



Autism

An Introduction for Parents

And Guide to Oregon's Human Service System

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A Note to the Reader

This booklet is for families who are new to autism. It has basic information about the disability, answers to frequently asked questions and a summary of help available from Oregon's Department of Human Services (DHS). This agency serves individuals and families and provides services that focus on daily living activities.

Please note that this booklet does not include information about school. A different agency, the Oregon Department of Education, provides special education services along with your local school district. See [Educational Resources](#) for information on how to contact the Department of Education and other organizations about special education for your child.

The phrase “child with autism” is used throughout this booklet; however, the information is applicable to adults with autism as well.

This booklet will be available in Spanish.

All information in the booklet was current as of September 2005.

Catherine Strong and Mary Anne Seaton first produced this booklet in 1996 as a labor of love. Both are parents of children with autism. They met when Catherine's daughter was diagnosed 12 years ago and Mary Anne visited their home to answer the questions that Catherine and her husband Ted had about autism. That kitchen-table conversation was the inspiration for this booklet.

Before becoming a full-time mom, Catherine worked as a grant writer and public policy analyst. Mary Anne has advocated for people with autism and their families for over 20 years. She helped to start the Autism Training Project in 1990 and continues to provide help to families in her work at Oregon Technical Assistance Corporation.



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General Information

What is autism?

- Autism is a life-long developmental disability.
- Autism is a physical disorder affecting the brain that prevents individuals from properly processing and integrating information from their senses and surroundings.
- This brain disorder may cause severe problems in learning, communication and behavior.
- Autism is a spectrum disorder — symptoms range from very mild to severe and can occur in different combinations from one individual to the next.
- Autism usually becomes apparent in the first three years of life but can be identified at any point in life.
- Autism can occur with other disabilities. A significant percentage of people with autism also have mental retardation.
- Autism does not prevent learning. People with autism grow, change, learn and acquire new skills throughout their lives.

What are the characteristics of autism?

People with autism usually have these characteristics in common, to one degree or another:

Poor understanding of social relationships. People with autism usually have poor eye contact and limited play and social interactions. They may prefer being alone. It is hard for them to understand social cues — such as facial expressions and body language — and the feelings of other people.

Significant language and communication problems. Studies show that about 40% of people with autism do not speak. For those who do, language is slow to develop and may include unusual speech patterns and repetitive phrases, questions and topics. People with autism often have difficulty understanding instructions or language out of context. They often need extra time to think about the words they have heard or said and to act on them. It may be hard for them to communicate their needs.

High need for sameness, predictability. People with autism may become upset with changes in the environment, schedules and the people around them. They are easily confused and often develop elaborate rituals — such as lining up objects — to organize themselves. They usually have a limited number of interests and activities.

Impaired thinking abilities. To one degree or another, most people with autism have problems with judgment and understanding the meaning of things. They usually focus on details and are unable to see the whole or how the parts fit together. It is hard for them to separate what's important from what's not. Making choices can be troublesome. Generalization is often a challenge: for example, a child may be able to tie his or her shoes at home but not at school. People with autism typically find it very difficult to grasp abstract concepts such as clean-vs.-dirty.

Organizational problems. People with autism usually have difficulty with beginnings and endings. They may not know where to start an activity or understand what “finished” looks like. Many individuals have trouble putting tasks in order and figuring out what comes next.

Sensory and perception problems. People with autism often have inconsistent and unusual sensory responses. They can be both over-reactive and under-reactive — seemingly deaf to a siren but distressed by the vacuum cleaner. They may stare at lights, lick or smell things, and be attracted to or repelled by certain textures, especially in food. Their pain threshold is often high. In general, they are distracted by sensory information and are unable to filter out the unimportant details.

Uneven pattern of development. Typically, the skills of a person with autism are scattered. They may do some things well and others not at all. A child may be able to read, for example, but unable to talk.

What is most difficult for people with autism?

Language and social skills are the biggest challenges for most people with autism.

Even the most mildly affected people with autism struggle with the complexity and abstraction of language. A person with severe autism may not understand the purpose of language — that people talk to communicate with each other. Social situations also confuse individuals with autism because of the many subtle cues and personal judgments involved in personal interactions.

What are the strengths of people with autism?

Abilities vary from one individual to the next, but generally people with autism share these strengths:

- excellent memory, especially for detail.
- ability to follow routines.
- appreciation for precision and accuracy.
- strong visual skills.
- ability to make associations quickly.

What is the learning style of children with autism — how do they learn best?

Most students with autism are strong visual learners. This means they understand information they can see much better than information they hear. "I think in pictures," says Temple Grandin, a woman with autism who has written several books. She explains, "pictures are my first language and words are my second language." The thinking and organizational problems common to autism ([see characteristics](#)) also affect the way students with autism learn.

Most school programs are language-based and need to be modified for students with autism. There are a variety of educational approaches. Helping students understand their environment through concrete learning is one of the most useful strategies for students at all levels of autism. Adaptations that make the classroom and schoolwork less confusing should be part of every child's school program, regardless of the educational approach used. These and other teaching strategies help most children with autism to:

- better understand cause and effect relationships.
- focus on relevant details.
- understand where to begin and what's next.

- understand concepts such as time.
- manage compulsiveness and minimize distractions.

How is autism diagnosed?

Currently there are no medical tests or physical “markers” that indicate a child has autism. Instead, professionals observe the behavior of the child and study his/her developmental history to identify characteristics typical of autism. Doctors and other professionals often use the criteria listed in the American Psychiatric Association's Diagnostic and Statistical Manual (called the DSM-IV) to determine if a child has autism. There are other standard checklists used to diagnose autism, especially in very young children.

As parents, you play a critical role in the diagnostic process because you have the most comprehensive information about your child’s development and behavior.

Obtaining a diagnosis can be difficult because many doctors and other professionals are not familiar with autism. In Oregon, doctors at the Child Development and Rehabilitation Center have expertise in diagnosing autism. ([see Medical Evaluation and Support](#))

What is a medical diagnosis verses educational eligibility for autism?

A medical diagnosis is often based on standard psychiatric criteria for identifying disorders. It does not necessarily make your child eligible for special education, even though medical information can be used in the educational evaluation process. A medical diagnosis is necessary for SSI support ([see DHS services](#)) and may help your family access health insurance benefits for speech and other therapies. However, *some insurance providers routinely deny or greatly limit benefits for treatment relating to autism and other developmental disabilities.*

The educational definition of autism is broader and focuses more on learning abilities and impairments. It is used solely to determine eligibility for special education services under federal and state law. Educators assign the term “autism” to any child who meets the educational criteria for autism spectrum disorder even if the medical diagnosis uses a different label such as “Asperger’s syndrome” or “Pervasive Developmental Disorder.”

What causes autism?

No single cause for autism has been identified. Research suggests that several factors may be involved, such as viral infections during pregnancy, metabolic disorders, birth complications and genetic factors. Experts know that autism is a brain disorder, but they don't know exactly how and why the brain does not work properly in an individual with autism. There are no medical tests that show the cause of autism.

Autism is not caused by bad parenting. Until autism was identified as a neurological disorder in the 1960's, many professionals blamed parents for their children's difficulties.

Is there a cure?

No. Some individuals have made remarkable gains in language and social development and can function relatively well in society but they still have autism. Behaviors may fade or change as the child grows and treatments may relieve specific symptoms but the brain dysfunction does not ever go away.

Because experts know so little about what causes autism, even less is known about possible cures. However, research is going on in many areas including genetics, the auto-immune system, possible drug treatments and brain function. The scientific understanding of autism is growing more rapidly than ever. Current information on research efforts is usually available from the Autism Society of America ([see Resources](#)).

Autism is treatable. With careful instruction and support, most people with autism can learn to function at home and in the community. Many lead happy and fulfilling lives.

What can help a person with autism?

Most people with autism benefit from:

- a consistent and predictable environment. They need concrete ways to make sense of the world — to understand what happens where and when.
- an individualized learning program that is tailored to their unique learning style and builds on their strengths and interests.
- early identification and intervention.

How can I best help my child?

One of the most important things parents can do is to become the experts on autism in their child. Learn everything you can about the disability and how it affects your child. Learn to see the world from your child's point of view and help others understand also. Remember, you know your child best and you are your child's best advocate.

Remember, too, that your child is more than a cluster of characteristics. He or she is a child first, a child with autism second. Like all children, your child with autism needs love, acceptance and understanding. Enjoy this unique person.

What can I do today to help my child?

Focus on safety problems first. Are you worried that your child will wander out the front door? put his hand on a hot stove? injure the baby? Put extra childproofing and prevention plans in place around your home to address safety issues such as these.

Then think of simple, concrete ways that you can give your child predictability. Most children with autism are confused about what happens where...what they are supposed to be doing...and what happens next ([see characteristics](#)).

You can help by making the places and activities in your home as clear and organized as possible. For example, establish a bedtime routine that you follow every night. Make a spot at the table that's just for your child at mealtime. Show your child a picture of Grandma before she arrives for a visit. Hand your child a favorite tub toy when you tell her that it's bathtime. In other words, make your expectations as obvious as you can so your child's world makes more sense to him.

It's natural to feel urgent about helping your child, especially when you first get the diagnosis. Parents who have been at this a long time will tell you that one of the best things you can do is take one step at a time. You can't learn everything all at once and neither can your child.

And don't forget — help is available. See "[Resources](#)" for how to get started.

What is the best treatment or therapy for my child?

Even though there is no cure for autism, there are drugs, therapies, diets and other treatments that may help some children. (See "[Recommended Reading](#)" for some books that review treatment options.)

Autism looks so different in each child that no one treatment for its symptoms works with everyone. For example, the drug that helps one child to sleep better may agitate another; the nutritional supplement that helps to calm one child may have no effect whatsoever for another. You are the expert on your child and will know best what works and what doesn't.

While treatments may help with some of the accompanying problems of autism, the approach that stands the test of time is individualized instruction.

What about language — will my child talk?

Your child may or may not develop verbal language — most experts would agree that it is very hard, if not impossible, to predict.

In any case, it is critical to encourage your child's overall communication and help him/her learn to communicate more effectively. Remember, communication is more than speech — gestures, sign language or picture boards are some of the non-verbal ways people can still "talk." Also, communication is a two-way process. *Receptive* communication, or what a child understands, is as important as *expressive* communication, or what a child "says." A complete program should focus on both.

There are a variety of approaches for improving communication in children with autism. Some parents choose clinical language therapy that involves intensive one-on-one instruction to encourage speech. Others opt for speech/communication therapy in natural settings with an emphasis on functional, spontaneous communication that may include tools such as picture boards. Carefully choose a program that matches your child's needs, skills and strengths.

What can be done about problem behaviors?

Dealing with problem behavior is one of the thorniest challenges in parenting a child with autism. Because autism can range from mild to severe, problem behaviors also run the full spectrum. For a child with mild autism, behavior difficulties may be primarily social such as repetitive questions or inappropriate laughing. For children more severely affected with autism, problem behaviors may include screaming, biting or even self-injury.

Many parents find that traditional child-rearing methods don't work very well for the problem behaviors unique to their children with autism. It often helps to try these ideas:

- Observe your child to see how the behavior may relate to the environment or what your child may be trying to communicate or understand.
- Many parents discover that the problem behavior is directly related to their child's autism. It is important to think about the characteristics of autism, including difficulties in the areas of communication, social understanding and sensory

processing ([see characteristics list](#)). These characteristics may contribute to problem behavior. **Here are some examples:**

A child who pushes other children while standing in line may not know an appropriate way to communicate a need for more personal space or how to ask for help. He may have a poor understanding of social relationships. He may not know how or where to stand in line, or understand the "rules" for sharing space with other people. He may be overwhelmed by the sensations of other people in close proximity because of sensory processing problems. His reaction may be a protective one — he pushes to ease his distress and confusion.

A child who has a toileting problem may not make the connections among the many steps in the toileting process or understand the order of the steps. She may not correctly process or understand the signals from her body. She may be distressed or overwhelmed by sensory issues such as the feel of the toilet seat or the echo in the bathroom. She may not know how to communicate a need to use the toilet.

- Identifying the underlying cause of the problem behavior can often suggest possible solutions. A behavior that comes mainly out of communication difficulties, for example, may be reduced if information is made more clear to the child and he is taught alternative, appropriate ways to communicate. Problem-solving a sensory issue, such as lowering the volume of the phone or removing scratchy labels from clothing, can go a long way toward reducing behavior problems related to those sensations.

Sometimes it is important and necessary to develop a specific support plan to address difficult behavior. Support plans usually describe when, where and why the behavior might be happening and list some positive strategies for intervening. Strategies might include social skills training, new communication tools, or step-by-step procedures for preventing and responding to aggressive behavior. These support plans help everyone involved to deal consistently with the behavior and that consistency, in turn, helps the child.

A good resource for behavior challenges is Oregon Intervention System (OIS) training that is used throughout Oregon's developmental disabilities system. It teaches parents and other caregivers ways to determine what the child is trying to communicate through challenging behavior. It's a person-centered approach that emphasizes the rights and dignity of the individual with the disability. OIS also teaches pro-active strategies to prevent crisis behavior, positive ways to respond and non-aversive strategies for keeping safe during crisis episodes. Talk to your county developmental disabilities case manager or call OTAC ([see Resources](#)) for more information about OIS.

Family issues and support

How does autism affect family life?

Every family will respond to the challenge of autism in its own way. Most parents agree that caring for a child with autism requires tremendous energy, patience, resourcefulness and flexibility. Often, adaptations are necessary. A sense of humor is a must.

Ordinary parenthood is demanding enough, but when a child has social, communication and behavior problems, getting through a typical day can be exhausting and frustrating. Many families face huge challenges caring for a child with autism:

- The continual support and supervision most children with autism need takes time and energy away from other family members and needs.
- The daily activities of home life — from breakfast to bedtime — can be enormously complicated and disrupted by the needs of the child with autism. The intricate supports the child may require can transform even a simple meal into a highly stressful activity.
- Community outings, holidays, social events and even a trip to the grocery store often must be carefully orchestrated to minimize anxiety and confusion for the child with autism. As a result, families are often isolated and limited by their child's autism.
- Even when the child with autism lives outside the family home, the emotional, physical and financial toll on parents can run very high.

Your family life will be different. It may be difficult. But it can still be good — even fun at times. Along the way, you will meet others who can support and encourage you over the rough spots.

What about my other children?

Autism disrupts the typical relationship between siblings. It may be especially difficult for your other children to understand why the child with autism gets so much of your attention. They may feel rejected or embarrassed by their sibling's communication and social difficulties. Some young siblings worry that they will “catch” autism and others wonder if they'll be responsible for their brother or sister's care.

Families report that it helps if each child feels special in the family and has a way to get his/her basic needs met. It also helps to explain autism to siblings in terms they are likely to understand. Several books have been written specifically for children to help them understand autism — ask other parents and families to recommend their favorites.

How can I cope with my child's autism and my painful feelings?

It may be very painful to learn that your child has autism. Certainly, it is normal to have powerful feelings about it. You may have heart-wrenching feelings of sadness, anger, fear, grief or other equally strong emotions. Most parents who have been down this road will tell you that it takes time to adjust and heal, but eventually you will feel better.

Meanwhile, most veterans of this experience would advise you to rely on the resources that usually help you with life's difficult experiences — counseling, faith, friends, etc. Many parents find comfort in talking to other parents of children with autism, especially those who are several years ahead in the process.

What can help families coping with autism?

Although each family is different, the supports many families need include:

- information and knowledge about autism. It helps to understand the disability.
- skilled respite care. Even the most dedicated parents need a break.
- practical, expert help to organize daily living for the child with autism and teach self-care skills in the home.
- effective strategies for dealing with difficult behaviors.
- help in finding and accessing services and resources in the community.
- support and understanding from family, friends, and neighbors.
- contacts and friendships with other families who have children with autism.

What about the future — what will my child be like as an adult?

It's very hard to predict. Having opportunities to learn can help to prepare your child for a meaningful and productive adult life. Like everyone else, people with autism learn and grow throughout their lives. Their skills, interests and strengths may change — and even improve significantly — but they will not outgrow autism.

Most adults with autism need support and guidance at some level in their daily life. Some can live alone with minimal support; most are in supervised living arrangements.

Legal guardianship is an alternative that many parents pursue when their child is not capable of making decisions about matters such as money management and health care. Only a court can grant guardianship. It can be limited to certain areas of decision-making or it can be a full guardianship. Your county developmental disabilities case manager or an advocacy organization such as The Arc's Guardianship, Advocacy & Planning Services Program ([see ARC](#)) can help you understand the guardianship process and requirements.

A good tool for developing a plan for the future is "Person Centered Planning." This process focuses on the particular needs and desires of the person with the disability. These needs and desires shape the plan of action for living, working, leisure and other aspects of adult life. It is a collaborative effort among the person with the disability and the family, school staff and service system people. A good time to begin this process is when your child starts the transition years in high school.

Can a person with autism have a job?

Definitely! Meaningful work is clearly a goal you and your child can strive for and expect. Like anyone else, people with autism do best in jobs that build on their strengths, skills and interests. In fact, it is critical that the work be individually suited to the person with autism.

The particular difficulties and abilities your child has will determine to a large extent what kinds of work will be suitable. The skills your child learns in school will also make a difference. And, as with any job seeker, a lot will depend on the job market and what's happening with the businesses and organizations in your community.

Most individuals with autism need specific job training and on-going support. More and more people with autism are employed in the community. In some cases, families working closely with a case manager from the County Developmental Disabilities Program and their child's high school transition team have developed these jobs.

When your child turns 16, the law requires the school district to develop an action plan that will prepare your child for the transition from high school graduation to community living and work. The school district must provide this transition program from the age of 16 until your child leaves school.

Students with disabilities and an Individualized Education Plan have the right to stay in school through the academic year that they turn 21. During the years from age 18 to 21, your child may receive some services for adults from the County Developmental Disabilities Program, or Brokerage. But the school district has primary responsibility for providing school services that lead to employment, independent living and community inclusion. This means that job training activities, including transportation, that are needed during the school day (and an extended school year if needed and in the student's plan) are the responsibility of the school district.

Adult resources available through the County or Brokerage will be used for supports that relate to home, not school. These resources may be used to work on community-related goals during hours or times that school services are not available (evenings, weekends, vacations).

It's never too early to begin planning for your child's future. In school, children are expected to be exposed to possible work or career options. Students also learn basic work concepts as well as the skills they will need for jobs when they have finished their

formal education. Because children with autism sometimes need help learning these concepts, good work behaviors should be part of their educational plan. It also is important for them to see others with disabilities working and learning good work behaviors.

How does the Department of Human Services support the families?

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. ([see Services](#))

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. (See page 15.)

- 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.

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.

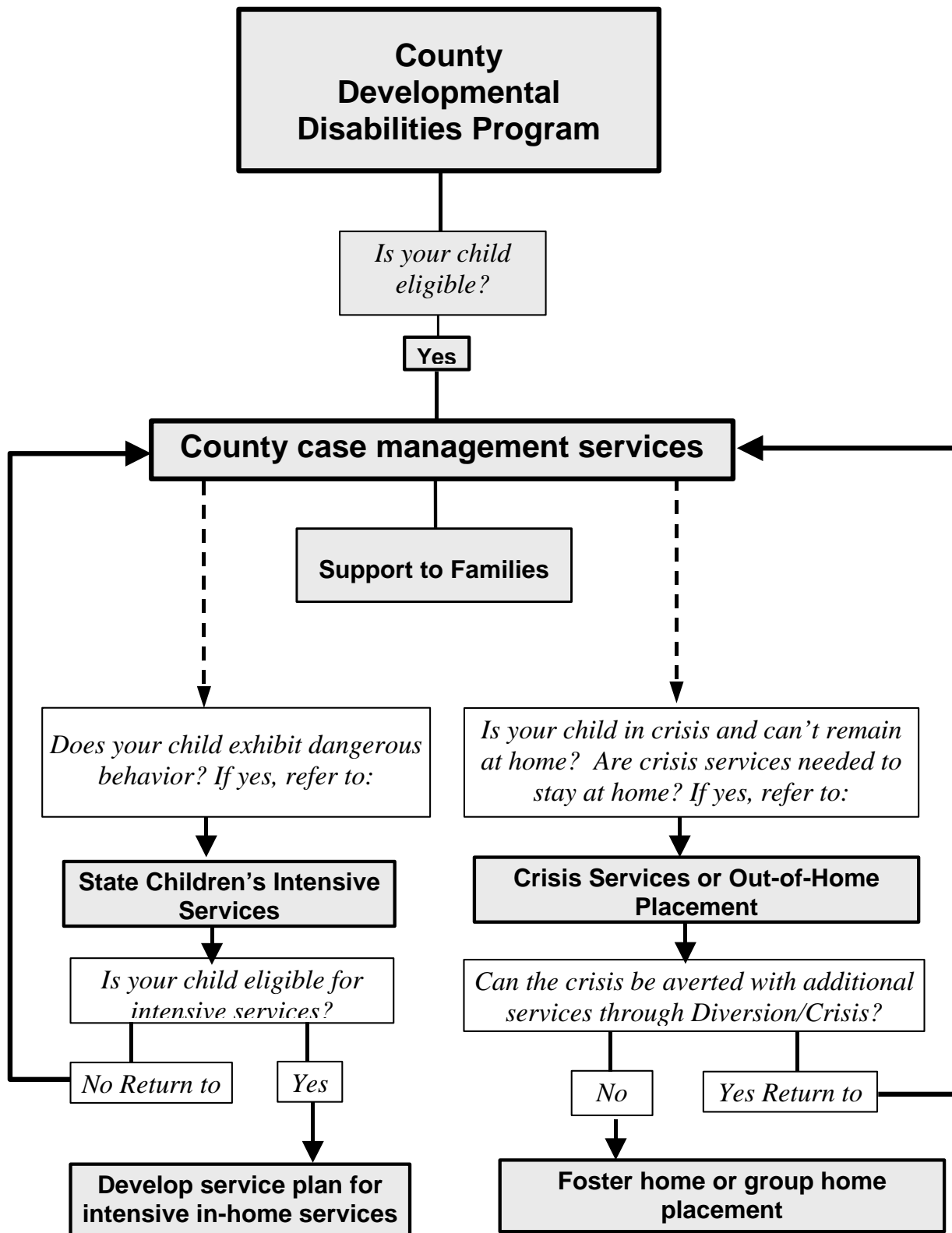
A legal agreement with the State is required. It is called the Developmental Disabilities Child Placement Agreement. Also, a plan will be written to include ways that families can remain involved with their children during placement. Families are required to authorize the Oregon Program for Seniors and 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.

Services Map

Children Under 18 years old with Disabilities and Their Families



What types of services are available for adult children 18 years and older?

Please note: If your child is 18 and enrolled in school, the school district is required to provide a transition program until your child turns 21. This program must be designed to prepare students with skills needed to transition successfully from high school to work and community living. Although county developmental disabilities case managers may work with school personnel to develop the transition plan, the school district must pay for and provide the program. Remember, educational services are provided by the Department of Education and your local school district, NOT the Human Services Department. ([see “Can a Person with Autism Have a Job?”](#) .)

Services provided by the Department of Human Services:

Support Services for Adults with Developmental Disabilities

This program focuses on adults with developmental disabilities living at home (on their own, with family members or with friends). It offers basic supports such 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 the community. County developmental disabilities case managers will refer eligible people to organizations called “Support Service Brokerages” where specialists will help your son or daughter put together a plan.

If the available supports are not working and your adult child is in crisis, talk with your Support Service Brokerage specialists or your County Developmental Disabilities Program about the availability of crisis services.

“Comprehensive” Services for Adults with Developmental Disabilities

Under certain and limited circumstances, an adult may access “comprehensive” 24-hour services such as foster homes and group homes. This may also include in-home services for persons needing 24-hour types of supports. The conditions under which someone may enter these types of services are limited. Your county developmental disabilities case manager can talk with you about the availability of these services.

Supplemental Security Income (SSI)

SSI is a federal program that provides income and medical insurance through Medicaid to eligible adults with disabilities or chronic illness. When your adult child turns 18 years old, only his or her income (not your family’s income) will be considered to determine eligibility. 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.

What can I do to be a good advocate for my child?

- **Tell it like it is.** Give an honest, complete description of the difficulties that your child and family face. Don't hide or gloss over your child's problem behaviors, no matter how hard it may be to talk about them. It's natural to want to present your child in the best possible light — just don't do that when you are requesting services. Remember, you need help for the tough times, not the good times. Describe them.
- **Know your priorities.** Even though most programs and case managers are deeply committed to helping families, the reality is that resources are limited. All of your needs cannot be met. So choose the most important ones first, such as safety issues. It also helps to begin with some practical skills you can learn to make daily life easier for your child. If you aren't sure what you need most, ask for help to figure that out.
- **Focus on the needs your child has at home, not at school.** What will help with weekends, nights, and the hours before and after school? That's what the family support services are for — the “activities of daily living” such as eating, dressing, chores, hygiene and leisure. Even though school is a big part of your child's day and can profoundly affect home life, family support services cannot replace or fix a school program.
- **Keep the focus on your child and your family.** After all, these service programs are dedicated to being family-centered and family-friendly. So begin where you are, not where the program is. Ask for what you truly need even if it isn't listed on the forms. Make sure the help you get is actually helpful and passes the Real Life test.
- **Approach the service system as a partner.** Remember, you are doing the lion's share of the work caring for your child. You need help, but that doesn't mean you are helpless. You bring a lot to the bargaining table. List the hours, money and work you already contribute to your child's special needs. Explain how the help you are requesting fits into the total effort to support your child. Show that your family is a good investment.
- **Be a good steward of any public funds you receive.** Take time to understand the rules and stick to them. Follow the reporting procedures. Be prepared to account for each taxpayer dollar you receive for your child's care.
- **Help others understand who your child is** and how autism affects his daily life. If you're not sure, ask for help to learn more about your child's autism.
- **Plan ahead.** Don't wait until your child's 18th birthday to look into adult services, for example. Start early. Research the services available. Find out the eligibility requirements. Develop relationships with the people at your county office. Remember, it takes time to put things together.

Resources

Where do I start to find help?

One of your first phone calls should be to the Developmental Disabilities Program in your local county. This program is usually located in the Mental Health Department of your county offices. Look in the blue pages in your phone book for the number. Your local Developmental Disabilities Program can provide information and referral. Developmental disabilities case managers can talk with you to see if your child is eligible for services, help you figure out what kind of help your child and family needs and work with you to develop a service plan. ([see DHS supports](#))

For families with young children, the local education system is another place to begin. If your child is school age, call your local school district office. If your child is an infant or toddler, call the Oregon Department of Education, Office of Student Learning and Partnerships (503-378-3600 Ext. 2326) and ask for the referral and evaluation agency in your county for Early Intervention and Early Childhood Special Education.

It is important to understand what “case manager” means. There are case managers in both the Oregon Department of Education special education system and in the County Developmental Disabilities Programs. Although both go by the title “case manager,” they are not the same. For example, a school case manager will not be able to help you with services you may need at home from the county family support program. For that you will need to talk to your county developmental disabilities case manager.

Recommended Reading

Understanding the Nature of Autism: A Guide to the Autism Spectrum Disorders, Second Edition by Janice E. Janzen. Therapy Skill Builders, 2002. *Written by an Oregon educator with 25 years experience in autism. It looks like a textbook but, it has lots of useful information for parents and caregivers, including a good explanation of the unique learning style common to people with autism and practical suggestions for common problems.*

Autism: Facts and Strategies for Parents by Jan Janzen. Therapy Skill Builders, 1999. *Written by an Oregon educator with 25 years experience in autism, this is a helpful, positive book.*

Helping Children With Autism Learn: A Guide to Treatment Approaches for Parents and Professionals, by Bryna Siegel, Univ. of California, 2003. *A developmental psychologist with 25 years experience in autism explains the strengths and weaknesses of autism and reviews various treatment options.*

Autism — Understanding the Disorder by Gary B. Mesibov, Lynn W. Adams and Laura G. Klinger. New York: Plenum Press 1998. *This book includes a clear historical perspective on autism and discusses the various approaches to helping people with autism.*

Thinking in Pictures by Temple Grandin. New York: Doubleday 1996.

([web site:www.autism.org/temple/](http://www.autism.org/temple/)) *This is a fascinating personal description of what it's like to have autism. Dr. Grandin writes about her work in animal science, so it can be disconcerting to read about autism and slaughterhouses in the same chapter but it's worth it for the glimpse into the world of a person with autism.*

Exiting Nirvana: A Daughter's Life with Autism by Clara Claiborne Park. Little, Brown, 2001. *In this book, a mother reflects on her adult daughter's successes and challenges. It includes fascinating examples of literal thinking and other common autism characteristics.*

Parent Survival Manual: A Guide to Crisis Resolution in Autism and Related Developmental Disorders, edited by Eric Schopler. New York: Plenum Press, 1995. *Using examples and ideas from parents, this book explores common behavior problems in autism and discusses underlying issues and practical solutions.*

Asperger's Syndrome: A Guide for Parents and Professionals, by Tony Atwood. 1998.
A good book for understanding the unique challenges and abilities of people with Asperger's.

The North Carolina chapter of the Autism Society of America operates the largest autism-specific bookstore and mail-order house in the country, offering over 500 titles, both classic and contemporary. Ask for a free catalog or visit the web site:

Autism Society of North Carolina Book Orders
505 Oberlin Road Suite 230
Raleigh, NC 27605-1345
(919) 743-0204
Fax (919) 743-0208
www.autismsociety-nc.org

Resource Guide

General Information

Oregon Council on Developmental Disabilities

This is Oregon's federally-funded organization that advocates for Oregonians with developmental disabilities and their families. Members are appointed by the Governor and oversee projects such as Partners in Policy-making, which help people with developmental disabilities and their families to become involved in the public policy-making process. The Oregon Council on Developmental Disabilities publishes *The Clarion*, a quarterly newspaper. Call for a free subscription.

Oregon Council on Developmental Disabilities
540 - 24th Place NE
Salem, OR 97301-4517
(503) 945-9941 or 1-800-292-4154
fax 1-503-945-9947
<http://www.ocdd.org/>
email: <mailto:ocdd@ocdd.org>

The Autism Society of America

Created by parents over 30 years ago, the Autism Society of America is a national organization that works to provide information and promote public awareness about autism. Activities include an information and referral service, a national newsletter (*The Advocate*, published six times a year), an annual national conference and advocacy work. There is a membership fee that can be coordinated with the Oregon chapter.

Autism Society of America
7910 Woodmont Avenue, Suite 300
Bethesda, MD 20814-3067
(301) 657-0881 or 1-800-328-8476
<http://www.autism-society.org/>

The Autism Society of Oregon

The ASO is a state chapter of the Autism Society of America. There is a small membership fee. The ASO sponsors an annual symposium and provides information through a statewide information and resource network. A calendar of local autism events

is listed on the ASO's web site which includes links to other Oregon web sites on autism. **The net**, ASO's quarterly newsletter has lots of information for Oregon families.

Autism Society of Oregon
PO Box 396
Marylhurst, OR 970036-0396
(503) 636-1676 or 1-888-Autism-1 (toll free)
email: <mailto:info@autismoregon.com>
www.autismoregon.com/

The Arc of Oregon

The Arc is a private, non-profit agency that advocates for people with mental retardation or other developmental disabilities, including autism. It is affiliated with The Arc of the US which was created by parents over 40 years ago. Some of the local chapters of The Arc provide training, respite information and other assistance to families.

The Arc of Oregon
1745 State Street
Salem, OR 97301
(503) 581-2726
toll free: 1-877-581-2726
fax (503) 363-7168
<http://www.arcoregon.org/>

The Autism National Committee (AUTCOM)

AUTCOM advocates for community living through respectful treatment and support of individuals with autism and related disabilities. It was founded in 1990 to advance and protect the human rights and civil rights of people with autism, PDD and related disabilities. AUTCOM publishes a newsletter for members (there is a small fee), sponsors an annual conference and provides information and referral.

AUTCOM
PO Box 6175
North Plymouth, MA 02363-6175
<http://www.autcom.org/>

Medical Evaluation and Support

Child Development and Rehabilitation Center (CDRC)

Housed in the Oregon Health Sciences University, the Child Development and Rehabilitation Center is a statewide public services agency serving individuals with disabilities and their families. Services include identification and diagnosis, treatment, counseling and therapy. Clinic visits are billed based upon the patient's medical diagnosis and the family's resources and residency. There is a CDRC clinic in Eugene also.

Child Development and Rehabilitation Center
Oregon Health Sciences University
707 SW Gaines Road
PO Box 574
Portland, OR 97207-0574
(503) 494-8095 or 1-800-452-3563
<http://www.ohsu.edu/cdrc/>
email: <mailto:cdrcinfo@ohsu.edu>

Child Development and Rehabilitation Center — Eugene
Regional Services Center,
Clinical Services Building
901 E. 18th
Eugene, OR 97403
(541) 346-3575 or 1-800-637-0700

Northwest Autism Foundation

Founded in 1997, this organization provides information and education to families, caregivers and professionals, including health care workers. NWAFF has sponsored lectures and workshops on health care for people with autism and related topics. Ask for a copy of NWAFF's resource directory.

Northwest Autism Foundation
Willamette Falls Hospital Health Education Center
519 15th Street
Oregon City, OR 97045
(503) 557-2111
<http://www.autismnwaf.org/>

Family Support

State and Local Developmental Disability Services

In addition to the state office in Salem, there are local offices for Developmental Disability Services (DDS) throughout Oregon, usually located in each county's Mental Health Department. ([see DHS supports](#)).

State of Oregon — Department of Human Services
Seniors and People with Disabilities
500 Summer Street NE
Salem, OR 97301
(503) 945-9774
TTD: (503) 945-9836
<http://www.oregon.gov/DHS/index.shtml>

Check the blue pages in your phone book for the Mental Health and Developmental Disabilities office in your county. This is where you should begin your request for information and help.

The Arcs

Local chapters of The Arc may provide respite information and referral for families. Check the white pages in the phone book for The Arc in your community or call state office in Salem at (503) 581-2726.

Lifespan Respite Care Networks

Oregon counties have information/referral and training services for caregivers needing respite. The program is open to people of all ages and in all types of caregiving situations, including disability-related care. The Lifespan Respite program can help families find and train respite providers but it doesn't pay for the actual respite care.

Oregon Lifespan Respite Care Program
500 Summer Street NE, #E-10
Salem, OR 97301-1076
(503) 945-6401
<http://www.oregon.gov/DHS/index.shtml> (search for "Lifespan Respite".)

To find out about Lifespan Respite in your county, call the number listed above or visit the web site.

Education

Oregon Department of Education

Office of Student Learning and Partnerships

Public Service Building

255 Capitol Street NE

Salem, OR 97310-0203

(503) 378-3600

TDD: (503) 378-2892

fax: (503) 378-5156

<http://www.ode.state.or.us/>

Jay Gense, Director of Low Incidence Programs (503) 378-3600

(Autism is part of this program.)

Oregon Advocacy Center

The Oregon Advocacy Center (OAC) is a resource for legal information. It is a private, non-profit agency designated under federal law as the “Protection and Advocacy” system for Oregonians with disabilities. OAC services include information, consultation, and legal representation about rights in schools, institutions and the community. OAC’s “Special Education Guide” for parents is available free of charge, in both English and Spanish.

Oregon Advocacy Center

620 SW Fifth Avenue, 5th Floor

Portland, OR 97204-1428

1-800 452-1694 or (503) 243-2081

TTY: (800) 556-5351 or (503) 323-9161

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

Oregon Parent Training and Information Center (PTI)

PTI is a parent-to-parent organization that offers training and support to help parents of children with disabilities to be more effective in working with schools. It is funded by a grant from the US. Department of Education.

PTI

2295 Liberty Street NE

Salem, OR 97303

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

Training and Technical Assistance

Oregon Technical Assistance Corporation (OTAC)

Through grants from state agencies and other organizations, OTAC provides training and technical assistance throughout Oregon to organizations and individuals working with people who have developmental disabilities. Current OTAC projects include person-centered planning, essential lifestyle planning, supported employment, positive behavioral support strategies, crisis and community supports and the Oregon Intervention System.

OTAC emphasizes proactive strategies that help people with autism to understand their environment and become more independent in daily life. Autism trainings focus on visual structure and positive behavior supports. Workshops are available specifically for families and support providers.

OTAC
3886 Beverly Avenue NE
Building I, Suite 21
Salem, OR 97305
(503) 364-9943, ext. 16
<http://www.otac.org/>

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Autism

An Introduction for Parents And Guide to Oregon's Human Service System



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