school program at no cost to families, to meet unique needs of a child with a disability.

Speech and language therapy is provided with the goal of improving an individual's ability to communicate. This includes verbal and nonverbal communication.

Spoken language (also referred to as expressive) use of verbal behavior, or speech, to communicate thoughts, ideas, and feelings with others.

Stereotyped behaviors are repeated behaviors or actions. They may include repetitive movements like rocking, spinning, hand flapping or posturing of the body or fingers.

Stereotyped patterns of interest or restricted patterns of interest refer to a pattern of intense preoccupation with a narrow range of interests and activities.

Stim or "self-stimulation" behaviors help stimulate one's senses. Some "stims" may be helpful (calming, increasing concentration, or shutting out an overwhelming sound).

Symbolic play describes play in which children pretend to do things or to be something or someone else. It typically develops between the ages of two and three years. Also called make believe, or pretend play.

Tactile defensiveness is a strong negative response to a sensation that would not be upsetting to most people, such as touching something sticky or the feeling of soft foods in the mouth. The term is specific to touch.

Training and Education of Autistic and Related Communication Handicapped Children (TEACCH) is a therapy based on the idea that individuals with ASD more effectively use and understand visual cues to increase functional behaviors.

The above glossary is an edited version of the glossary from: The 100 Day Kit version 2.0 by the Autism Speaks organization. You can view the kit at: www.autismspeaks.org

Autism Clinic at OHSU Doernbecher
Child Development and Rehabilitation Center

Mail code BTE355
700 S.W. Campus Drive
Portland, OR 97239-3098

Tel 503-494-8811
Fax 503-418-5199

www.ohsudoernbecher.com

OHSU

DOERNBECHER
CHILDREN’S
Hospital

DCH 21489387 8/17