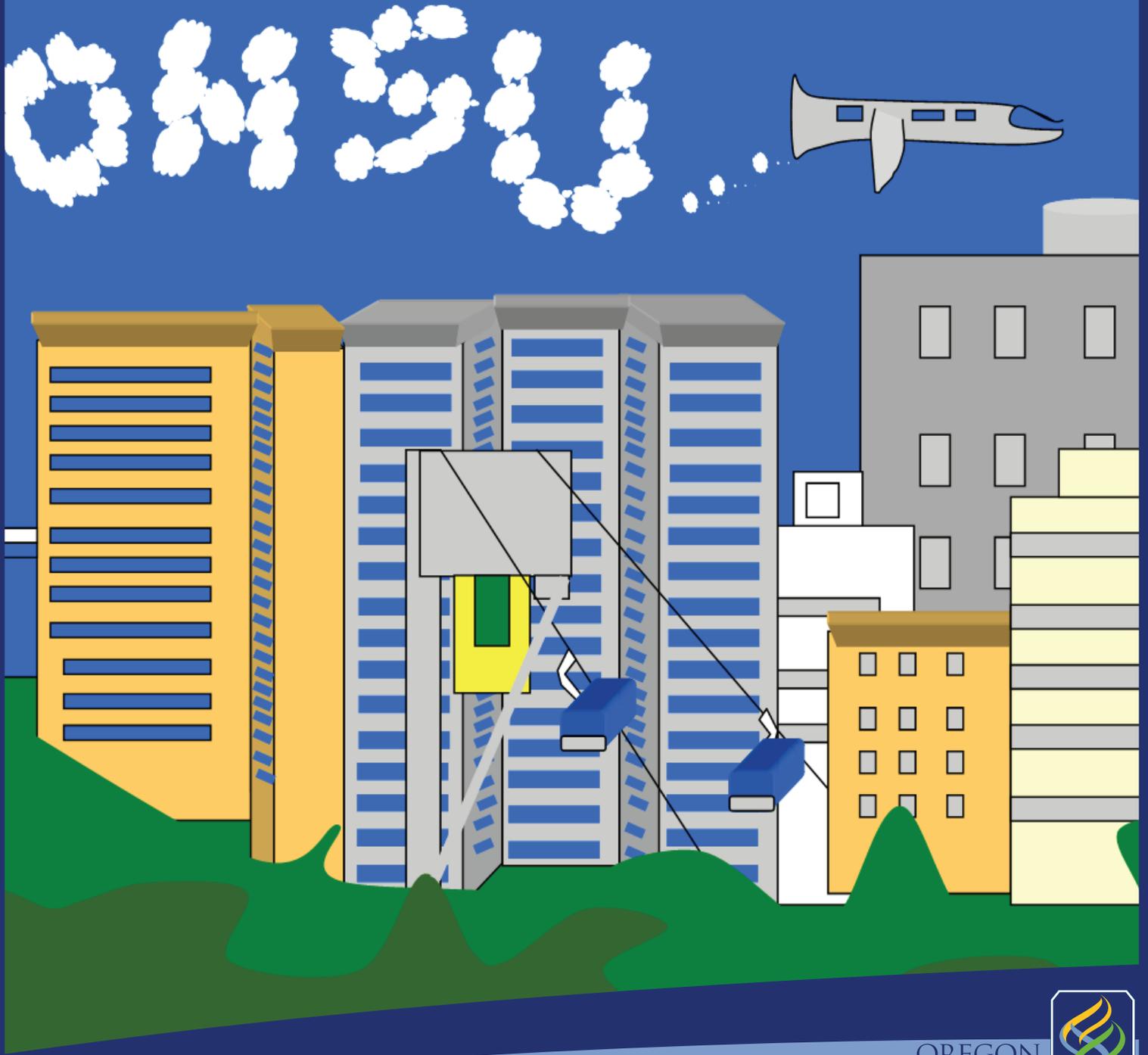


Autism Family Guide

Child Development & Rehabilitation Center



About this Book

How to Use This Book

This book was written for 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. It is our hope that as questions arise, you will be able to find the information you need.

Tips for Parents When Using This Book:

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. Keep the book handy so you can use it when new questions arise.
4. Keep your notes and other paperwork in the back to take with you to your child's appointments.

Creating This Book:

The CDRC participates in a leadership training program called Leadership and Education in Neurodevelopmental Disabilities (LEND). This program brings students from all over the country together to learn about working with children and families who are living with disabilities. Each year there is a parent of a child with a disability who participates in this program. Like all participants, the parent is required to complete a project as a part of the program.

As the LEND parent participant, Misti Moxley compiled this book. This quality improvement project looked at the information parents were given upon receiving a diagnosis of Autism for their child. The purpose of the project was to provide accurate, helpful and supportive information to families throughout their journey.

The art work in this book was created by Griffin Moxley a 10 year old child with Asperger's Syndrome, and Misti's son.

Contact Information

We appreciate the opportunity to meet you and your child and to help you better understand Autism. Please think of us as a resource for you to answer questions, or help you find what you need.

If you have specific questions about the report you received from the Autism clinic, please make a list of questions and call our team member who gave you the information at your visit. Their name and phone number is listed on the report.

Feel free to contact our family consultant Shelley Barnes with questions or feedback about your evaluation (503-494-0604).

Thank you again for trusting us with the care of your child.

Shelley Barnes , Family Consultant	503-494-0604
Kameron Beaulieu , Speech Language Pathologist	503-494-4024
Jill Dolata , Speech and Language Pathologist	503-418-0689
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What Do I Do Now?

Every child and family member that comes to CDRC is unique, and comes with their own set of expectations and questions. Some families are ready to hear that their child has Autism, and others may take 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 to you and coming up with a plan to help 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 clinic.

Schedule an appointment with your child’s primary care doctor.

- Bring a copy of the summary sheet you were given at the end of your evaluation at CDRC Autism clinic.
- Discuss the recommendations you were given, and get referrals if needed.
- Make sure your child’s doctor is comfortable working with a child with an Autism spectrum disorder.

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

- Begin an early intervention program right away if your child is not already participating in one. These programs are almost always free in Oregon and Washington.

If your child is school age, consider sharing information with their 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.

Talk to another parent of a child with Autism.

- There is a family consultant at the Autism clinic that would be happy to talk with you.
- The Autism Society of Oregon can connect you with other parents in your area.
- Ask teachers or other parents at your child’s school for help.

Dealing With your Child's Diagnoses:

Finding out that your child has Autism can be a very emotional time for your family.

All families react in different ways, but many parents report that they felt like they were grieving. As a parent, you love your child so much, and you want so much for them that it is heart breaking to think that things will be hard for them.

There are some common stages that families report experiencing. Stages of the grieving process may include:

Shock or Confusion



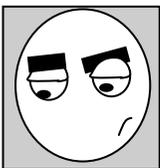
The day your child is diagnosed with Autism can be very overwhelming and confusing. Some people may deal with this by not agreeing with the diagnosis, and wanting a second opinion. Some may completely ignore it, while others just feel overwhelmed and confused. It takes a bit of time to really process the news you have been given.

Sadness



Some families feel like they are mourning the loss of what they thought their child might become. Also, the realization of how unfair it will be that their child will struggle with many things is hard to accept. It is OK to be sad, and it is even healthy to cry. It is important to not let the sadness consume you because the thing that your child needs most is you. Starting to come up with a plan on how you are going to help your child can move you forward and help you feel more in control, even if it is just one thing to start with.

Guilt



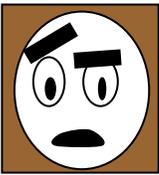
Many parents feel guilt. They wonder if they may have caused their child's Autism, or if they could have done something to prevent it. Even though the causes of Autism are not completely known, we do know that it is nothing you could have controlled. Research suggests that Autism is often a genetic disorder, but that there may be some environmental things that make it more likely to occur. The Autism rates are similar across ethnic and racial groups, so it is widely accepted that it is not caused by diet.

Anger



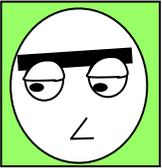
It is very hard to watch your child struggle with things that come naturally to other children. Sometimes you might feel angry at others, yourself, or anger that is not directed at anyone in particular. This is a natural part of the grieving process. Even if you feel like you have accepted that your child has Autism, there will be times when things seem so unfair and it will make you angry. Talking to others about your child can help. It is comforting to know you are not alone. Many times others do not understand that you are hurting or that you may need support.

Denial



There may be times when you feel like it is not true. They must have seen your child on a bad day, or maybe they did not really ask all the right questions. Many parents feel this way, and it is a way of coping with something that is overwhelming. Make sure you are aware of this and continue to provide the support your child needs.

Loneliness



This can often come and go for a parent whose child has a disability. It always seems that no one will understand, or others don't have to go through the same things. Others who do not have a child with a disability may find it hard to understand what you are going through. It is up to you to tell them what it is like, so they can support you. It is also very helpful to talk to other parents who have children with Autism or other disabilities. They most likely will know exactly how you feel.

Acceptance



This means that you know your child has Autism, and you are ready to advocate for what they need. Creating a plan and taking steps to help your child is ultimately what will give them the best chance for success.

*Reality is what you have today,
but today's reality does not end
tomorrow's possibilities.*

Taking Care of Your Family:

Many times families work so hard trying to meet the needs of their child, that they may neglect the needs of the rest of the family. It seems that there is always more that can be done. It is important to balance what you do for your child with the needs of the rest of the family. Tired and burned-out parents are not parenting at their best. Make sure to take time for yourselves and your other children, especially in the first few weeks after your child is diagnosed. Take time to experience the emotions you are having and find support in others that are close to your child. Don't be afraid to talk to a mental health professional if you need to, or find a support group.

When you are ready to learn about your child's diagnosis, we encourage each family member to take some time to search the internet, find support groups, and read books about Autism. Also, keep track of your questions and bring them with you to your child's appointments. Understanding Autism is a large part of being able to help your child. Keep an open mind, and listen to others, but also know that what may seem to work for one family may not work for your family. Remember you know your child best!

Next, we encourage you to join parent support groups and begin to develop a treatment program that is comfortable. Support groups provide emotional support for families, but they are also a great place to learn from other parents. Many of whom are ahead of you on this journey and can provide guidance in how to access services, find good providers, and just what to expect.

Remember that the child you knew before the diagnosis is exactly the same child after the diagnosis. A diagnosis is just a label that describes some of their characteristics; it does not change who your child is. Your child has the potential to do great things; however, a lot of time, effort, and energy, on everyone's part may be needed to make that happen.

Siblings

Siblings of a child with Autism often have their own set of challenges. It is important that you take time alone with your other children. They are often overshadowed by the demands of their sibling with Autism. It is also important to find activities that siblings can enjoy together. Teach your other children to be proud of their brother or sister with Autism, and to recognize that each child is special in different ways.

Grandparents and Other Family Members

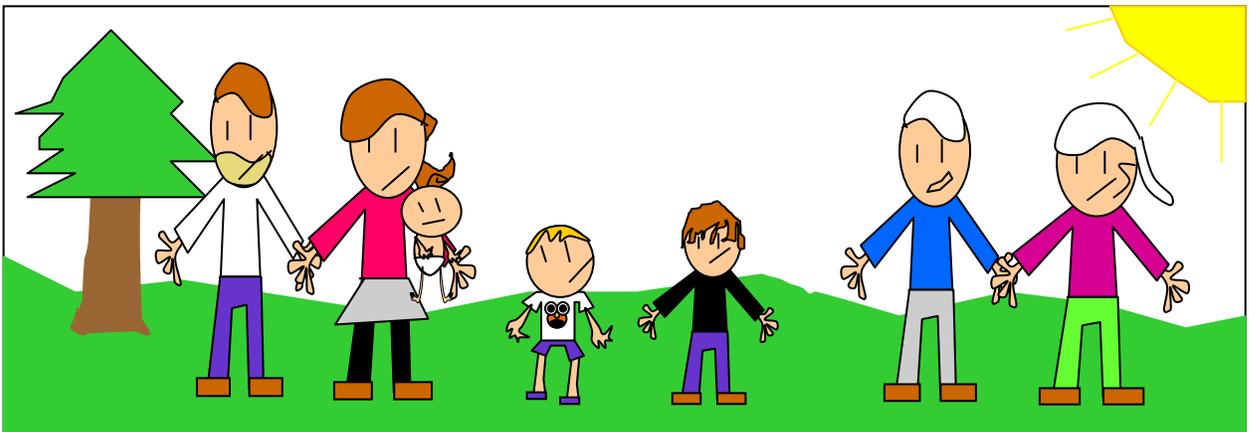
Others in your family who are close to you and your child will deal with your child's diagnosis in a different way, just like every parent deals with it differently. Keep in mind that they have not been to all of your appointments and heard all of the information that you have. Also, sometimes parents have to deal with finding out their child has Autism before they are ready to talk about it with family members. Don't forget that they love your child too and they may be grieving and confused.

Encourage them to:

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

Autism is treatable!

- Getting your child diagnosed early so they can receive help at an early age will allow for the greatest amount of improvement.
- Children with Autism are able to form strong relationships with others.
- Children with Autism grow, change, learn new skills, and make progress toward reaching their potential every day.



Welcome To Holland

by Emily Perl Kingsley ©1987

I am often asked to describe the experience of raising a child with a disability - to try to help people who have not shared that unique experience to understand it, to imagine how it would feel. It's like this.....

When you're going to have a baby, it's like planning a fabulous vacation trip - to Italy. You buy a bunch of guide books and make your wonderful plans. The Coliseum. The Michelangelo David. The gondolas in Venice. You may learn some handy phrases in Italian. It's all very exciting.

After months of eager anticipation, the day finally arrives. You pack your bags and off you go. Several hours later, the plane lands. The stewardess comes in and says, "Welcome to Holland."

"Holland?!?" you say. "What do you mean Holland?? I signed up for Italy! I'm supposed to be in Italy. All my life I've dreamed of going to Italy." But there's been a change in the flight plan. They've landed in Holland and there you must stay. The important thing is that they haven't taken you to a horrible, disgusting, filthy place, full of pestilence, famine and disease. It's just a different place.

So you must go out and buy new guide books. And you must learn a whole new language. And you will meet a whole new group of people you would never have met. It's just a different place.

It's slower-paced than Italy, less flashy than Italy. But after you've been there for a while and you catch your breath, you look round....and you begin to notice that Holland has windmills....and Holland has tulips. Holland even has Rembrandts. But everyone you know is busy coming and going from Italy... and they're all bragging about what a wonderful time they had there.

And for the rest of your life, you will say "Yes, that's where I was supposed to go. That's what I had planned." And the pain of that will never, ever, ever, ever go away... because the loss of that dream is a very very significant loss.

But... if you spend your life mourning the fact that you didn't get to Italy, you may never be free to enjoy the very special, the very lovely things ... about Holland.

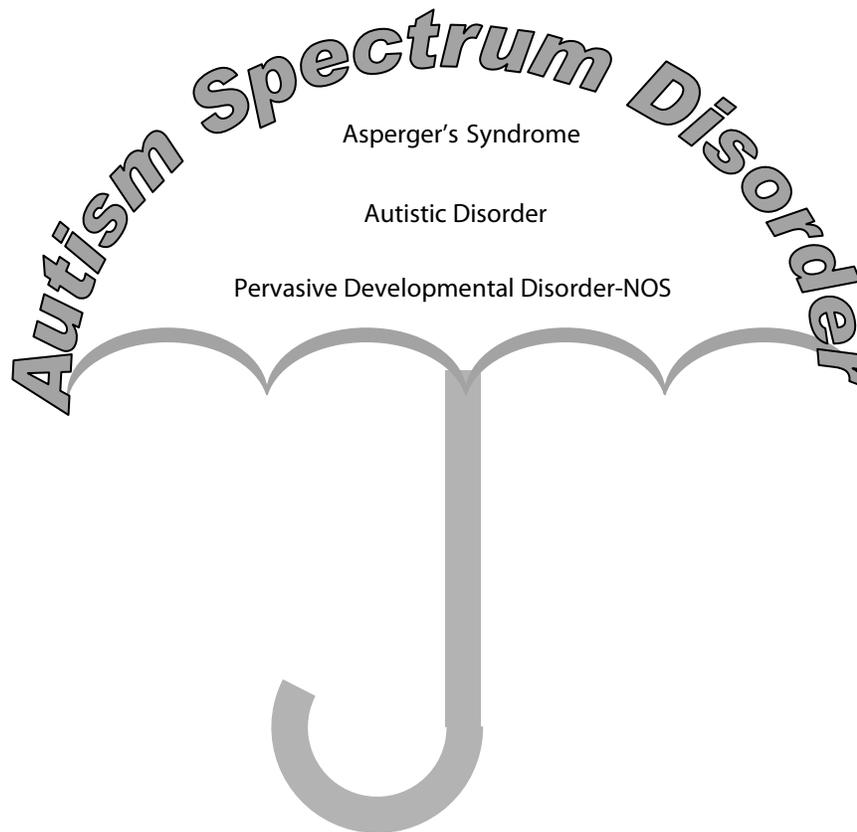
Understanding and Diagnosing Autism

Understanding Autism

Autism, also known as Autistic Disorder, is one of five Disorders known as Pervasive Developmental Disorders (PDDs). The rules for diagnosing these Disorders are taken from the *Diagnostic and Statistical Manual of Mental Disorders fourth edition (DSM -IV)*. This document outlines what symptoms a child must have to be diagnosed with an Autism Spectrum Disorder (More information on the DSM IV can be found in the appendix).

Autism Spectrum Disorders (ASDs) are a group of developmental disabilities caused by the way a child's brain develops. Symptoms of Autism Spectrum Disorders usually appear during the first three years of life, and include significant delays in a child's ability to relate to and communicate with other people. The three Disorders that are considered Autism Spectrum Disorders are:

1. Autistic Disorder (also called Classic Autism, or Autism)
2. Asperger's Syndrome
3. Pervasive Developmental Disorder- Not Otherwise Specified



How is Autism Diagnosed?

There is no blood test that can be done to tell parents if their child has Autism. These tests are known as “standardized” or “validated” tests. These usually require a trained person (a doctor or psychologist) to play and interact with the child while looking for some very specific behaviors. They write down the behaviors they observed, and then they score their observations. This tells them how the child’s behavior and skills compare to typically developing kids and other kids with Autism.

The following chart is a list of some of the tests that might be used in the CDRC Autism clinic. There are a variety of tests listed, and they provide all kinds of information about a child. It is important for the providers to get a clear picture of how a child is functioning in many areas.

Test Name	Purpose of the test
Child Behavior Check List	This a blue form that the parents fill out. It asks questions about the child’s behavior in many areas of their life. This helps the providers to get a good picture of the child in different settings.
Sensory Profile	This form is filled out by the parents. It asks questions about any difficulties the child is having with sensory input (light, sound, textures, foods...)
Autism Diagnostic Observation Schedule (ADOS)	This is a play-based test that looks at a child’s play in many different ways. It is specifically for diagnosing Autism. It looks at interaction, communication, and play.
Mullen Scale of Early Learning	This norm referenced test looks at the overall development of a child.
Vineland Adaptive Behavior Scale	This is a test that looks at a child’s adaptive skills, or how they are get along in their daily lives.
Speech and Language Evaluation	A variety of tests and observations may be used. The purpose is to see how the child’s speech (the sounds) and their language (how they use the words) is developing. Also how they are using their speech to communicate.
Motor skills Evaluations (fine and gross motor skills)	An Occupational Therapist will evaluate a child’s motor skills by interacting and playing with the child. They may use a variety of tests to measure the fine and the gross motor skills.

Autistic Disorder

Autistic Disorder is sometimes called Classic Autism. A child with Autistic Disorder would have delays in the three core areas; social skills, communication skills, and restrictive or repetitive behaviors.

Social Skills

Many children with Autism or Autistic Disorder are not interested in playing with other children. Some reasons why they might rather play alone may include:

- It is hard to “read” the social cues of the playmate.
- It is hard for them to understand that others have different needs from their own.
- It is just easier to play alone.

Communication Skills

Children with Autistic Disorder have a delay in their speech or communication development. This can include a variety of different things:

- They may not understand that speaking, pointing and gesturing are ways to help others understand what they need.
- Often when speech does develop it is repetitive or echoes what others are saying.
- It is common for a child with Autism to use a combination of real words and jargon or made up words when they speak. The words are not always used for communication.

Restricted and/or Repetitive Behavior

Some form of repetitive behavior is common in a child with Autistic Disorder. Some common repetitive behaviors are:

- Always wanting to play with the same toy.
- Watching the same video over and over.
- Wanting to wear the same clothes.
- Insisting on using the same cup.
- Daily routines.
- Body movements like spinning, or flapping hands.
- Always talking about the same topic (e.g., trains).

To receive a medical diagnosis of Autistic Disorder, a child must have impairment in each of these areas. Because it is a “Spectrum” Disorder, Autism can look very different in each child.

Asperger's Syndrome

Children with High-functioning Autism and Asperger's Syndrome have many characteristics in common.

To receive a diagnosis of Asperger's Syndrome, a child must show symptoms in the categories of social skills and restrictive or repetitive behaviors. They do not have delays in the area of language. They also have average or above average intelligence.

Common Characteristics of Asperger's Syndrome

Social Skills

Many children with Asperger's Syndrome have a hard time playing with other children. Some reasons why they might choose to play alone may include:

- It is hard to "read" the social cues of the playmate.
- It is hard for them to understand that others have different needs from their own.
- It is just easier to play alone.

Communication Skills

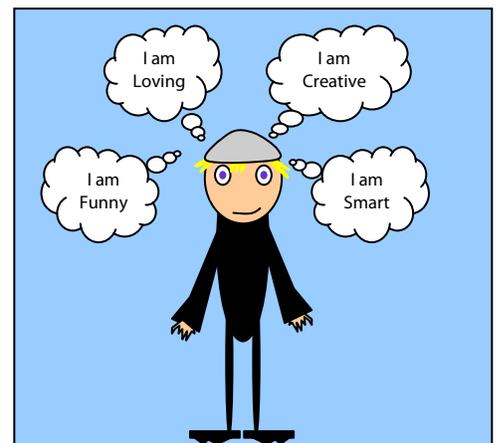
Children with Asperger's Syndrome do not have a delay in their language development, but they often do have different speech patterns than typically developing children. This can include a variety of different things:

- They see the world concretely and speak the same way.
- Often it is hard for them to change the tone of their voice in the right places.
- Their language often sounds mature.

Restricted and/or Repetitive Behavior

Repetitive behavior is common in a child with Asperger's Syndrome. Some common behaviors are:

- Always wanting to play with the same toy.
- Wanting to wear the same clothes.
- Focusing on the parts of the toys.
- Daily routines.



Pervasive Developmental Disorder (PDD-NOS)

Pervasive Developmental Disorder - Not Otherwise Specified (PDD-NOS) is often referred to as PDD and is an Autism Spectrum Disorder. To receive a diagnosis of PDD-NOS, a child must have some but not all of the symptoms of Autistic Disorder.

Many doctors and psychologists describe this diagnosis as being a less severe form of Autism. Children who are very young (under 3 years) will often receive this diagnosis to start with.

It is a bit confusing to say it is a less severe form, because many children with PDD are severely affected by the symptoms they have. The difference is that they do not have as many symptoms as a child who has Autistic Disorder.

Kids Who Are Different

Here's to the kids who are different,
The kids who don't always get A's,
The kids who have ears twice the size of their peers,
And noses that go on for days...
Here's to the kids who are different,
The kids they call crazy or dumb,
The kids who don't fit , with the guts and the grit,
Who dance to a different drum...
Here's to the kids who are different,
The kids with the mischievous streak,
For when they are grown, as history's shown,
It's their difference that makes them unique.

Other Characteristics of Autism Spectrum Disorders

Sensory Processing Differences

Being under, or over responsive to sound, light, touch, textures, or pain is very common in children with an Autism Spectrum Disorder. A few of the common symptoms of sensory processing differences are:

- Very picky eater.
- Hate's to get dirty.
- Get very upset at loud noises.
- Hide's in small spaces.
- Love the feel of some things (squeezing, rubbing).

Delayed Thinking

Some children with Autistic Disorder or PDD may have impairment in their thinking skills. Children under 5 years old may have a Global Developmental Delay. This means that their general thinking is behind what their typical peers would be able to do. If the child is still significantly behind after age 5, they may receive the diagnosis of Intellectual Disability (also known as Mental Retardation).

Advanced Thinking

Children with an Autism Spectrum Disorder also can be very smart. They sometimes have one area they are interested in, and they become an expert in that area. Even the children who are very smart 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

This is when a child is delayed or behind in many areas of their lives. Global simply means that the delay can be seen across most areas of the child's abilities. This diagnosis is for children 6 years old and under.

Intellectual Disability

If a child has a low IQ and their adaptive skills or "life skills" are significantly delayed areas after age six, it is called Intellectual disability or mental retardation.

Anxiety and Depression

Some children with an Autism Spectrum Disorder suffer from anxiety and/or depression. This is more common as children get older and become more socially aware. It is important to keep in mind that mood changes over a period of time should be discussed with the child's therapist or the primary doctor.

Pica

This is where children regularly eat items that are not food (clay, dirt, crayons). Most children do this sometimes, but children with Pica do it often and it continues over time.

Seizure Disorder

Some children with Autism also have seizures.

Genetic Disorders

Some children have Autism as a part of a genetic Disorder. Fragile X syndrome is a genetic disorder that can cause Autism. Having a child tested for a genetic disorder will not cure their Autism, but it will tell families why the child has Autism. It can also help in planning and understanding who else in the family may be at risk for passing on the syndrome to their children.

Clumsiness

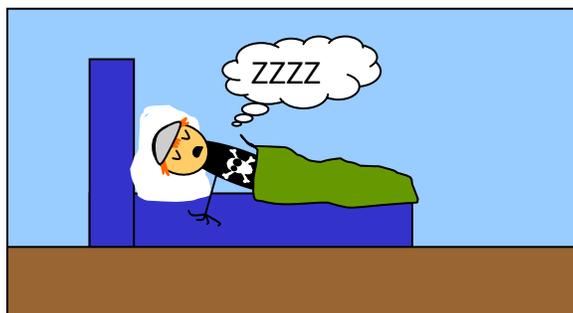
Some children with Autism are clumsy and may have trouble developing motor skills. Some also have weak upper body strength and may have delayed coordination development.

Gastrointestinal Disorders

Many parents report gastrointestinal (GI) or stomach problems in their children with Autism. Children with Autism may have problems such as chronic constipation or diarrhea.

Sleeping Problems

Many children with Autism have trouble falling asleep, or staying asleep at night. This can be very hard on the child and the rest of the family. If your child is having trouble with sleep, talk to their doctor about things you can do to help.



What Causes Autism?

Scientists do not know exactly what causes Autism Spectrum Disorders (ASDs). There is a lot of research being done to answer that question. It is likely that within the next 20 years there will be much more information available to explain what causes ASDs. For now, there are some things that are known or widely accepted.

- ASD are caused by the way the brain develops.
- There is not one single cause of Autism. There are many factors that may make a child more likely to have Autism.
- Genes are one of the risk factors. A child with a sibling or parent who has an ASD is more likely to have an ASD.
- 10% of children that have an ASD also have a genetic Disorder (Down Syndrome, Fragile X Syndrome, and others).
- Some drugs taken during pregnancy have been linked to higher rates of ASDs.
- There is some evidence that some children are born with a susceptibility to Autism, yet the “triggers” that lead to Autism have not been identified.

What does not cause Autism?

The cause of Autism has not been proven, but some things have been ruled out.

- Vaccines have been rumored to cause ASDs. There have been many studies done, and no link between vaccines and ASDs have been found.
- Bad parenting was once thought to be a cause of ASDs. This is not true.
- There is some question whether diet is a factor, but many ethnic groups have similar Autism rates and their diets are very different.

Why are there so many children with Autism?

There are many theories about why Autism rates are rising. The *Centers for Disease Control and Prevention* reports that about 1 in 110 children in the United States have an ASD. This number has risen drastically in the last 10 years. Some reasons why this number is increasing may include:

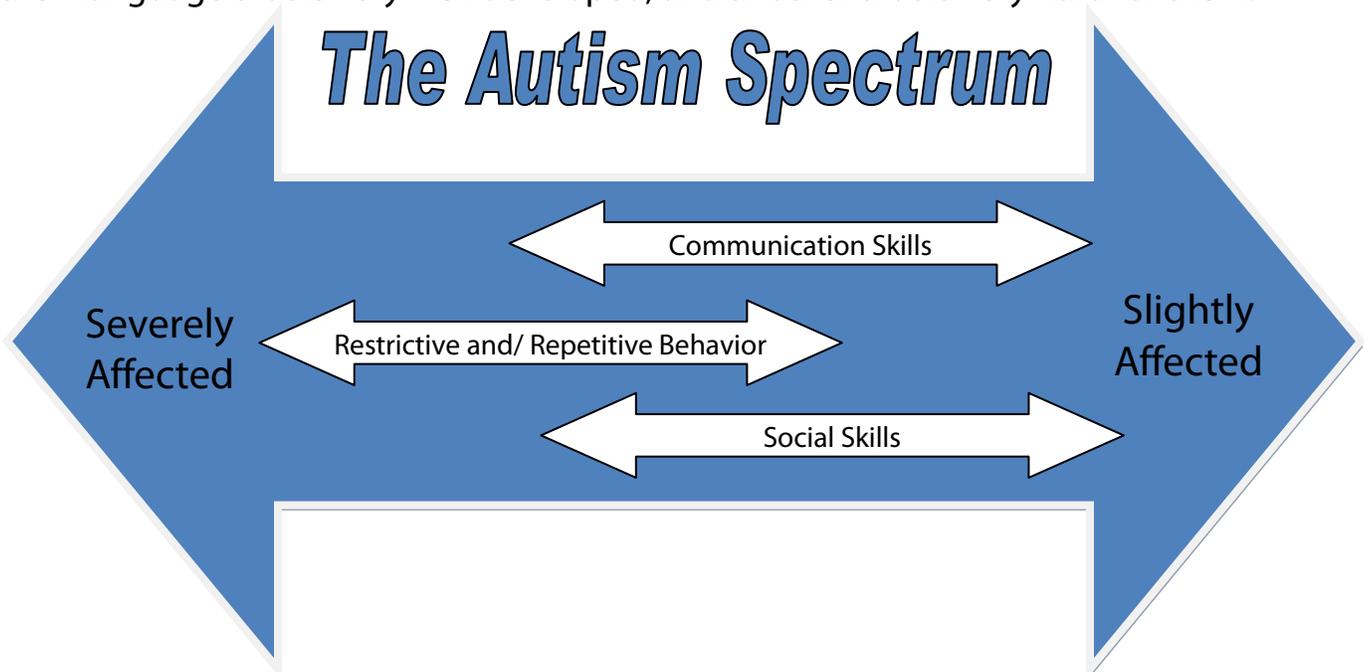
- More public awareness of Autism.
- A broader definition of ASDs.
- Better efforts to diagnose ASDs.
- More people actually have ASDs.

Defining “The Spectrum”

The Autism “Spectrum” simply means that symptoms are very different for each child. It is a wide range of symptoms that affect children in a wide range of different ways, along a Spectrum or continuum.

To receive a medical diagnosis of Autism (Autistic Disorder), a child must have impairment in each of the three areas (social skills, communication, repetitive behaviors). Many children also have impairment in the area of sensory integration (sounds, textures, smells, etc.) Because it is a “Spectrum” Disorder, it can be very different in each child. One child may have a very hard time with social skills and have very few repetitive behaviors. Another child might be consumed by the repetitive behaviors and have an easier time with social skills.

Each symptom a child has can fall anywhere along “the Spectrum”. They may have one area of their language that is very well developed, and another that is very hard for them.



High-Functioning Autism

A child who has High function Autism (HFA) would have the same symptoms as a child with Autistic Disorder. The difference would be the child with HFA must have average or above average thinking skills.

Many families ask what “level” of Autism their child has. There is not a system of levels, only the different diagnoses (Asperger’s, High Functioning Autism, and Autistic Disorder).

Education Eligibility/Label versus Medical Diagnosis

A medical diagnosis is given by medical professionals who evaluate a child and base their findings on specific symptoms that are described by the Diagnostic Manual. This diagnosis is what you received at CDRC.

Educational eligibility/label is given by a team of professionals within the public school system. Sometimes the educational eligibility/label is referred to as an educational diagnosis and this can be very confusing to parents.

All children with an ASD have some defining things in common. In order to have a diagnosis of an Autism Spectrum Disorder (ASD) a child must have impairments in three major areas for a medical diagnosis, and four major areas for educational eligibility/label.

Educational Label	Medical Diagnosis
Communication	Communication
Social Interactions	Social Interactions
Repetitive Behaviors	Repetitive Behaviors
Sensory Integration	

Oregon

Many children who receive the educational eligibility/label of ASD at school (Oregon) will not meet the qualifications for a medical diagnosis. The public schools are required to place a child into a category in order to provide special education services to that child. Many children have symptoms of ASDs in one or more areas, but do not fit the criteria to qualify for a medical diagnosis. In this case, the school can say the child has an educational eligibility/label of Autism. This label allows the school to provide individual services for the child.

If the child has a medical diagnosis of Autism, but the school does not think the child's Autism is affecting their school functioning, they do not have to provide special education services.

Washington

A child in Washington State cannot be given an educational eligibility/label of Autism unless they have a medical diagnosis. This means that often the child can qualify for school services due to one of their impairments, like speech but not for Autism unless they have a medical diagnosis.

Public Services Birth-21 Years

Special Education (0-Kindergarten)

Once a child has been identified as having an ASD, they are eligible for special education services. 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).

- For children under 3 years old it is called Early Intervention.
- Children between the ages of 3 years (at the time they start) and kindergarten receive Early Childhood Special Education.

For young children who qualify, Early Intervention and Early Childhood Special Education (EI/ECSE) are the two programs that are available. 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 performing at that time, and the goals they will be working towards. Some of the things that ESDs may provide include:

- Speech therapy (speaking and using language, feeding)
- Occupational therapy (sensory, self care, fine motor skills)
- Physical therapy (mobility or movement, gross motor skills)
- Behavioral therapy
- Training for parents and families

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.

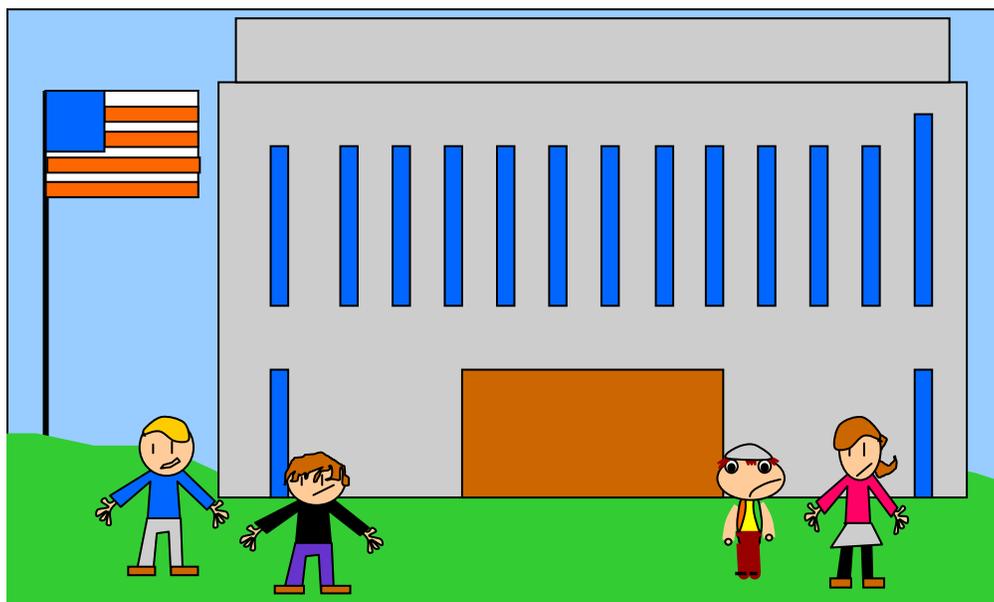
The contact information for the Oregon and Southwest Washington ESDs are located in the appendix.

Special Education Services (Kindergarten-age 21):

Children between the ages of 5 and 21 receive special education services through their local public school district. These programs always include an Individualized Education Program (IEP). This is where a team of school professionals and the child's parents decide on 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 a 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 for other children it is more important to have positive social role models and they may remain in the regular education classroom.

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. Often parents have to insist on different placements or interventions for their child before the school is able to make them happen. This is not because the school does not care about the child, it is more likely that they are over loaded and have many other children to manage. Parents know their child best, and it is often the parent who guides this process to make sure their child gets what they need at home and at school.



How does the Oregon Department of Human Services support the families?

Autism 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 Autism. 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 will probably 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 for the program. 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 Autism and other developmental disabilities. (Oregon has no specific institution or residential public school for children with Autism.) 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 a challenging and complex task, 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 Autism. Instead, services are provided through county and state programs that serve people with developmental disabilities, including children and adults with Autism.

If your child is under 18 years of age, 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 a public education, there is no law that requires services to young children with disabilities — even if they are eligible for them.

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.

If your adult child is 18 years or older and meets the developmental disability eligibility requirements, he or she is entitled to support services in Oregon. This entitlement is the result of a recent lawsuit that requires "access to support services" for adults with developmental disabilities who are living at home. Counties are working now to enroll eligible people in the system and that could take some time.

By June 30, 2009, any person 18 years of older who is eligible is entitled to receive support services based on an individual plan. Services can include such things as respite care, in-home staffing, job coaching and employment supports, community inclusion activities or other supports that help a person to live and work in his or her community. The lawsuit also allows, under certain circumstances, eligible adults to receive foster home or similar 24-hour services. However, access to these types of services is limited

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

- If your child is younger than 18 years, the case manager will help you figure out what kind of help you need and work with you to develop service options.
- If your child is 18 years or older, the county case manager will work with your son or daughter and you to identify the options and help you begin accessing available services.

Therapy and Treatment:

Therapy Outside of School

Experts agree that early intervention programs that provide 20-25 hours a week directly working with the child at home, school or therapy gives the child the best chance for success.

As your child's parent, you must be an active and equal partner in deciding on intervention programs. You know your child best, and will be able to provide valuable information to educators and other professionals. Collaboration among the treatment providers and the parents is an essential part of the intervention. The parent is the "glue" that holds the team together.

In general, interventions for children with Autism can be divided into three different service delivery "systems." These systems include:

- Your local public school district or Education Service District (ESD).
- Licensed professionals in community or hospital based settings.
- In-home therapy programs often supervised by an Autism specialist but implemented by parents, family, friends, or college students.

Community-Based Services

Children who receive special education services may also benefit from other professional services in the community. Most interventions are available through private providers and many of them may be covered by a child's health insurance. The family often still has to pay a portion of the fee. Some programs do offer financial aid to families who meet an income requirement.

In-Home Therapy Services

Some families choose to participate in therapy that takes place in their home. A variety of therapies are available, but the cost is usually the responsibility of the family.

Some common examples of Community-Based or In-Home Therapies that can be found are:

- Speech Therapy
- Occupational Therapy
- Behavioral Therapy
- Applied Behavioral Analysis

How to Decide on a Therapy

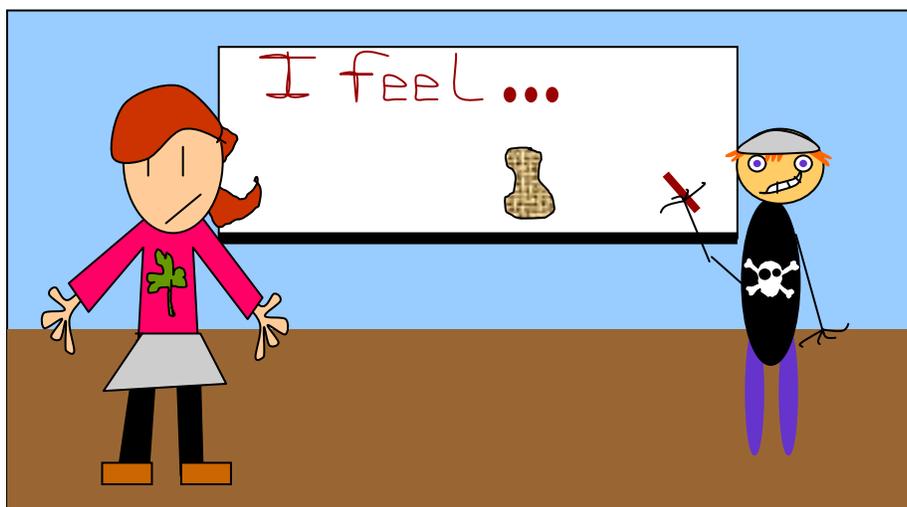
It can be overwhelming trying to find a place to start. Unless you have an idea of what your child needs to work on, you do not know what kind of therapy to look for.

- Discussing this with your child's doctor or other professionals that have worked with your child can help.
- Another place to begin is by looking at the milestones that children who do not have Autism are meeting. A milestone is simply an average range for children to complete a specific task. By looking at the milestones that are included in this packet, you can decide what area your child needs the most support in, and find a therapy to support that skill.
- Talking with other parents about their children with or without Autism can help you to understand your child's development. They may also be able to tell you what types of interventions have helped their children, and which ones have not been helpful.
- The Autism Society of America has developed some guidelines to explain and evaluate different interventions for children with Autism.

Children with Autism have many different needs and no one method is going to be effective in treating all areas. A combination of treatments is usually the most effective.

Two things to focus on are:

- Treat the specific symptoms that interfere with functioning.
- Teach skills that foster healthy relationships.



Things to Consider When Deciding on a Therapy

1. Most importantly, could the therapy harm your child in any way?
2. Will the therapy cause undue hardship on your family?
3. Is the therapy scientifically based and widely accepted?
4. How will the success of the therapy be measured?
5. Are you learning so you can work with your child at home?
6. Is the person qualified to do the therapy?

It is also important to focus on the symptoms that are the most delayed for the child, or are causing the most frustration for the child and family. Use the milestones in this book to decide where your child is the most delayed.

There are many different types of therapies that are recommended by different people to treat Autism. It is important to choose therapies that are the most beneficial to your child. The following pages are explanations of the different therapies you may hear or read about.

It is important to know that no one therapy is going to solve all the issues a child with Autism might have. A combination of therapies is often done by a provider, or several providers to help your child make the most progress.

Understanding the Different Available Therapies

In the following section called *Types of Therapies Available*, many therapies are described. They are listed as:

- *Scientifically Based,*
- *A Promising Practice, or*
- *Limited Supporting Information for Practice.*
-

This information was taken from an article called *Evidence-Based Practices and Students With Autism Spectrum Disorders* by Richard L. Simpson. It was based on a study that evaluated many therapies and the evidence for those therapies. A copy of the article summary is in the appendix.

There is also a category called "Widely Excepted". This information is not taken from the article, but is referring to the overall view of the therapy listed. Some therapies do not have much scientific research to support their outcomes, but they are still good strategies to use with children. These would be listed as "Widely Excepted".

Applied Behavior Analysis: Skill Based Therapy

Classification	Meaning	Recommendation
Scientifically Based and Widely Accepted	There has been a lot of research for this therapy that has shown children with Autism make improvements when involved in this type of therapy.	Highly Recommended for young children with Autistic Disorder or PDD-NOS, and especially if there is a global developmental delay.

Background

Applied Behavioral Analysis (ABA) is an intensive, one-on one, structured method of teaching behaviors and skills. It may also be referred to as Behavioral Intervention, Behavioral Treatment, Pivotal Response, Discrete Trial Therapy (DTT), or Lovaas Treatment.

ABA's focus areas

ABA can be used to teach a child acceptable behavior, play skills, social skills, language skills, academic skills, self-help skills, fine motor skills, and many other life skills. In a typical ABA program, the child may have therapy for up to 40 hours a week for 2 or more years.

Designing an Individual Program

The foundation of an ABA program is the collection of precise, objective data. The data is used to identify the needs of the child, measure progress, judge skill mastery, document progress, and develop teaching plans. Once the child's needs have been identified, a tailor made ABA program can be developed. It will focus on teaching the skills that the child does not demonstrate, and maximize skills that are emerging.

How it works

Generally the program will start with the easiest skills and gradually move towards more difficult ones. Each lesson or skill is broken down into small, measurable elements. Each element is then taught individually through repeated trials.

Adult Directed, and Child Centered

There are two main ways that ABA is used with kids. First, the Adult Directed type where new skills are taught in a very systematic way (Discrete Trial). Second is a Child Centered approach. This is where the adult uses the child's interests and behaviors to teach desired behaviors. Both approaches motivate the child by using rewards.

TEACCH: Skill Based Curriculum

Classification	Meaning	Recommendation
Promising Practice and Widely Accepted	There has been some research that may show that children with Autism improve when using this curriculum.	Recommended a classroom based curriculum.

Background

Treatment and Education of Autistic and related Communication – handicapped Children (TEACCH) is a program that was developed in North Carolina to use in the school classroom for children with Autism. It is based on the idea that the child’s environment should adapt to them, not the other way around.

TEACCH’s Focus Areas

This program uses structured teaching to develop new skills for each individual child. Each child is tested to see what skills they already have. Then a plan that uses those skills as a place to start is put in place.

Designing an Individual Program

This is an individualized program, but there are also many things about structuring the child’s environment that are going to be similar for many kids who have Autism. Making the daily activities predictable and providing many visual supports like charts and schedules are essential to this program.

Research

There has not been a lot of research done on this program, but many people who work with children who have Autism find the visual strategies and structured environment essential.

Where to Go

There are not many schools that use the TEACCH program outside of North Carolina, but most schools use some of the same ideas. For more information on the TEACCH program you can look at their website: www.teacch.com

Floortime: Relationship Based Therapy

Classification	Meaning	Recommendation
Limited supporting information for practice.	There has been some research that may show that children with Autism improve when using this curriculum	Recommended as a part of therapy for Autistic Disorder or PDD-NOS especially if there is a global developmental delay.

Background

Floortime is a program that is based on Dr. Stanley Greenspan's model called Developmental Individual Difference Relationship Model (DIR). It was developed in the 1980's and is used to help children build relationships and communication skills.

Floortime's Focus Area

This is a type of therapy that is usually done by a therapist or a parent where the adult follows the child's lead and interacts with them at their level. This often is done by playing with the child "on the floor".

Goals of the Program

The goal of Floortime is to help the child reach 6 developmental milestones that are like walking up a ladder. The steps are:

- Self Regulation and interest in the world
- Intimacy or a special love for the world of human relations
- Two-way communication
- Complex Communication
- Emotional ideas
- Emotional thinking

Research

There has not been a lot of research done on this program, but many therapists and parents who work with children who have Autism find this program helpful to get the child to engage with them. It is most often used along with other behavior therapies.

Where to go

To find more information of Floortime, visit their website at: www.floortime.org

Relationship Development Intervention (RDI): Relationship Based

Classification	Meaning	Recommendation
Limited supporting information for practice and Widely Accepted	There has been some research that may show that children with Autism improve when using this therapy.	Recommended as a part of therapy for Autistic Disorder or PDD-NOS especially if there is a global developmental delay.

Background

Relationship Development Intervention is very similar to Floortime, but one main difference is that it was created as a program for parents to do at home with their child. RDI is a child centered program designed to improve relationship skills through systematic interactions where the adult is interacting at the child's level, and slowly moving them forward.

RDI's Focus Areas

RDI claims that by teaching a child with Autism to interact socially it will allow them to achieve many other things in their lives.

Who can Provide RDI

Parents, teachers and other professionals can do this type of therapy with children. This therapy is often done as a part of another behavioral therapy.

Research

There has not been a lot of research done on this program, but many therapists and parents who work with children who have Autism find this program helpful to get the child to engage with them. It is most often used along with other behavior therapies.

Where to go

To find more information of RDI, visit their website at: <http://www.rdiconnect.com/>

PECS / Picture Exchange Communication System: Skill Based Therapy

Classification	Meaning	Recommendation
Promising Practice and Widely Accepted	There has been some research that shows that children with Autism improve when using this curriculum	Recommended as a communication strategy for non verbal or early language development.

Background

PECS is a program that teaches children and adults who have limited communication skills to communicate using a picture system and rewards. It was developed in 1985 and was first used in the Delaware Autistic Program.

PECS Focus Areas

This program is used to teach speech and communication. It starts out with basic one picture that is something the child wants. The child is rewarded for using the picture and over time is able to understand that symbols represent real things. As the child progresses, the pictures can get more complicated to help them use actual sentences.

Who can Provide PECS

Parents, teachers and other professionals can do this type of therapy with children. A variation of this therapy is often done in schools for children who do not speak.

Research

There has been some research done on PECS, and those studies have shown that this program helps children and adults with Autism or other disabilities when they have little or no speech.

Where to go

Standard PECS pictures can be purchased as a part of a PECS manual (PECS Training Manual, 2nd Edition, by Lori Frost and Andrew Bondy), or pictures can be created by the adult.

Sensory Integration: Biologically Based Therapy

Classification	Meaning	Recommendation
Promising Practice and Widely Accepted	There has been some research that may show that children with Autism improve when using this curriculum.	Recommended for children who have identified sensory sensitivities.

Background

Sensory Integration Therapy is a type of therapy that helps a child with Autism process sensory information (touch, taste, smell, sounds...). The therapy is usually conducted by an Occupational Therapist and its purpose is to help a child who is over or under stimulated by their environment learn how to cope. This therapy is child centered, and involves the adult playing with the child.

Sensory Integration Therapy's Focus Areas

Many children with Autism have trouble with sensory processing. Some may hate loud noises or certain pitches; others may get upset at very colorful room, while others only like to eat certain textures of foods. This type of therapy works with children to cope with their individual sensory problems.

Who can Provide Sensory Integration Therapy

Occupational Therapists usually work with children on sensory integration, but it is very important that parents are able to also work with their child at home on the same issues.

Research

There has been some research done on Sensory Integration Therapy that shows that it is effective for some children in treating sensory problems, but not all. The research suggests that it may be more effective for younger children.

Social Stories: Cognitive Based Intervention

Classification	Meaning	Recommendation
Promising Practice and Widely Accepted	There has been some research that shows children with Autism improve when using this curriculum.	Recommended for social development in children with Asperger's or HFA.

Background

Social Stories are a way to make a social situation concrete and understandable for a child with Autism. A social story is simply an explanation of what a child might expect in a certain situation. It is not a therapy on its own, but is commonly used by therapists, schools and families to help a child with Autism deal with a situation.

Social Stories focus areas

These stories are usually written in the first person and they allow a child to think about a situation that may be hard for them, how to respond to the situation, and what they can expect others to do. They usually have a lot of concrete information for the child to think about.

Who can use social Stories

Anyone can write and use a social story. Often teachers and parents use these for a situation a child is struggling with, or a situation that will be coming that they know will be hard for the child.

Research

There has been some research done on Social Stories as an intervention, but more needs to be done before this is called a scientifically based intervention. People who work with children who have Autism find this tool extremely helpful.

Example

The following is a short example of a social story taken from a book called: Sticker Strategies: Practical Strategies to Encourage Social Thinking and Organization, by Michelle Garcia Winner. This example would be used for an older child.

Family Dinner Time: Answering Questions

Your parents like it when you show you are thinking about them. When they ask "what did you do at school today?" think of one activity you did in one class and explain it. We talk about information not because it is fascinating, but because by telling a little bit about our lives we let people learn about what we do and feel.

Prescription Medications: Biologically Based Therapy

Classification	Meaning	Recommendation
There is not a prescription medication to treat or cure Autism.	There are some medications that treat different symptoms that a child with Autism may have (e.g. depression, hyperactive...)	This is for you and your child's pediatrician, developmental pediatrician, or psychiatrist to decide.

Background

There is no prescription medication to treat Autism, but some medications can treat the symptoms a child with Autism may have. Some of the symptoms that may be treated with medication include hyperactivity, impulsivity, poor attention, aggression, anxiety, depression, and mood swings.

Goals of treating with prescriptions

When treating a child with Autism the goal of the prescription medication is to reduce a symptom so the child can respond better to the other types of therapy they are getting. It is a part of a intervention program, not a treatment on its own.

Warnings

Given the potential side effects of medication, drug interactions, and unpredictability of how the child will react, it is strongly recommended that a medical doctor with expertise in managing medications for children with Autism be involved. A developmental pediatrician or a child psychiatrist both specialize in this area.

Research

There has been a lot of research conducted on medications. For information on a specific medication that is recommended to you, ask your pediatrician to explain the research for that medication, and also where you can look to find it yourself.

Vitamins and Supplements: Biologically Based Intervention

Classification	Meaning	Recommendation
Limited supporting information for practice.	There is little or no research to support this therapy.	This is for you and your child's pediatrician, developmental pediatrician, or psychiatrist to decide.

Background

Many parents and professionals claim to see some improvement in children who have Autism when given certain vitamins. There is little or no scientific research supporting this, and parents should be very careful because some vitamins can be toxic.

Goals of treating with vitamins and supplements

There are many different claims to why children with Autism need different supplements. Some of the more common goals are to encourage better digestive health, or to help the body absorb things they need and discard things they don't.

Warnings

There are many professionals such as naturopathic specialists who can provide help in this area. It is important to also seek the advice from your child's pediatrician. They can help you decide if the potential outcome of the supplement outweighs the potential harm.

Research

There is little or no scientific data that says vitamins are effective in treating Autism.

Dietary Interventions: Biologically Based Intervention

Classification	Meaning	Recommendation
Not scientifically based	There is no valid research to support this therapy.	This is for you and your child's pediatrician, developmental pediatrician, or psychiatrist to decide.

Background

Many people claim to have seen improvements to their child's Autism after changing their diet. The two most common dietary interventions are Gluten and Casein -Free and Yeast-Free diets.

- Gluten and Casein free diets call for the removal of all wheat, oats, rye, and dairy products. The thought is that children with Autism do not process these foods and they cause a disruption in certain processes in the brain. Others will state that the change in their child was due to the fact that their digestive system was working better allowing their child to be more comfortable.
- Yeast Free diets call for the removal of all yeast from the diet. The theory is that children with Autism have an overgrowth of yeast caused by tiny holes in the gastrointestinal tract. Sometimes anti-fungal medications are also used to eliminate the yeast.

Warnings

There are many professionals such as naturopathic specialists who can provide help in this area. It is important to also seek the advice from your child's pediatrician. They can help you decide if the potential outcome of the diet outweighs the potential harm.

Specific allergy testing is recommended to determine what your child is allergic to. It is important that if you are going to try an elimination diet that you are working closely with a doctor, or a clinical nutritionist. Malnutrition can be more harmful to your child's health than the possible allergen. If you are planning on trying an elimination diet, a support group can be helpful.

Research

There is little or no scientific data that says the above diets are effective in treating Autism.

Heavy Metal Detox: Biologically Based Intervention

Classification	Meaning	Recommendation
Not scientifically based	There is no valid research to support this intervention to treat Autism, and some to show that it is harmful. There have been cases of children dying from this type of therapy.	Not Recommended and can be harmful.

Background

Some people believe that Autism is caused by the child being exposed to heavy metals, particularly mercury. To get rid of the heavy metal in the child they support the use of Chelation. This is a process where a child uses a lotion, takes a pill, or has an IV to flush out the metal in their body. Several children have died from this treatment. It is very controversial.

Warnings

We at CDRC do not endorse detoxification for children with Autism.

Research

There is no scientific research that says Autism is caused by heavy metals.

Music, Art, and Animal Therapy: Relationship Based Intervention

Classification	Meaning	Recommendation
Limited supporting information for practice and Widely Accepted	There is no research that says these therapies treat Autism, but there are many positive aspects of each of these therapies.	Recommended for relationship building, or self esteem.

Art and Music Therapy

Art and music classes have many positive outcomes for children in general, art and music therapy are no different. Many children with Autism are very artistic or musically gifted, and providing an opportunity for them to be good at something can help their self esteem. In combination with other goals, art and music therapy can have positive effects in sensory integration, and possibly other areas as well. There are no harmful effects to art or music classes, and many children love it.

Animal Therapy

Owning a pet or interacting with an animal is something most children enjoy. There are many positive aspects of having a pet like: learning responsibility, caring for something, having something to love and love you back.

Horse therapy (Equine therapy or hippotherapy) is used to allow children to interact and care for a horse. This is said to help the child's self esteem.

Therapy dogs are being used in different ways for children with Autism. Some are highly trained to assist in keeping the child safe.

Developmental Milestones

The following pages are milestones that can help you better understand where your child's skills may be advanced or delayed. They are things that typically developing children would do during a particular age range.

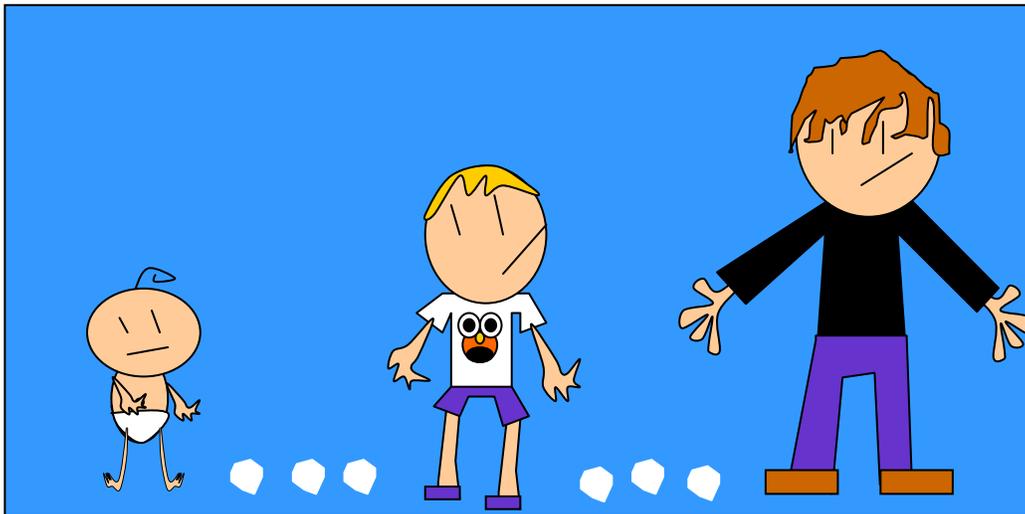
The information was taken from two resources, and you can find them online if you are interested in reading more about developmental milestones.

The Center for Disease control (CDC) has a resource called The Act Early Campaign. On their website you can read and print, or order free copies of the developmental milestones in English and in Spanish.

The CDC's web address is www.cdc.gov

The second is the *Zero to Three Campaign*. This resource is produced by the National Center for Infants, Toddlers, and Families. The milestones are available to read or print in English or in Spanish.

The Zero to Three web address is www.zerotothree.org



0-3 Month Milestones

Social Emotional

- Begins to develop a social smile
- Enjoys playing with other people and may cry when playing stops
- Becomes more expressive and communicates more with face and body
- Imitates some movements and facial expressions

Movement

- Supports upper body with arms when lying on stomach
- Opens and shuts hands
- Pushes down on legs when feet are placed on a firm surface
- Brings hand to mouth
- Takes swipes at dangling objects with hands
- Grasps and shakes hand toys

Vision

- Watches faces intently
- Follows moving objects
- Recognizes familiar objects and people at a distance
- Starts using hands and eyes in coordination

Hearing and Speech

- Smiles at the sound of your voice
- Begins to babble or make sounds
- Begins to imitate some sounds
- Turns head toward direction of sound

What you can do with your baby:

- Talk and sing to them
- Hold and snuggle them
- Watch and learn your babies signals (hunger cry, tired cry, happy)
- Respond to their signals; when eyes are bright and awake it is play time
- Give them something to hold on to or reach for (toy or finger)
- Comfort them when they cry. Soothing makes them feel safe and loved
- Read to your baby

3-6 Month Milestones

Social Emotional

- Enjoys social play
- Interested in mirror images
- Responds to other people's expressions of emotion and appears joyful often

Movement

- Rolls both ways (front to back, back to front)
- Sits with, and then without, support on hands
- Supports whole weight on legs
- Reaches with one hand
- Transfers object from hand to hand
- Uses hand to rake objects

Vision

- Develops full color vision
- Distance vision matures
- Ability to track moving objects improves
- Finds partially hidden object
- Explores with hands and mouth
- Struggles to get objects that are out of reach

Hearing and Speech

- Responds to own name
- Begins to respond to "no"
- Can tell emotions by tone of voice
- Responds to sound by making sounds
- Uses voice to express joy and displeasure
- Babbles chains of sounds

What you can do with your baby:

- Place your baby in different positions to help develop new skills like rolling and crawling (play on back and stomach, sit with support) Always put them on their back to sleep.
- Offer interactive toys for them to play with (different sizes, shapes, sounds, textures)
- Talk to your baby and have back and fourth conversations (when they babble you answer)
- Create routines to help them learn things like going to bed (i.e. bath, books, feeding, song, bed)
- Read to your baby

6-9 Month Milestones

Social Emotional

- Learning to solve problems (if a toy drops they look for it)
- Copy what they see others do (play peek-a-boo)
- Understand harsh tones

Movement

- They can pick up small objects
- They can sit on their own
- May crawl, scoot, or pull up on furniture
- Vision

Vision

- Develops full color vision
- Distance vision matures
- Ability to track moving objects improves

Hearing and Speech

- They babble a lot
- When talked to they make sounds back
- Use their voice to show feelings (anger, joy)
- Copy actions like waving or shaking their head no

What you can do with your baby:

- Let your baby explore interesting objects like toys with buttons to push
- Talk to your baby and tell them when you like what they are doing
- Let them start trying to pick up baby safe foods to eat
- Give them time to move around on their own to build muscle and coordination
- Read to your baby

9-12 Month Milestones

Social Emotional

- Shy or anxious with strangers
- Cries when mother or father leaves
- Enjoys imitating people
- Prefers certain people and toys
- Tests parental responses to behavior
- May be fearful in some situations
- Prefers mother and/or regular caregiver over all others
- Repeats sounds or gestures
- Finger-feeds himself
- Extends arm or leg to help when being dressed

Movement

- Reaches sitting position without assistance
- Crawls forward on hands and knees
- Pulls self up to stand
- Walks holding on to furniture
- Stands or walks momentarily without support
- Uses pincer grasp
- Bangs two objects together
- Puts objects into and out of container
- Lets objects go voluntarily
- Pokes with index finger

Cognitive

- Explores objects in different ways (shaking, banging, throwing)
- Finds hidden objects easily
- Looks at correct picture when the image is named
- Imitates gestures
- Begins to use objects correctly (drinking from cup, brushing hair)

Language

- Pays increasing attention to speech
- Responds to simple verbal requests
- Responds to "no"
- Uses simple gestures, such as shaking head for "no"
- Changes tone when babbles
- Says "dada" and "mama" and directs it to them
- Uses exclamations ("Oh-oh!")
- Tries to imitate words

What you can do with your baby:

- Talk to your baby (tell them what is happening and what will happen next)
- Interpret what your baby is doing by using words (you are pushing your food away, you must be all done)
- Name the things your baby looks at and points to (i.e that is the moon)
- Give them time and a safe place to practice crawling and walking
- Play hide-and-seek games with objects
- Help them take the next steps in their play (instead of banging blocks stack them)
- Read to your child

24 Month Milestones

Social Emotional

- Imitates behavior of others, especially adults and older children
- More aware of herself as separate from others
- More excited about other children
- Shows increased independence
- Begins to show defiant behavior
- Separation anxiety increases toward midyear then fades

Movement

- Walks alone, begins to run
- Pulls toys behind while walking
- Stands on tiptoe
- Kicks a ball
- Climbs onto and down from furniture unassisted
- Walks up and down stairs holding on to support
- Scribbles on his or her own
- Builds tower of four blocks or more

Cognitive

- Finds objects even when hidden under two or three covers
- Begins to sort by shapes and colors
- Begins make-believe play

Language

- Points to object or picture when it's named for him
- Recognizes names of familiar people, objects, and body parts
- Says several single words (by 15 to 18 months)
- Uses simple phrases
- Uses 2- to 4-word sentences
- Follows simple instructions
- Repeats words overheard in conversation

What you can do with your baby:

- Let your child scribble with crayons or markers
- Help them practice physical activities like climbing and pedaling
- Introduce new vocabulary words
- Talk with them about things in their world
- Be patient with their why questions
- Help them deal with conflicts around taking turns

36 Month Milestones

Social Emotional

- Imitates adults and playmates
- Spontaneously shows affection for familiar playmates
- Can take turns in games
- Understands concept of "mine" and "his/hers"
- Expresses affection openly
- Expresses a wide range of emotions
- By 3, separates easily from parents
- Objects to major changes in routine

Movement Hand and Finger Skills

- Climbs and runs well
- Walks up and down stairs, alternating feet (one foot per stair step)
- Kicks ball and pedals tricycle
- Bends over easily without falling
- Makes up-and-down, side-to-side, and circular lines with a crayon
- Turns book pages one at a time
- Builds a 6 block tower
- Screws and unscrews jar lids
- Turns rotating handles

Cognitive

- Makes mechanical toys work
- Matches an object in her hand or room to a picture in a book
- Plays make-believe with dolls, animals, and people
- Sorts objects by shape and color
- Completes puzzles with three or four pieces
- Understands concept of "two"

Language

- Follows a two-three part command
- Recognizes and identifies almost all common objects and pictures
- Understands most sentences
- Understands placement (on, in)
- Uses 4 to 5 word sentences
- Can say name, age, and sex
- Uses pronouns (I, you, me, we, they) and some plurals (cars, dogs, cats)
- Strangers can understand most of her words

What you can do with your baby: •

- Talk to your baby and repeat their two word requests as a sentence (more milk = you want more milk in your cup)
- Put their feelings into words (I know you are mad)
- Play pretend
- Practice sorting objects with them
- Help them solve problems on their own
- Read with them and ask them questions about the story

Appendix and Additional Resources

Included in the Appendix:

1. What do All of These People do? A list of the different professionals that may work with a child with Autism.
2. Glossary
3. Some Extremely Reasonable Suggestions for “Typical” Parents, Family, and Teachers on Behalf of Kids With Asperger’s Syndrome
4. Diagnostic Criteria for Autistic Disorder
5. Books and Video Suggestions
6. Websites Resources
7. Oregon and Washington Education Service District contact information
8. Article Summary: *Evaluation of Interventions and Treatment for Learners With Autism Spectrum Disorders*

What Do All of These People Do?

Pediatrician: This is your child's primary care doctor. Their role is to focus on your child's general health care needs, screen for developmental delays, and to provide referrals for issues that they feel need further investigation or treatment.

Developmental Pediatrician: Consults with the child's primary care doctor and with families about health issues, behavior problems, and managing medications.

Child Psychiatrist: Help manage medications, but also help with behavior problems and emotional issues.

Clinical Psychologist: Specialize in understanding the impact of developmental disabilities on the individual and family system. They document developmental progress, as well as cognitive strengths and weaknesses through standardized assessments. Provide behavior management training, social skills training, and support to parents and other family members. They can also provide behavioral therapy.

Occupational Therapist: Works toward improving fine motor skills and practical self-help skills that will improve independent living. For children with Autism, they also work on sensory integration and coordination of movement.

Physical Therapist: Works with fine and gross motor skills to help improve a child's coordination.

Speech and Language Pathologist: Communication skills, social interactions, and play are the main areas of focus. Speech (sound production), language, and feeding.

Other Therapists: Children also work with other therapists who provide less traditional interventions such as art, music, or horse riding.

Certified Behavior Analysts: Requires extensive training in the area of Applied Behavior Analysis, specializing in developing in-home therapy and community-based intervention programs.

Some Extremely Reasonable Suggestions for “Typical” Parents, Family, and Teachers on Behalf of Kids With Asperger’s Syndrome

By Jennifer McIlwee Myers, *Aspie-at-Large*

www.Autismdigest.com November-December 2005

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 ASD’s (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 ASD’s in earnest. I interviewed parents, teachers, OT’s, 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.”

The 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 Autism/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.

Diagnostic Criteria for Autistic Disorder

Source: The American Psychiatric Association: Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Washington D.C., American Psychiatric Association, 1994.

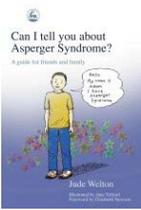
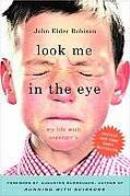
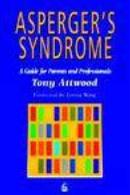
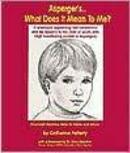
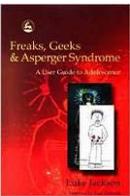
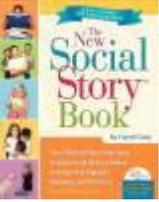
A. A total of at least six items from (1), (2), and (3), with at least two from (1), and one each from (2) and (3):

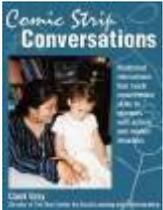
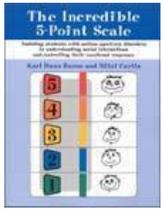
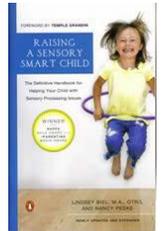
1. Qualitative impairment in social interaction, as manifested by at least two of the following:
 - marked impairment in the use of multiple nonverbal behaviors such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction.
 - failure to develop peer relationships appropriate to developmental level
 - a lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g., by a lack of showing, bringing, or pointing out objects of interest)
 - lack of social or emotional reciprocity
2. Qualitative impairments in communication as manifested by at least one of the following:
 - delay in, or total lack of, the development of spoken language (not accompanied by an attempt to compensate through alternative modes of communication such as gesture or mime)
 - in individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others
 - stereotyped and repetitive use of language or idiosyncratic language
 - lack of varied, spontaneous make-believe play or social imitative play appropriate to developmental level
3. Restricted repetitive and stereotyped patterns of behavior, interests, and activities, as manifested by at least one of the following:
 - encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus
 - apparently inflexible adherence to specific, nonfunctional routines or rituals
 - stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping or twisting, or complex whole body movements)
 - persistent preoccupation with parts of objects

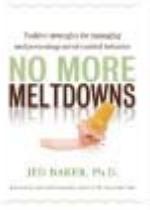
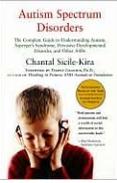
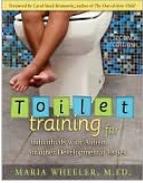
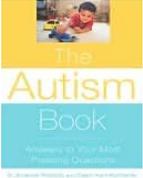
B. Delays or abnormal functioning in at least one of the following areas, with onset prior to age 3 years: (1) social interaction, (2) language as used in social communication, or (3) symbolic or imaginative play.

C. The disturbance is not better accounted for by Rett's Disorder or Childhood Disintegrative Disorder.

Books & Websites

	<p>Can I tell You about My Asperger's Syndrome? By Jude Welton, Jane Telford, and Elizabeth Newson (2003)</p> <p>In this book, Adam helps others understand the difficulties faced by a child with AS; he tells them what AS is, what it feels like to have AS and how they can help children with AS by understanding their differences and appreciating their many talents.</p>
	<p>Look Me in the Eye: My Life with Asperger's by John Elder Robison (2008)</p> <p>This is a story of one man's struggle growing up with Asperger's Syndrome. It is a very real story that is also inspirational. The author has become quite successful at many things. It is interesting to see the world through his eyes.</p>
	<p>Asperger's Syndrome: A guide for parents and professionals By: Tony Attwood and Lorna Wing (1998)</p> <p>Tony Attwood is a world renown expert on Asperger's Syndrome. His guide will assist parents and professionals with the identification, treatment and care of both children and adults with Asperger's Syndrome.</p>
	<p>Asperger's What does it mean to me? By Catherine Faherty and Gary B. Mesibov (2000)</p> <p>A workbook explaining self awareness and life lessons to the youth with high functioning Autism or Asperger's Syndrom.</p>
	<p>Freaks, Geeks, and Asperger's Syndrome A user guide to adolescence by Luke Jackson (2002)</p> <p>This book is written by a 13 year old boy with Asperger's Syndrome. It addresses social situations from his perspective.</p>
	<p>Socially Curious and Curiously Social: A Social Thinking Guidebook for Teens & Young Adults with Asperger's, ADHD, PDD-NOS, NVLD, or other Murky Undiagnosed Social Learning Issues by Michelle Garcia Winner and Pamela Crooke</p> <p>An anime-illustrated, get-real guidebook for teens and young adults to read themselves about how the social mind works. From texting to dating, the book provides many practical strategies and some "ah-ha moments."</p>
	<p>The New Social Story Book by Carol Gray (2010)</p> <p>Social Stories provide REAL social understanding! The book promotes social understanding in children with Autism Spectrum Disorders. Social Stories are a standard approach for teachers and parents all over the globe.</p>

	<p>Comic Strip Conversations by Carol Gray (1994)</p> <p>This book is a how to guide for using comic strips to teach social interactions and conversations</p>
	<p>The incredible 5 Point Scale by Kari Dunn Buron and Mitzi Curtis (2004)</p> <p>This book uses a 5-point scale to help students understand and control their emotional reactions to everyday events. It breaks down a given behavior and develops a scale that identifies the problem and suggests alternative, positive behaviors at each level of the scale.</p>
	<p>Sticker Strategies to Encourage Social Thinking and Organization by Michelle Garcia Winner</p> <p>This book has 80 stickers that each contain a mini social story. They are useful for targeting behaviors in a very concrete way.</p>
	<p>Clay Marzo Just Add Water DVD by Quick Silver</p> <p>Clay Marzo is a world class surfer who was diagnosed with Asperger's Syndrome. The DVD has a lot of information about Asperger's, and shows that people with ASD's can accomplish many things.</p>
	<p>Since We're Friends: An Autism Picture Book by Celeste Shally and David Harrington (2007)</p> <p>This is a book about a boy who is trying to be a good friend to his friend Matt who has Autism. Matt's symptoms may be a bit glossed over, but the point of the book is that the boy recognizes they are different, but still cares.</p>
	<p>Raising a Sensory Smart Child by by Lindsey Biel and Nancy Peske (2009)</p> <p>For children with sensory integration issues-those who have difficulty processing everyday sensations and exhibit unusual behaviors such as avoiding or seeking out touch, movement, sounds, and sights-this groundbreaking book is an invaluable resource.</p>

	<p>Ten Things Every Child With Autism Wishes You Knew by Ellen Notbohm (2005)</p> <p>This book has very practical information on how to extend common courtesies to people with Autism. It has many good ideas to help others understand people with Autism.</p>
	<p>No More Meltdowns Positive Strategies for Managing and Preventing Out-of-control Behavior by Jed Baker (2008)</p>
	<p>Thinking in Pictures by Temple Grandin (1996)</p>
	<p>Autism Spectrum Disorders : The Complete Guide to Understanding Autism, Asperger's Syndrome, Pervasive Developmental Disorder, and Other ASDs by Chantal Sicile-Kira</p>
	<p>Toilet Training for Individuals with Autism or Other Developmental Issues <i>by Maria Wheeler,</i></p>
	<p>The Autism Book : Answers to Your Most Pressing Questions <i>by Johanna Robledo</i></p>

Oregon Summer Camps and Social Skill Groups:

Camp Quest (www.asdoregon.org)

- Overnight camp for kids with High Functioning Autism or Aspergers Syndrome
- Non-profit organization who works hard to make camp affordable and to find financial assistance from community organizations for families who need it.
- A typical summer camp experiences with trained staff and lots of structure.
- Activities include: fishing, swimming, canoeing, sports, computers and much more.

Aspiring Youth (www.aspiringyouth.net)

- For kids with HFA, Aspergers, ADHD...
- They have programs for 9-24 year olds.
- This is a fun and interactive day camp that has sessions throughout the year.
- They are located in the Portland area (West side)
- The cost is about \$450 a week.

Play Connections: Melanie Shaw (www.playconnections.com)

- Social Development Summer Camp
- These groups run throughout the year and serve children from toddler -third grade.

Amazing Grace Farm Camp

- This is a day camp program for children with disabilities. There is also a session for siblings. The kids learn to work with all kinds of farm animals.
- The cost is \$250 for 4 days.
- www.gemchildren.org has a listing that includes the contact info.
- This is a day camp program for children with disabilities.
- There is also a session for siblings. The kids learn to work with all kinds of farm animals.

Wiz Kids Day Camp

- 2nd-6th grade day camp that is social skill based. Play games and have fun while improving social skills.
- \$200-\$350 a week
- It is in Hillsboro Oregon.

Blue Compass (www.bluecompasscamps.com)

- This is a program in Washington that takes kids from 7-9 for day camp, and 13-18 for adventure camp where they go backpacking, kayaking, and camping overnight.

ACAP (503-649-2066)

- Autistic Children's Activity Program
- A day camp in Portland that does field trips and a variety of activities.
- Cost \$1200-\$3000 depending on how many days and weeks.

SocialKraft: www.socialkraft.net 503-381-9344

- Social skills groups
- Individual social skills
- Summer groups

Clackamas Speech LLC (www.clackamasspeech.com)

- Reaching Beyond Boundries Summer program:
(Milwaukie Oregon at the East Side Athletic Club 503-659-1516)

Playful Interventions LLC (503-735-5870) Charla Cunningham LMFT, RDT

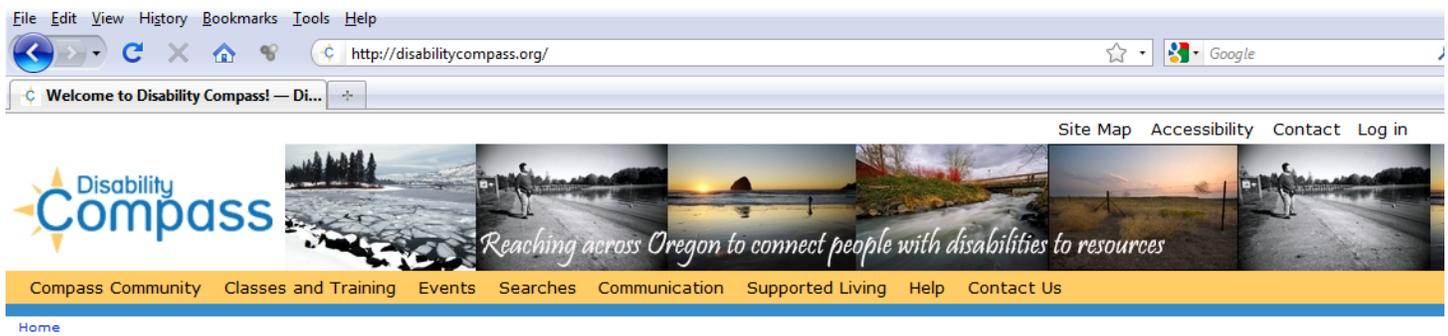
- Social skills theater
- Summer programs involving theater and drama skills.

Disability Compass

Disability Compass is a part of:

Oregon Council on Developmental Disabilities. This is a website that can help people find services in their area. They also offer training for parents. This is a free service to families.

<p>Oregon Council on Developmental Disabilities 1-800-292-4154 www.ocdd.org</p>	<p>Disability Compass 503.292.4964 www.disabilitycompass.org</p>
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Welcome to Disability Compass!

 <h3>Search</h3> <p>Click on Searches at the top of the page for our three one-of-a-kind searches: Community Resources, Personal Service Providers Search, and the Inclusive Child Care Search.</p>	 <h3>Community</h3> <p>Click the Events option to view upcoming events in Oregon. Click the Compass Community option to learn more about Disability Compass and how to become a part of this community-focused project.</p>	 <h3>Tools</h3> <p>Click the Classes and Training option to learn more about the Region One DD Training Consortium and our developing collection of online learning opportunities. Click the Communication option for our electronic publications.</p>
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The December issue of [Compass Points: Information Keys](#) is now available.

Working Together: Community Vision and Compass

Upcoming Events
<p>Estilos de Vida Saludables Augustana Lutheran Church, Portland, Mar 22, 2010</p>
<p>Working with the Professionals in Your Child's Life Medford Public Library, Mar 29, 2010</p>
<p>What Every Parent Needs to Know About the IEP Swindells Center - Portland, OR, Mar 30, 2010</p>
<p>Working with the Professionals in Your Child's Life Umatilla Morrow ESD -</p>

Autism Society of America

The Autism Society of America is a national organization that provides information on a variety of issues related to Autism.

Autism Society of America
7910 Woodmont Ave, Suite 300
Bethesda, MD 20814-3067
1-800-328-8476
www.Autism-society.org

The Oregon chapter is called:
Autism Society of Oregon
503-636-1676 or 1-800-Autism-1
www.Autismoregon.com

The screenshot shows the Autism Society of America website homepage. At the top, there is a navigation bar with links for Home, En Español, Print this Page, and Tell a Friend. Below this is a search bar and a login section. The main content area is divided into several sections:

- Left Sidebar:** Contains a menu with links for ABOUT AUTISM, LIFE WITH AUTISM, RESEARCH & PROGRAMS, AUTISM COMMUNITY, and ABOUT US. Below the menu are logos for AUTISM SOCIETY CHAPTERS, Autism source (labeled #1 in Autism Information), and a Bounce for Autism logo with the text "REGISTER TODAY!".
- Center Section:** Features the headline "imagine the possibilities" and three columns of testimonials:
 - I'M A FAMILY MEMBER:** My son Landon, 26, was diagnosed with autism at three and a half ...
 - I'M ON THE SPECTRUM:** My name is Daniel John Svoboda. I am 25 years old.
 - I'M A PROFESSIONAL:** As a professional who once had family with severe developmental...Each testimonial includes a "Read My Story" link.
- Right Sidebar:** Contains several promotional banners:
 - VOTE 4 AUTISM!** with an American flag graphic.
 - SIGN UP FOR E-NEWSLETTER** with a star graphic.
 - Safe & Sound** with the Autism Society logo.
 - 41ST National Conference & Exposition** in Dallas, Texas, July 7-10, 2010.
 - Visit Our eStore Today!** with a shopping cart icon.
 - I WANT TO HELP** with a star graphic.
- Bottom Section:** Titled "AUTISM SOCIETY NEWS" and "Autism in the Headlines". It features a news item: "Health-care Reform Bill Passes Both Houses" with sub-links for "Bounce for Autism" this April, "Join the Movement - Check out 1Power4Autism Today!", and "Landmark Consensus Articles Published in Pediatrics Acknowledge the Need to Improve Evaluation and Treatment of Gastrointestinal Disorders in Individuals with Autism". There are "More news ..." and "Read more ..." links.

The ARC of Oregon

The ARC of Oregon advocates for people with developmental disabilities including Autism. ARC provides training, respite information and other help to families.

The ARC of Oregon

(503) 581-2726

1-877-581-2726

www.arcoregon.org

The screenshot shows a web browser window with the URL <http://www.arcoregon.org/>. The browser's address bar and menu bar are visible. Below the browser window is a banner for The Arc of Oregon. The banner includes the organization's name in a stylized font, contact information (1745 State Street NE, Salem, OR 97301, (503) 581-2726, Toll Free 1-877-581-2726, Fax (503) 363-7168), and a tagline: "Advocating since 1954 for Oregonians with intellectual and related developmental disabilities".

Below the banner is a navigation menu with the following items: Home, Calendar of Meetings, Search The Arc of Oregon, and Contact Us. The main content area is divided into two columns. The left column contains a list of programs and resources, including OSNT (The Oregon Special Needs Trust), GAPS (Guardianship, Advocacy and Planning Services), Public Policy, RESOURCES (Upcoming Events, Chapter and Member Services, STALEY (Self Directed Support Service for Adults), Disability Resources, The Arc of the United States, and Membership (Join The Arc of Oregon)). The right column contains the organization's mission and vision statements.

Mission: *The Arc of Oregon, together with its network of members and affiliated chapters, advocates for the rights and full community participation of all children and adults with intellectual and developmental disabilities.*

Vision: *The Arc of Oregon envisions a world in which all persons have the support and opportunities they need for personal development and independence, interdependence with family and friends, and inclusion in the community.*

Oregon Department of Human Services

The Oregon Department of Human Services (DHS) has local offices around the state for Developmental Disability Services (DDS). They are usually located in the county's Mental Health Department.

State Office for DHS:

(503) 945-9774

www.oregon.gov/DHS/index.shtml

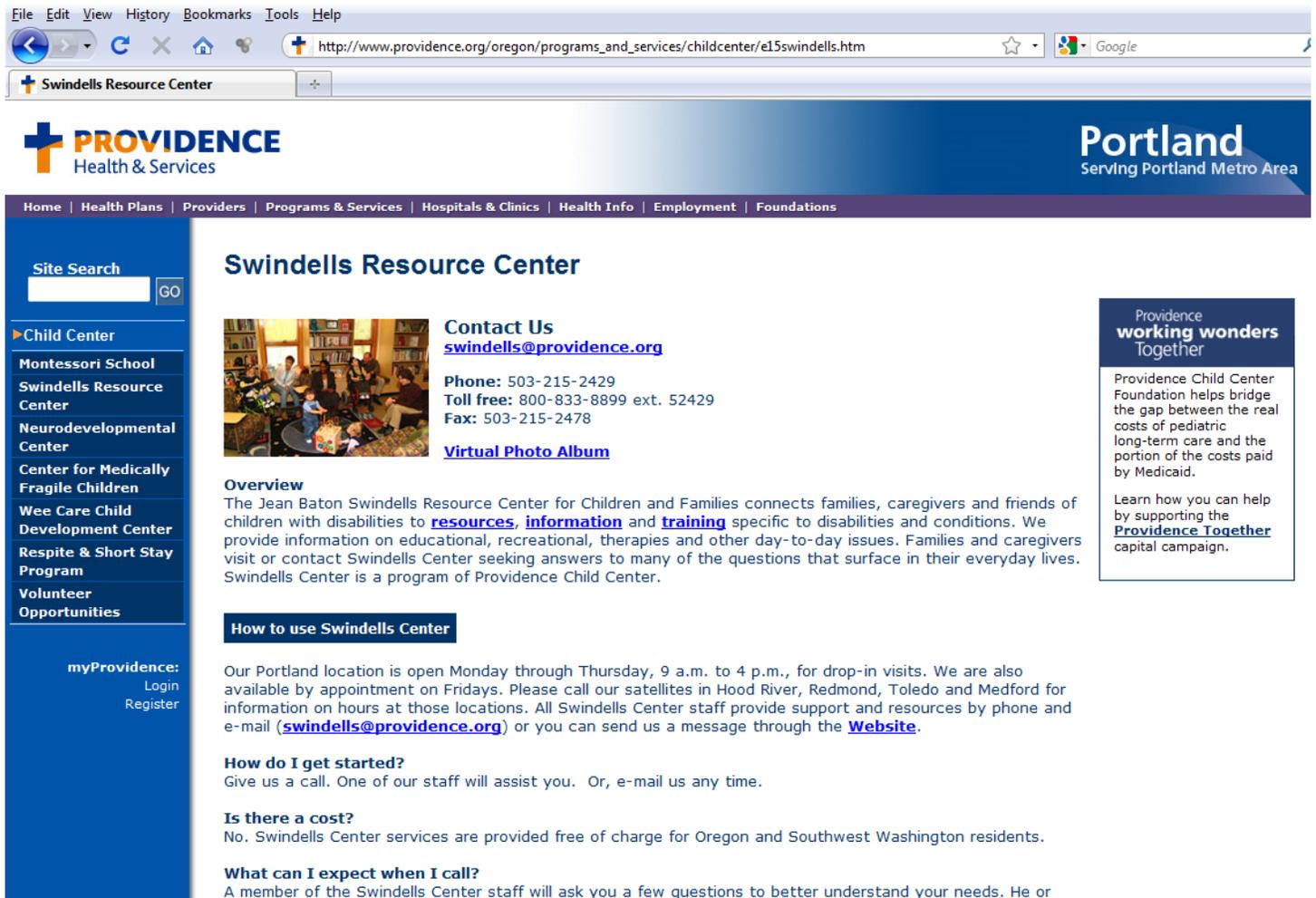
The screenshot shows the Oregon Department of Human Services (DHS) website homepage. The browser address bar displays "http://www.oregon.gov/DHS/index.shtml". The page features a dark blue header with the "OREGON.gov" logo and the DHS logo. A navigation menu on the left lists various services and information, including "About Us", "Contact Us", "DHS home", "A to Z at DHS", "Budget", "Data and reports", "Forms", "Jobs at DHS", "Legislative activity", "Local Offices", "News and opinion", "Publications", "Rules and policies", and "Search DHS". The main content area is titled "Celebrating Developmental Disabilities Month" and includes a photo of a woman in a wheelchair being assisted by a caregiver. Text below the photo describes a new campaign called "Employment First" aimed at creating job opportunities for people with developmental disabilities. A sidebar on the right lists various services such as "Abuse and neglect", "Addiction services", "Assistance services", "Children's services", "Disability services", "Health/medical services", "Mental health services", "Senior services", and "Other services". A "Quick links" section at the bottom right provides direct access to "A to Z at DHS", "Building closure information", "Get help now - crisis services", "Notice of Privacy Practices", "Oregon Health Authority", "Report abuse and neglect", and "Report financial fraud".

Swindell's Child Disability Resources

The Swindell Center provides information and training to families who have a child with a disability.

Website: http://www.providence.org/oregon/programs_and_services/childcenter/e15swindells.htm

Email: swindells@providence.org



The screenshot shows a web browser window displaying the Providence Health & Services website. The address bar shows the URL: http://www.providence.org/oregon/programs_and_services/childcenter/e15swindells.htm. The page header includes the Providence Health & Services logo and the text "Portland Serving Portland Metro Area". A navigation menu lists: Home, Health Plans, Providers, Programs & Services, Hospitals & Clinics, Health Info, Employment, Foundations. A sidebar on the left contains a "Site Search" box and a list of links: Child Center, Montessori School, Swindells Resource Center, Neurodevelopmental Center, Center for Medically Fragile Children, Wee Care Child Development Center, Respite & Short Stay Program, Volunteer Opportunities, and myProvidence: Login Register. The main content area is titled "Swindells Resource Center" and features a "Contact Us" section with the email swindells@providence.org, phone number 503-215-2429, toll-free number 800-833-8899 ext. 52429, and fax number 503-215-2478. There is also a link to a "Virtual Photo Album". An "Overview" section describes the center's mission to connect families and caregivers. A "How to use Swindells Center" section provides information on hours and services. A "How do I get started?" section encourages calling or emailing. A "Is there a cost?" section states that services are free for Oregon and Southwest Washington residents. A "What can I expect when I call?" section notes that staff will ask questions to understand needs. A sidebar on the right contains a "Providence working wonders Together" campaign message.

Swindells Resource Center

Contact Us
swindells@providence.org
Phone: 503-215-2429
Toll free: 800-833-8899 ext. 52429
Fax: 503-215-2478
[Virtual Photo Album](#)

Overview
The Jean Baton Swindells Resource Center for Children and Families connects families, caregivers and friends of children with disabilities to [resources](#), [information](#) and [training](#) specific to disabilities and conditions. We provide information on educational, recreational, therapies and other day-to-day issues. Families and caregivers visit or contact Swindells Center seeking answers to many of the questions that surface in their everyday lives. Swindells Center is a program of Providence Child Center.

How to use Swindells Center
Our Portland location is open Monday through Thursday, 9 a.m. to 4 p.m., for drop-in visits. We are also available by appointment on Fridays. Please call our satellites in Hood River, Redmond, Toledo and Medford for information on hours at those locations. All Swindells Center staff provide support and resources by phone and e-mail (swindells@providence.org) or you can send us a message through the [Website](#).

How do I get started?
Give us a call. One of our staff will assist you. Or, e-mail us any time.

Is there a cost?
No. Swindells Center services are provided free of charge for Oregon and Southwest Washington residents.

What can I expect when I call?
A member of the Swindells Center staff will ask you a few questions to better understand your needs. He or

Providence
working wonders
Together
Providence Child Center Foundation helps bridge the gap between the real costs of pediatric long-term care and the portion of the costs paid by Medicaid.
Learn how you can help by supporting the [Providence Together](#) capital campaign.

A Hope For Autism



A Hope For Autism

Email: gayle_ahfa@yahoo.com

Phone: 503-781-8954

Website: www.ahopeforAutism.org

A Hope For Autism Foundation, the culmination of years of research, training, and devotion to the treatment of Autism, was founded to provide **support and services scholarships** to families affected by Autism Spectrum Disorder. We believe every individual deserves the opportunity to be a part of our community and experience the life they deserve.

Autism, a unique, lifelong disorder, affects one in 110 school age children and an untold number of adults. Beginning in early childhood, children and adults with ASD vary in their abilities to learn, communicate, and relate to others. An Autism Spectrum Disorder may affect only some areas of development, or can present more pervasively: affecting all areas of development ranging from speech and communication to building friendships. With the right intervention, Autism can be a treatable disorder.

Applied Behavior Analysis is the only evidenced based and scientifically supported method of treatment for individuals with ASD. A Hope For Autism Foundation provides direct scholarships to families, professionals, and team members for ABA training, services, and support. We are the only Foundation in the state of Oregon dedicated solely to providing necessary financial support for this much needed intervention.

We:

- are committed to helping families and building a conscious and supportive professional community.
- are intent on building a community of doctors, clinicians, and support staff that are the best at what they do; helping individuals with Autism to thrive and succeed in their community.
- look forward to being a part of the larger community and working with insurance companies and school districts to provide the most effective interventions for these individuals.

We also focus on developing a program for family support and training. We focus on using a child's interests to motivate learning opportunities. We believe that learning should be fun as well as effective and efficient.

Beyond all, there is hope. We look forward to having the privilege of working with your child.

The Inclusive Child Care Program: Oregon Council on Developmental Disabilities

The Goals of the Inclusive Child Care Program are:

1. To support access to appropriate child care for families of children with disabilities, emotional/behavioral Disorders, or special health care needs.
2. To help all children be in inclusive child care settings with their peers.

The Inclusive Child Care Program serves children, families, child care providers, and communities through:

- **Child care subsidies.** The program coordinates subsidies that can help with costs of accommodations or supports that are necessary for safe, healthy child care for some children. Families may be eligible when parents are employed, students, or receiving child care assistance through the Oregon Department of Human Services. Family income must be less than \$4,592 per month for a family of 4. Eligible children and youth may be birth to 17 years of age and need a higher level of care and supervision.
 - **Individualized Planning** to support stable child care placements.
 - **Training and Consultation** to support child care providers in their efforts to include children with diverse abilities and needs.
 - **Information on community, state, and national resources** that support inclusive child care.

How is “inclusive child care” different?

It isn't. Inclusive child care just means that children and youth with and without disabilities, emotional/behavioral disorders, or special health care needs are all together in child care or out-of-school time programs. It also means that all children and youth participate in all of the settings, daily routines, and activities.

All child care and out-of-school time programs have the potential to be fully inclusive.

To make referrals or for more information, please contact:

Inclusive Child Care Program: Portland: 971-673-2286

Toll Free: 1-866-837-0250 Email: inclusivecc@oregonchildcare.org

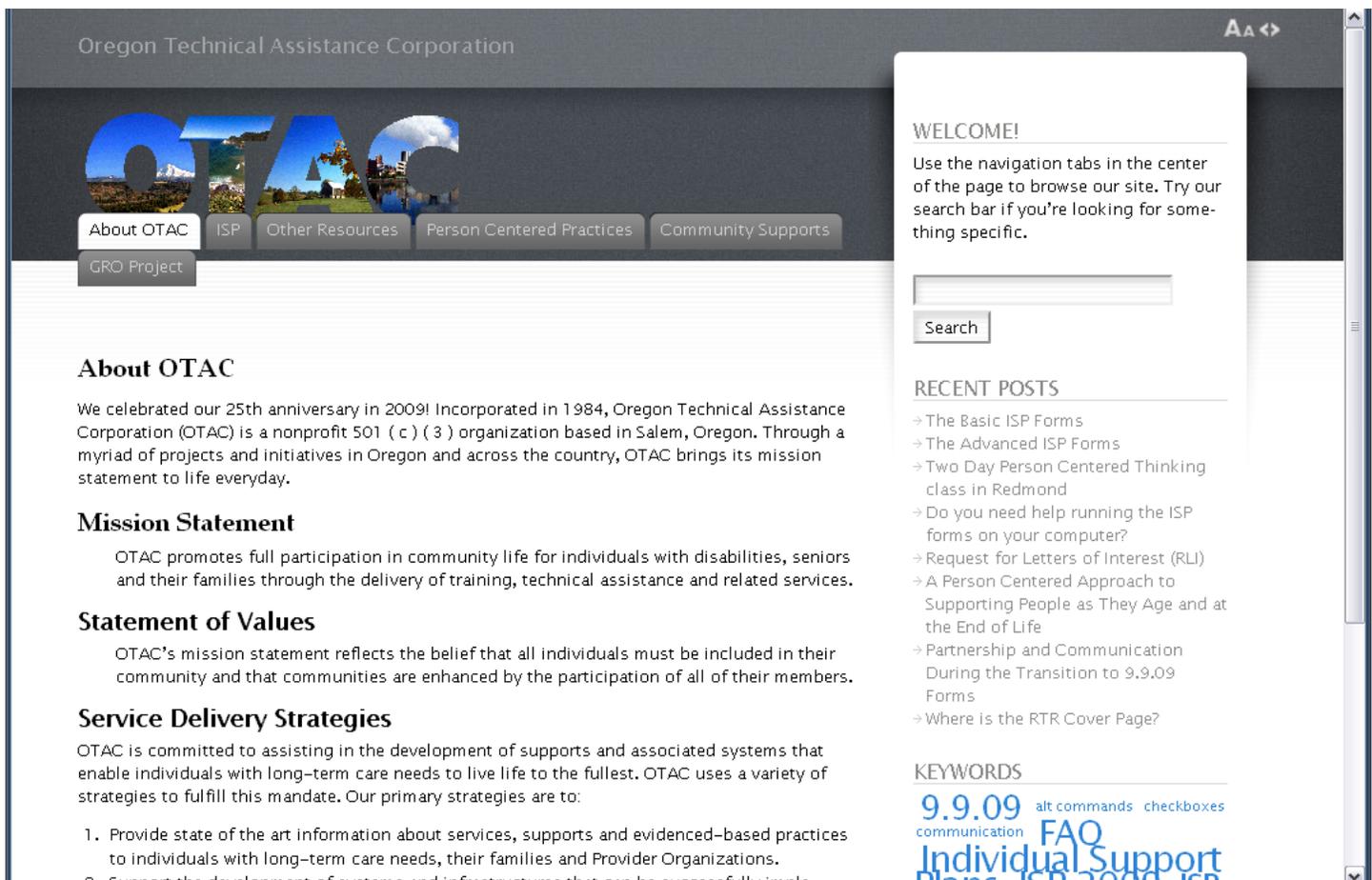
Oregon Technical Assistance Corporation (OTAC)

Oregon Technical Assistance Corporation (OTAC) has published: Autism an Introduction for parents and guide to Oregon's Human Service System 5th Edition (2005)

This resource can be downloaded from the OTAC website. If the download does not work call OTAC and they can send you the resource.

OTAC
(503) 364-9943

www.otac.org



Oregon Technical Assistance Corporation

WELCOME!

Use the navigation tabs in the center of the page to browse our site. Try our search bar if you're looking for something specific.

RECENT POSTS

- The Basic ISP Forms
- The Advanced ISP Forms
- Two Day Person Centered Thinking class in Redmond
- Do you need help running the ISP forms on your computer?
- Request for Letters of Interest (RLI)
- A Person Centered Approach to Supporting People as They Age and at the End of Life
- Partnership and Communication During the Transition to 9.9.09 Forms
- Where is the RTR Cover Page?

KEYWORDS

9.9.09 alt commands checkboxes communication **FAQ** Individual Support

About OTAC

We celebrated our 25th anniversary in 2009! Incorporated in 1984, Oregon Technical Assistance Corporation (OTAC) is a nonprofit 501 (c) (3) organization based in Salem, Oregon. Through a myriad of projects and initiatives in Oregon and across the country, OTAC brings its mission statement to life everyday.

Mission Statement

OTAC promotes full participation in community life for individuals with disabilities, seniors and their families through the delivery of training, technical assistance and related services.

Statement of Values

OTAC's mission statement reflects the belief that all individuals must be included in their community and that communities are enhanced by the participation of all of their members.

Service Delivery Strategies

OTAC is committed to assisting in the development of supports and associated systems that enable individuals with long-term care needs to live life to the fullest. OTAC uses a variety of strategies to fulfill this mandate. Our primary strategies are to:

1. Provide state of the art information about services, supports and evidenced-based practices to individuals with long-term care needs, their families and Provider Organizations.
2. Support the development of systems and infrastructure that can be successfully imple

Rethink Autism

Rethink Autism is a web-based program that provided on-going training and supports to families to teach them how to provide ABA therapy at home.

The cost is about \$100 per month. Below is some information from their home page:

www.rethinkAutism.com/

If your child has received an Autism diagnosis, you may have more questions than answers. How can I help my child learn to communicate with me? Make friends? Read or write? Live independently?

Studies show that children receiving early intensive treatment make the most substantial progress. Yet an Autism diagnosis is often followed by a long search for the right educational program and necessary treatment. rethink Autism can help.

Home About Autism About Us Community Login | Subscribe Now

rethink **a** autism.

Make this Mother's Day extra special!

A web-based autism treatment platform

For Professionals

- Create individualized ABA based curricula.
- Manage data online and generate automated reports.
- Train others in research-based interventions.

[Learn More >](#)

For Parents

- Customize a plan for your child.
- Learn from 1,200+ video exercises based on Applied Behavior Analysis (ABA).
- Coordinate your team and get online support.

[Learn More >](#)

Free 1 Week Trial!

[Check out our pricing >](#)

What parents are saying Quick tour: rethink autism Mother's day

In the News: abc CBS NEWS WUSA WUSAB.COM AUTISM SPEAKS WPIX stjocnews.net examiner.com medGadget

Happy Mother's Day!

Print out and create your very own Color-by-Numbers Mother's Day Card!

News

Videos of Twin With Autism Show Dramatic Results From Treatment

Our short 4-part video series helps raise

Free autism tips

Sign up to get free:

- practical daily living advice
- autism tip videos

Autism Speaks

Autism Speaks provides a free notebook for families who have a child who has been recently diagnosed with Autism or Asperger's Syndrome.

You can download the 100 day kit (notebook) at www.Autismspeaks.org, or call to request a free 100 Day Kit.

Families whose children have been *diagnosed in the last 6 months* may request a complimentary hard copy of the 100 Day Kit or the AS/HFA Tool Kit by calling 888-AUTISM2 (888-288-4762) and speaking with an Autism Response Team Coordinator.



Oregon Education Service Districts

ESD	Address	Phone #	Website
Clackamas	13455 SE 97th Ave, Clackamas, OR 97015	(503)-675-4000	www.clackesd.k12.or.us
Columbia Gorge	400 E Scenic Dr. Suite 207, The Dalles, OR 97058	541-298-5155	www.cgesd.k12.or.us
Douglas	1871 NE Stephens, Roseburg, Oregon 97470	(541) 440-4777	www.douglasesd.k12.or.us
Grant	835A South Canyon Blvd., John Day, OR	(541) 575-1349	www.grantesd.k12.or.us
Harney	PO Box 460 Burns, Oregon 97720	(541)-573-2122	www.harneyesd.k12.or.us
High Desert	145 SE Salmon Ave., St A, Redmond, Oregon 97756	541-693-5600	www.hdesd.org
Jefferson	295 SE Buff Street, Madras, OR 97741	541.475.2804	www.jcesd.k12.or.us
Lake County	357 North L Street, Lakeview, OR 97630	541.947.3371	www.lakeesd.k12.or.us
Lane	1200 Highway 99N, Eugene, OR 97402	541-461-8200	www.lesd.k12.or.us
Linn Benton	905 4th Avenue SE, Albany, OR 97321-1999	(541) 812-2600	www.lblesd.k12.or.us
Malheur	363 A Street West, Vale, Oregon 97918	(541) 473-3138	www.malesd.k12.or.us
Multnomah	P.O. Box 301039, Portland, OR 97220	503-255-1841	www.mesd.k12.or.us
North Central	PO Box 637, Condon, Oregon, 97823	541-384-2762	www.ncesd.k12.or.us
Northwest Regional	5825 NE Ray Circle , Hillsboro, OR 97124-6436	503-614-1428	www.nwresd.k12.or.us

Clatsop Service Center	3194 Marine Dr., Astoria, OR 97103	503-325-2862	www.nwresd.k12.or.us
Columbia Service Center	800 Port Ave., St. Helens, OR 97051	503-366-4100	www.nwresd.k12.or.us
Tillamook Service Center	2410 5th St. • PO Box 416, Tillamook, OR 97141	503-842-8423	www.nwresd.k12.or.us
Wallowa County (District 18)	107 Southwest First St., Enterprise, OR 97828	541-426-4997	www.wallowaesd.k12.or.us
South Coast (Coos Co.)	1350 Teakwood Avenue Coos Bay, Oregon 97420	541-269-1611 541-247-6681	www.scesd.k12.or.us
Southern Oregon	101 North Grape Street, Medford, OR 97501	541.776.8590	www.soesd.k12.or.us
Umatilla-Morrow	2001 SW Nye , Pendleton, Oregon 97801	541.276.6616	www.umesd.k12.or.us
Union-Baker	10214 Wallowa Lake Hwy., Island City, OR 97850	(541) 963-0920	www.ubesd.k12.or.us
Willamette Marion Center	2611 Pringle Rd. SE, Salem, OR 97302	503.588.5330	www.wesd.org
Willamette Yamhill Center	2045 SW Highway 18, McMinnville, OR 97128	503.435.5900	www.wesd.org

Washington Education Service Districts

ESD	Address	Phone #	Website
112	2500 NE 65th Avenue, Vancouver, WA 98661	360-750-7500	www.esd112.org
Battle Ground School District 119	11104 NE 149th Street Brush Prairie, WA 98606	360-885-5300	www.bgsd.k12.wa.us
Camas School District 117	841 NE 22nd Avenue Camas, WA 98607	360-833-5400	www.camas.wednet.edu
Roosevelt School District 403	615 Chinook Avenue PO Box 248 Roosevelt, WA 99356-0248	509-384-5462	
Castle Rock School District 401	600 Huntington Avenue South Castle Rock, WA 98611	360-501-2940	www.castlerock.wednet.edu
Centerville School District 215	2315 Centerville Highway Centerville, WA 98613	509-773-4893	
Skamania School District 2	122 Butler Loop Road Skamania, WA 98648	509-427-8239	www.skamania.k12.wa.us
Evergreen School District 114	13501 NE 28th Street PO Box 8910 Vancouver, WA 98668-8910	360-604-4000	www.egreen.wednet.edu
Glenwood School District 401	PO Box 12 Glenwood, WA 98619-0012	509-364-3438	www.glenwood.k12.wa.us

Stevenson-Carson School District 303	PO Box 850 Stevenson, WA 98648-0850	509-427-5674	www.scsd.k12.wa.us/
Green Mountain School District 103	13105 NE Grinnell Road Woodland, WA 98674	360-225-7366	www.greenmountainschool.us/
Hockinson School District 98	17912 NE 159th Street Brush Prairie, WA 98606	360-448-6400	http://www.hock.k12.wa.us/
Toutle Lake School District 130	5050 Spirit Lake Memorial Highway Toutle, WA 98649	360-274-6182	http://www.toutlesd.k12.wa.us/
Kalama School District 402	548 China Garden Road Kalama, WA 98625	360-673-5282	http://www.kalama.k12.wa.us/
Kelso School District 458	601 Crawford Street Kelso, WA 98626	360-501-1900	http://www.kelso.wednet.edu/
Trout Lake School District R-400	2310 Highway 141 Trout Lake, WA 98650-9799	509-395-2571	www.troutlake.k12.wa.us
Klickitat School District 402	PO Box 37 Klickitat, WA 98628-0037	509-369-4145	www.klickitat.wednet.edu/
La Center School District 101	725 Highland Road PO Box 1840 La Center, WA 98629	360-263-2131	www.lacenterschools.org/
Ridgefield School District 122	2724 South Hillhurst Road Ridgefield, WA 98642	360-619-1300	www.ridge.k12.wa.us
Longview School District	2715 Lilac Street Longview, WA 98632	360-575-7000	www.longview.k12.wa.us/

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Lyle School District 406	PO Box 368 Lyle, WA 98635-0368	509-365-2191	www.lyleschools.org
Vancouver School District 37	PO Box 8937 Vancouver, WA 98668	360-313-1000	www.vansd.org/
Mill A School District 31	1142 Jessup Road Cook, WA 98605	509-538-2522	www.milla.k12.wa.us
Mount Pleasant School District 029-93	152 Marble Road Washougal, WA 98671-9602	360-835-3371	www.wahksd.k12.wa.us
Wahkiakum School District 200	PO Box 398 Cathlamet, WA 98612	360-795-3971	www.wahksd.k12.wa.us
Naselle-Grays River Valley SD155	793 State Route 4 Naselle, WA 98638	360-484-7123	www.naselle.wednet.edu
Ocean Beach School District 101	PO Box 778 Long Beach, WA 98631	360-642-3739	www.ocean.k12.wa.us
Washougal School District 112-6	4855 Evergreen Way Washougal, WA 98671	360-954-3000	www.washougal.k12.wa.us
White Salmon Valley SD 405-17PO	Box 157 White Salmon, WA 98672	509-493-1500	www.schools.gorge.net
Wishram School District 94	PO Box 8 Wishram, WA 98673	509-748-2551	
Woodland School District 404	800 Third Street Woodland, WA 98674-8467	360-225-9451	www.woodlandschools.org

Therapy Research Article

The following page is the summary of a research article that was published in 2005. The article looked at many therapies that are often used to support kids with autism. The article reviewed many other studies that had looked at different therapies and placed the therapies into categories based on how strong the research and the results were.

The categories are:

Scientifically Based Practice- which means that there has been valid research and sound results for that therapy.

Promising Practice- which refers to the therapies that are generally accepted, but there is not much strong, reliable data to support the therapies.

Limited Supporting Information for Practice- this category includes therapies that have no valid research, and/or have negative research results.

For the purposes of this parent guide, there is a third category. These are the therapies that we consider widely accepted by medical professionals

-

TABLE 1
Evaluation of Interventions and Treatments for Learners With Autism Spectrum Disorders

Classification	Intervention and Treatment Categories				
	Interpersonal relationship	Skill-based	Cognitive	Physiological/biological/neurological	Other
Scientifically based practice		<ul style="list-style-type: none"> • Applied behavior analysis (Hagopian, Crockett, van Stone, DeLeon, & Bowman, 2000) • Discrete trial teaching (Committee on Educational Interventions for Children with Autism, 2001) • Pivotal response training (Hupp & Reitman, 2000) 	<ul style="list-style-type: none"> • <i>Learning Experiences: An Alternative Program for Preschoolers and Parents</i> (Strain & Hoyson, 2000) 		
Promising practice	<ul style="list-style-type: none"> • Play-oriented strategies 	<ul style="list-style-type: none"> • <i>Picture Exchange Communication System</i> (Pyramid Educational Consultants, 2005) • Incidental teaching (Charlop-Christy & Carpenter, 2000) • Structured teaching (e.g., TEACCH; Panerai, Ferrante, Caputo, & Impellizzeri, 1998) • Augmentative alternative communication (Ogletree, 1998) • Assistive technology (Tjus, Hinmann, & Nelson, 2001) • Joint action routines (Prizant, Wetherby & Rydell, 2000) 	<ul style="list-style-type: none"> • Cognitive behavioral modification (Zirpoli, 2005) • Cognitive learning strategies (Bock, 1999) • Social stories (Rogers & Myles, 2001) • Social decision-making strategies (Myles & Simpson, 2003) 	<ul style="list-style-type: none"> • Sensory integration (Case-Smith & Bryant, 1999) 	
Limited supporting information for practice	<ul style="list-style-type: none"> • Gentle teaching (Fox, Dunlop, & Buschbaker, 2000) • Option method (e.g., Son-Rise program; Option Institute and Fellowship, 2004) • Floor time (Green-span & Wieder, 2000) • Pet/animal therapy (McKinney, Dustin, & Wolff, 2001) • Relationship development intervention (Gustein & Sheely, 2002) 	<ul style="list-style-type: none"> • Van Dijk curricular approach (MacFarland, 2001) • Fast ForWord (Gillam, Loeb, & Friel-Patti, 2001) 	<ul style="list-style-type: none"> • Cognitive scripts (Krantz & McClannahan, 1998) • Cartooning (Rogers & Myles, 2001) • Power cards (Gagnon, 2001) 	<ul style="list-style-type: none"> • Scotopic sensitivity syndrome: Irlen lenses (Griffin, Christenson, Wesson, & Erickson, 1997) • Auditory integration training (Mudford et al., 2000) • Megavitamin therapy (Adams & McGinnis, 2001) • Feingold diet (Tsai, 1998) • Herb, mineral, and other supplements (Tolbert, Haigler, Wairs, & Dennis, 1993) 	<ul style="list-style-type: none"> • Music therapy (Brownwell, 2002) • Art therapy (Kornreich & Schimmel, 1991)
Not recommended	<ul style="list-style-type: none"> • Holding therapy (Walterhouse, 2000) 	<ul style="list-style-type: none"> • Facilitated communication (Perry, Bryson, & Bebko, 1998) 			

Note. Adapted from Simpson, R., de Boer-Ott, S., Griswold, D., Myles, B., Byrd, S., Ganz, J., et al. (2005). *Autism spectrum disorders: Interventions and treatments for children and youth*. Thousand Oaks, CA: Corwin Press. Used with permission of Corwin Press.

Glossary of Autism Related Terms

Americans with Disabilities Act (ADA) is the US law that ensures rights of persons with disabilities with regard to employment and other issues.

Applied Behavior Analysis (ABA) is a style of teaching using series of trials to shape desired behavior or response. Skills are broken into small components and taught to child through a system of reinforcement.

Asperger's Syndrome is a developmental Disorder on the Autism Spectrum defined by impairments in communication and social development and by repetitive interests and behaviors, without a significant delay in language and cognitive development.

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

Autism Diagnostic Observation Schedule (ADOS) is test considered to be current gold standard for diagnosing ASD and, along with information from parents, should be incorporated into a child's evaluation.

Autism Spectrum Disorders encompasses the following Disorders listed in DSM-IV: Autistic Disorder, Asperger's Disorder, PDD – Not Otherwise Specified, Childhood Disintegrative Disorder, and Retts Disorder.

Casein is protein found in milk, used in forming the basis of cheese and as a food additive.

Celiac Disease is a disease in which there is an immunological reaction within the inner lining of the small intestine to gluten, causing inflammation that destroys the lining and reduces the absorption of dietary nutrients. It can lead to symptoms of nutritional, vitamin and mineral deficiencies.

Childhood Disintegrative Disorder is a Disorder in which development begins normally in all areas, physical and mental. At some point between 2 and 10 years of age, the child loses previously developed skills. The child may lose social and language skills and other functions, including bowel and bladder control.

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

Cognition is mental process of knowing, including aspects such as awareness, perception, reasoning and judgment.

Cognitive Skills are any mental skills that are used in the process of acquiring knowledge; these skills include reasoning, perception and judgment.

Compulsions are deliberate repetitive behaviors that follow specific rules, such as pertaining to cleaning, checking, or counting. In young children, restricted patterns of interest may be early sign of compulsions.

Declarative Language is used to communicate what the mind is producing. It is what is most common in conversation, whereas Imperative Language is used to ask questions, make commands or give instructions.

Developmental Disorder refers to several disorders that affect normal development. May affect single area of development (specific developmental disorders) or several (pervasive developmental disorders).

Developmental Individual Difference Relationship (DIR) is therapy, known as Floortime, that seeks to move the child toward increasingly complex interactions through mutually shared engagement.

Developmental Milestones skills or behaviors that most children can do by a certain age that enable the monitoring of learning, behavior, and development.

Developmental Pediatrician is a medical doctor who is board-accredited and has received sub-specialty training in developmental-behavioral pediatrics.

Diagnostic and Statistical Manual the official system for classification of psychological and psychiatric disorders published by the American Psychiatric Association.

Discrete Trial Teaching (DTT), is technique incorporating principles of ABA, including positive reinforcement. Not in itself ABA. Used to teach behaviors in one-to-one setting. Concepts are broken down into small parts.

Dyspraxia is brain's inability to plan muscle movements and carry them out. In speech, this term may be used to describe Apraxia.

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 heard previously, either immediately after hearing word or phrase, or much later. Delayed echolalia occurs days or weeks later. Functional echolalia is using quoted phrase in a way that has shared meaning, for example, saying “carry you” to ask to be carried.

Expressive Labeling is the communication of a name for an object or person, see expressive language.

Expressive Language is communication of intentions, desires, or ideas to others, through speech or printed words. Includes gestures, signing, communication board and other forms of expression.

Extended School Year (ESY) Services are provided during breaks from school, such as during summer vacation, for students who experience substantial regression in skills during school vacations.

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

Floortime a developmental intervention for children with Autism involving meeting a child at his current developmental level, and building upon a particular set of strengths.

Fragile X is a genetic disorder that shares many of the characteristics of Autism. Individuals may be tested for Fragile X.

Gastroenterologist doctor specializing in diagnosis & treatment of disorders of GI tract, including esophagus, stomach, small intestine, large intestine, pancreas, liver, gallbladder & biliary system.

General Education is a pattern of courses in multiple subjects taught to the same grade level to deliver a well-balanced education.

Geneticist refers to a medical doctor who specializes in genetic problems. Genes are the unit in the chromosome that contain the blueprint for the transmission of inherited characteristics.

Gestures are hand and head movements, used to signal to someone else, such as a give, reach, wave, point, or head shake. They convey information or express emotions without the use of words.

Global Developmental Delay is diagnosis in children younger than 6, characterized by delay in two or more developmental domains, sometimes associated with mental retardation.

Gluten is a protein present in wheat, rye, and barley.

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.

Hyposensitivity, Hyporesponsiveness, is abnormal insensitivity to sensory input. Child who appears to be deaf, whose hearing is normal, is under reactive. Child who is under reactive to sensory input may have a high tolerance to pain, may be clumsy, sensation-seeking, and may act aggressively.

Hypotonia is a term that means low muscle tone.

Incidental Teaching teaches a child new skills while in their home or community, in natural context or “in the moment,” to help make sense of what they learn during formal instruction and generalize new skills.

Individual Family Service Plan (IFSP) is developed by a multidisciplinary team including family as primary participant. Describes child’s level of developmental in all areas; family’s resources, priorities, & concerns, services to be received and the frequency, intensity, and method of delivery. Must state natural environments in which services will occur.

Individualized Education Plan (IEP) identifies student’s specific learning expectations, how school will address them with appropriate services, and methods to review progress. For students 14 & older, must contain 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, regardless of degree or severity of disability. Effective inclusion takes place with planned system of training and supports; involves collaboration of multidisciplinary team including regular and special educators.

Joint Attention is the process of sharing one's experience of observing an object or event, by following gaze or pointing gestures. Critical for social development, language acquisition, cognitive development. 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 is where students are expected to participate in existing regular ed classes, whereas in an inclusive program classes are designed for all students. May be gradual, partial, or part-time process (e.g., student may attend separate classes within regular school, or participate in regular gym and lunch only).

Melatonin is a hormone produced by pineal gland, involved in regulating sleeping and waking cycles. Sometimes used for chronic insomnia. Consult your child's physician before giving melatonin; it is not recommended for all patients with sleep problems.

Mental Retardation describes person with limitations in mental functioning that cause them to develop more slowly than typical child. 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 or severe.

Modified Checklist of Autism in Toddlers (MCHAT) is a screening tool for identifying young children who may be referred to specialist for further evaluation and possible Autism Spectrum Disorder diagnosis.

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

Motor function (or Motor Skills) is the ability to move and control movements.

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

Nonverbal Behaviors are things people do to convey information or express emotions without words, including eye gaze, facial expressions, body postures, and gestures.

Obsessions are persistent and intrusive repetitive thoughts. Preoccupations with specific kinds of objects or actions may be an early sign of obsessions.

Occupational Therapy assists development of fine motor skills that aid in daily living. 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. *Occupational Therapist* helps minimize impact of disability on independence in daily living by adapting child's environment and teaching sub-skills of the missing developmental components.

Operant Conditioning is the modification of behavior through positive and/or negative reinforcement.

Perseveration is repetitive movement or speech, or sticking to one idea or task, that has a compulsive quality to it.

Pervasive Developmental Disorders (PDD) group of conditions involving delays in development of many basic skills, including ability to socialize with others, to communicate and use imagination. Includes Autism, Asperger's Syndrome, Childhood Disintegrative Disorder, Rett Syndrome and Pervasive Development Disorder - Not Otherwise Specified.

Pervasive Developmental Disorder – Not Otherwise Specified (PDD-NOS) a category of PDD referring to children having significant problems with communication & play, and some difficulty interacting with others, but are too social for diagnosis of Autism.

Physical Therapy uses specially designed exercises and equipment to help patients regain or improve their physical abilities.

Physical Therapists design and implement physical therapy programs and may work within a hospital or clinic, in a school, or as an independent practitioner.

Pica is persistent eating or mouthing of non nutritive substances for at least 1 month when behavior is developmentally inappropriate (older than 18-24 months). Substances may include items such as clay, dirt, sand, stones, pebbles, hair, feces, lead, laundry starch, vinyl gloves, plastic, erasers, ice, fingernails, paper, paint chips, coal, chalk, wood, plaster, light bulbs, needles, string, cigarette butts, wire, and burnt matches.

Picture Exchange Communication System (PECS) an alternative communication system using picture symbols. Taught in phases starting with simple exchange of symbol for desired item. Individuals learn to use picture symbols to construct complete sentences, initiate communication, & answer questions.

Pivotal Response Treatment (PRT) therapeutic teaching method using incidental teaching opportunities to target and modify key behaviors.

Receptive Language the ability to comprehend words and sentences. Begins as early as birth and increases with each stage in development. By 12 months a child begins to understand words and responds to his name and may respond to familiar words in context. By 18 to 20 months a child identifies familiar people by looking when named (e.g., Where's mommy?), gives familiar objects when named (e.g., Where's the ball?), and points to a few body parts (e.g., Where's your nose?). These skills commonly emerge slightly ahead of expressive language skills.

Reinforcement, or reinforcer, is any object or event following a response, increasing or maintaining the rate of responding. Positive reinforcer may be produced by, or be added after a response. *Relationship Development Intervention (RDI)* a therapeutic teaching method based on building intelligence competencies of social connection -- such as referencing, emotion sharing, coregulation, and experience sharing -- that normally develop in infancy and early childhood.

Respite Care is temporary, short-term care provided to individuals with disabilities, delivered in the home for a few short hours or in an alternate licensed setting for an extended period of time. Respite care allows caregivers to take a break in order to relieve and prevent stress and fatigue.

Self Regulation and self-control are related but not the same. Self-regulation refers to both conscious and unconscious processes that have an impact on selfcontrol, but regulatory activities take place more or less constantly to allow us to participate in society, work, & family life. Self-control is a conscious activity.

Sensory Defensiveness is a tendency, outside the norm, to react negatively or with alarm to sensory input which is generally considered harmless or non-irritating to others. Also called hypersensitivity.

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

Sensory Integration Dysfunction a neurological disorder causing difficulties processing information from the five classic senses (vision, hearing, touch, smell, & taste), sense of movement (vestibular system), and positional sense (proprioception). Sensory information is sensed normally, but perceived abnormally. May be a disorder on its own, or with other neurological conditions.

Sensory Integration Therapy is used to improve ability to use incoming sensory information appropriately & encourage tolerance of a variety of sensory inputs.

Sensory stimulus agent, action or condition, internal (e.g., heart rate, temperature) or external (e.g., sights, sounds, tastes, smells, touch, & balance) that elicits physiological or psychological response. Response depends on ability to regulate & understand stimuli & adjust emotions to demands of surroundings.

Sleep Hygiene a set of practices, habits & environmental factors critically important for sound sleep, such as minimizing noise, light & temperature extremes & avoiding naps & caffeine.

Social Reciprocity back-and-forth flow of social interaction. How behavior of one person influences & is influenced by behavior of another & vice versa.

Social Stories, developed by Carol Gray, are simple stories that describe social events & situations that are difficult for a child with a PDD to understand. For example, a social story might be written about birthday parties if the child appears to have a difficult time understanding what is expected of him or how he is supposed to behave at a birthday party.

Social Worker is a trained specialist in the social, emotional & financial needs of families & patients. Social workers often help families & patients obtain the services they have been prescribed.

Special Education is specially designed instruction, at no cost to families, to meet unique needs of child with disability, including instruction conducted in the classroom, in the home, in hospitals & institutions, & in other settings & instruction in physical education.

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

The treatment is specific to the individual's need.

Spoken Language (also referred to as expressive) use of verbal behavior, or speech, to communicate thoughts, ideas, & feelings with others. Involves learning many levels of rules - combining sounds to make words, using conventional meanings of words, combining words into sentences, and using words & sentences in following rules of conversation.

Stereotyped Behaviors refer to an abnormal or excessive repetition of an action carried out in the same way over time. May include repetitive movements or posturing of the body or objects.

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

Stim, or “self-stimulation” behaviors that stimulate one's senses. Some “stims” may serve a regulatory function (calming, increasing concentration, or shutting out an overwhelming sound).

Symbolic Play is where children pretend to do things & to be something or someone else. Typically develops between the ages of 2 & 3 years. Also called make believe, or pretend play.

Syndrome is a set of signs & symptoms that collectively define or characterize a disease, Disorder or condition.

Tactile Defensiveness is a strong negative response to a sensation that would not ordinarily be upsetting, such as touching something sticky or gooey or the feeling of soft foods in the mouth. Specific to touch.

Training and Education of Autistic and Related Communication Handicapped Children (TEACCH) is a therapeutic approach broadly based on the idea that individuals with Autism more effectively use & understand visual cues.

Typical Development (or healthy development) describes physical, mental, & social development of a child who is acquiring or achieving skills according to expected time frame. Child developing in a healthy way pays attention to voices, faces, & actions of others, showing & sharing pleasure during interactions, & engaging in verbal & nonverbal back-and-forth communication.

Verbal Behavior is a method of Applied Behavioral Analysis (ABA) for teaching children with Autism, based on B.F. Skinner's description of the system of language.

The above glossary is a shortened 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

Personal Information

Things to Add to This Area

- Test Results and Reports
- Provider Information
- IEP documents
- Other Relevant Information