Strive for Your Child's Development

A book for parents of children with disabilities and the first steps to help

Dear Parents: Welcome to this booklet that will help you understand how to help your child if they have a disability or a delay in their development.

Some children in our community have what we call a "disability." Disability is when our children have a condition in their body or mind that makes it difficult for them to do regular activities and interact with the world around them. Having a disability is ok and a family should not feel shame. If your child has a disability or needs more time to develop than other children, please know this is natural.

All our children in the community deserve to get the care and support they need to be successful and healthy. It is important to:

- understand the signs of a disability
- help make goals for our child
- become informed and find support in the community
- educate the community about your child and how to interact with people with disabilities respectfully.

There are many resources in our community for families to learn about their child's health and wellness. The information in this book is meant to help you understand some of the places you can go to get help, who can help you, and about how to talk about your child's disability.

We believe it is important that every child reach their full potential and families are heard, seen, and feel understood, while understanding their child's development. When you feel overwhelmed, remember that the love, guidance, and nurturing you give the child now will help them follow their dreams and reach their goals.

We hope this book helps make that journey easier to support your child. In this book, we talk about how to get support from your doctor and your school and share some community resources that can also help you. We hope you enjoy it!

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The All:Ready Network
Disability Inclusion Project

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"Hi, our names are Antonio and Grace. We both have disabilities. We are excited to take you through our journey of getting help from different people in our community, as we get support for our health and wellness.

We thought we would help you understand different disabilities! Here are some disabilities we learned about."

Hi! I'm Grace. My disability is something called Autism. I have big feelings and pay a lot of attention to details. Lots of noises and loud sounds can be hard for me, so sometimes I wear noise-cancelling headphones. If someone starts talking to me with all the loud noises, it can be hard for me to concentrate. Turning down noises so I can focus is very helpful for me. I also have different ways of learning and moving. At school I have a paraprofessional and teachers, who takes care of me and get special education services and supports.

Our friend Kayse has attention deficit hyperactive disorder (ADHD). It is hard for him to pay attention, sometimes he does stuff without thinking what the result might mean. He can be very active and it can sometimes be hard to calm him down. He has lots of big feelings too! He has people in the health world to help him learn to calm down and focus, especially in settings like school and in the community!"

WHAT IS DISABILITY?

A disability is any **condition of the body or mind** that makes it more difficult for the person to do regular activities interact with the world around them.

Disability can affect:

- Vision
- Movement
- Thinking
- Remembering
- Learning
- Communicating
- Hearing
- Mental health
- Social relationships

Although "people with disabilities" sometimes refers to a specific disability, this is actually a diverse group of people with a wide range of needs and strengths. Two people with the same type of disability can be affected in very different ways. Some disabilities may be hidden or not easy to see, sometimes called an "invisible disability."

Hi, how's it going? I'm Antonio. My disability is something we call cerebral palsy which means my brain has a hard time helping my muscles move. It is hard for me to move and keep balance and posture, so I use a wheelchair to get around.

My name is Jin and I am visually impaired and have vision loss. It can be caused by damage to the eye itself, by the eye being shaped incorrectly, or even by a problem in the brain. I use a cane and a guide dog to get around. The school helped me to learn Braille, a language that helps me read with my hands by feeling things on a paper. I have something called a screen reader that helps me understand things on my phone or computer. I have someone who organized our house to make it easy for me to get around and find things.

We have another friend, Ahmed, who has trouble hearing. Hearing loss can happen when any part of the ear is not working in the usual way. It can affect a child's ability to develop speech, language, and social skills. But he gets to learn a special language called American Sign Language and can read and move just like you and me!

We have more friends with disabilities that are a part of our community, and some are even our parents! We believe it is important that every child reaches their full potential and families are heard, seen and feel understood, while understanding their child's development. When you feel overwhelmed, remember that the love, guidance, and nurturing you give the child now will help them follow their dreams and reach their goals.

BEING RESPECTFUL

It's so important that we all talk about each other in a way that is kind and makes us feel included!

We want everyone to feel respect so when we talk about people who have disabilities, we don't want to call them "sick" or "broken" because they are not. Some children may have behaviors that may seem disrespectful in a culture such as not making eye contact or focus on a family member or moving their hands and bodies quite a bit. These are part of who they are and not meant to show a lack of care or understanding. It takes time to learn about each child's unique abilities and how to talk with and about your friends' and family with disabilities. Here's some helpful tips:

- ✓ **Emphasize everyone's abilities, not their limitations.** For example, when I see my friend Antonio, I don't talk about her wheelchair all the time. I do not say she is confined or restricted. I just say she is a person who uses a wheelchair.
- ✓ **Do not use language that can be offensive.** For example, do not call someone broken, or invalid, or deformed or lame. Consider someone's strengths.

Here are some words to help!

Recommended	Not recommended
✓ Person who uses a wheelchair	x Confined or restricted to a wheelchair, wheelchair bound
✓ Person who uses a device to speak	x Can't talk, mute
✓ Person with a disability	x Disabled, handicapped
✓ Person with cerebral palsy	x Cerebral palsy victim
✓ Person with multiple sclerosis	x Afflicted by multiple sclerosis
✓ Accessible parking or bathroom	x Handicapped parking or bathroom
✓ Person with a physical disability	x Crippled, lame, deformed, invalid, spastic
✓ Person with an intellectual, cognitive, developmental disability	x Slow, simple, moronic, defective, afflicted, special person
✓ Person with an emotional or behavioral disability, a mental health impairment, or a psychiatric disability	x Insane, crazy, psycho, maniac, nuts
✓ Person without a disability	x Normal person, healthy person

SELF-DETERMINATION

When I first learned that I had a disability, I worried and so did my parents. I wondered if I would be able to go to school, get a job and more. As I started to understand my disability, I realized that all people with a disability get to determine their own unique needs. I started to:

- ✓ Choose and set my own goals
- ✓ Get involved in my school decisions and think about what I wanted to do in life
- ✓ Speak up for myself and ask for what I need for help

I learned what it means to be "self-determined," which means making things happen in my own life, instead of having others do things to, or for me. People who are self-determined know what they want and how to get it. They choose and set goals, then work to reach them. They advocate on their own behalf, and are involved in solving problems and making decisions about their lives. They don't have to do everything for themselves, but instead, they make or cause things to happen in their lives that improve the quality of their lives.

WHERE DO I GET STARTED?

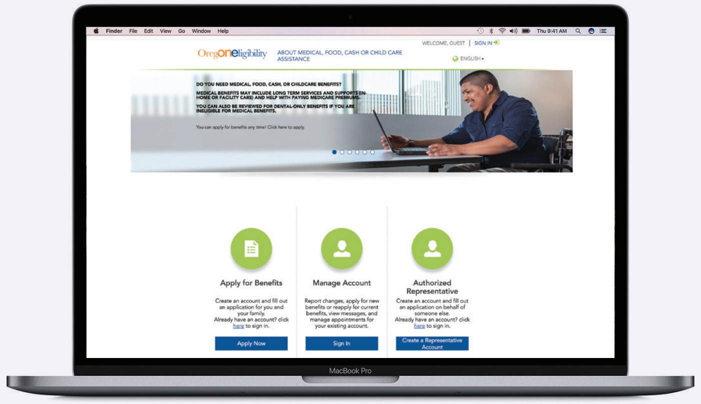
There can be quite a few things to do, and places to go to get help, so here is a checklist! We will go in detail about these in the next few pages.

- ☑ If you do not have health insurance, **you want to sign up for a health plan** so you have help paying for all the services that a child with disabilities may need.
- ☑ After you get your insurance, they will help you **find a doctor**. Make sure to ask for interpretation services when you call your doctor.
- ☑ When you go to the doctor, **bring some information** about your child to the doctor, which we call a "child profile." Bring it plus your insurance information to the visit.
- ☑ At the doctor's office, they will **check your child's health and wellness** by asking you questions about how they act or what they say.
- ☑ When your child has what we call a "diagnosis", for example that they are visually impaired, you can call your child's school and **ask about special education**. They will help make a special plan for your child at school so they can get support while they learn.
- ☑ **Call the Office of Developmental Disabilities in your county (Washington, Multnomah and Clackamas) and get a case worker** who will help you with other services you may need.
- ☑ **Talk to your friends, organizations, and mosque leaders for help.** Many community organizations are here to help.

How Do I Get Health Insurance?

There are several health care programs available for low-income Oregonians through the Oregon Health Plan (OHP).

A coordinated care organization (CCO) is a network of all types of health care providers (physical health care, addictions and mental health care and dental care providers) who work together in their local communities to serve people who receive health care coverage under the Oregon Health Plan.



How to Apply:

- To apply for OHP online, go to **ONE.Oregon.gov** and click "Apply Now." You will need to create a new ONE account if you don't already have one.
- You can also apply using the OHP application form found on this website: **https://www.oregon.gov/oha/HSD/OHP/Pages/Apply.aspx**
- You can also apply by calling this number: **1 (541) 485-2155** (open 7 a.m. to 6 p.m. Pacific Time, Monday through Friday)
- If you do not have access to the internet, you can also do a paper application by calling OHP at **(800) 699-9075**. Lastly you can download the form in multiple language options and fax it to **(503) 378-5628** or mail to OHP Customer Service, P.O. Box 14015, Salem, OR 97309-5032.

When will I find out if I am accepted for Medicaid (OHP) insurance?

- If you applied by mail, you can call ONE Customer Service at **1 (800) 699-9075**.
- If you applied online, you can view the status of your application in your dashboard at **ONE.Oregon.gov**.

What are some places I can call for help in finding a doctor or care?

In Washington, Clackamas and Multnomah County, you can contact **Trillium Community Health Plan** and **HealthShare of Oregon**. They will help in connecting you, as their member, to resources and benefits. These plans have registered nurses that can offer education and care coordination. Care coordinators can assist in both physical and behavioral health needs, and connect you to primary providers and specialists that are covered by the plan, also referred to as "in-network providers".

- Call **Health Share Customer Service (503) 416-8090**, or toll free at **1 (888) 519-3845 (TTY/TDD 711)**
- Call **Trillium Member Services at 1 (877) 600-5472 (TTY: 711)**.

Preparing for Your Doctor's Visit

It is important we share our child's age, grade level, and some of their favorite things that make them happy and foster connection. Sharing what works and doesn't work for your child is also important. We suggest writing down all this information in what we call a "profile," or a document that describes your child. Here is an example:

Child's Name and Age:

For example, "My name is Ryan and I am 8 years old."

Your child's favorite things:

I love movies, dancing and all of my pets. I love music.

Your child's Vision and Goals: *For example,*

- To be able calm down and regulate my behavior.
- Sit and read a story
- Getting ready for school without supervision and being more independent with homework or self-care

Your child's Strengths and Interests:

- Interested in health
- Dancer/athlete
- Active participant
- iPhone/desktop skills for further research
- Good vocabulary can learn new words
- Team player who wants to work towards being healthy

What supports does your child need:

- Modified content
- Sit by a family member or support person
- Extra time for answering questions
- Visual supports for routine exams and tests

My community supports, the family members and helpers that are very important to me:

- Parent(s) name, phone number and/or email

Children have so many "milestones," such as the first smile, the first laugh or the first time they hold their heads up. Parents can observe the ways their child grows. For example, can I crawl on my belly, can I stack blocks or can I say words or talk by a certain age.

Often, we work with a pediatrician, or a nurse who comes to our home or a Community Health Worker at a play space who supports us to understand around social and emotional development, communication, and fine motor schools. This "Ages and Stages Questionnaire" that we fill out together helps us map the positive of our children and understand where we may need supports.

Schedule the appointment for a day and time when the doctor's office is less crowded. This means less rush and stress for you, your child, and your child's provider. The office staff should be able to tell you the best time for your visit.

Make a list of questions you have about your child. Any concern you have is important, no matter how small it may seem! Prioritize your questions, so you can be sure to get answers to the most important questions before the visit ends. If you have asked about something more than once, reminder your provider, so that they realize that it is important.

Sample questions to ask:

- What medical emergency(s) is my child at risk of?
- What should I do and who should I call in case it happens?
- What other health care professionals should my child be seeing?
- What resources and support are available to me and my child?
- When should I schedule our next visit?
- How do I get in touch with the doctor or nurse if I have more questions?
- Is there anything important to know about my child's medications or diet?

Bring a favorite toy or book to keep your child busy and calm. Play a game or use an app with your child while you are waiting for the doctor.

Take another adult to the appointment with you. Someone who is familiar with your family can not only provide moral support but help you remember key points from the visit.

Record the visit with your cell phone or other device. As the parent or primary caregiver for your child with special needs, it may be difficult for you to remember details or instructions. You might not have time to write everything down. The recording will come in handy for not only you, but others who help care for your child.

Preparing Your Child for the Doctor's Visit

Explain what will happen at the appointment *both* verbally AND visually to your child.

- Call the doctor's office to ask what the procedure is for the type of appointment that your child is having. Ask about any equipment that will be used, like a stethoscope, blood pressure cuff, or X-ray.
- Talk through everything you learn with your child. Include activities like measuring their height, weight, and blood pressure, along with any expectations to remove shoes or change clothes.
- There are videos and images for most common exams and visits.
- Ask your child if they feel ready, or if they want to review the steps again.
- Encourage communication and problem solving.

If you know the steps of the appointment, review them in order with your child. Write down "facts" about the situation – both ones that are positive to your child, and ones that may be perceived negatively.

- Ask your child what they think the easiest part of the visit will be. Praise them for their confidence in being able to participate in those parts of the appointment.
- Ask them what they think the hardest parts of the appointment will be. Work with your child to figure out what they can do to make the hard parts easier. This may include bringing a few comfort items from home, or sitting on your lap.
- Always encourage your child to ask questions and express their feelings or concerns! These are opportunities for them to figure out what will make things better.

Plan a fun activity or reward for after the visit.

- Give your child some choices of fun activities that they can do when the visit is done – for example, going to lunch, visiting the park, or playing with a special toy.
- Include this in the steps that you review and practice.
- During the appointment, remind them that something fun is coming when they are done.

Check in with your child during the visit.

- During the visit, praise your child as they move through the steps of the visit.
- Remind them what steps they have already completed, and what steps are still to come.
- Encourage them to ask questions, request a brief break, or a coping tool. For example, some kids like the provider to count to three before drawing blood or giving a shot. Encourage your child to request this, if it's what they want.
- Tell your child you're proud of them for following directions.

The Doctor's Visit

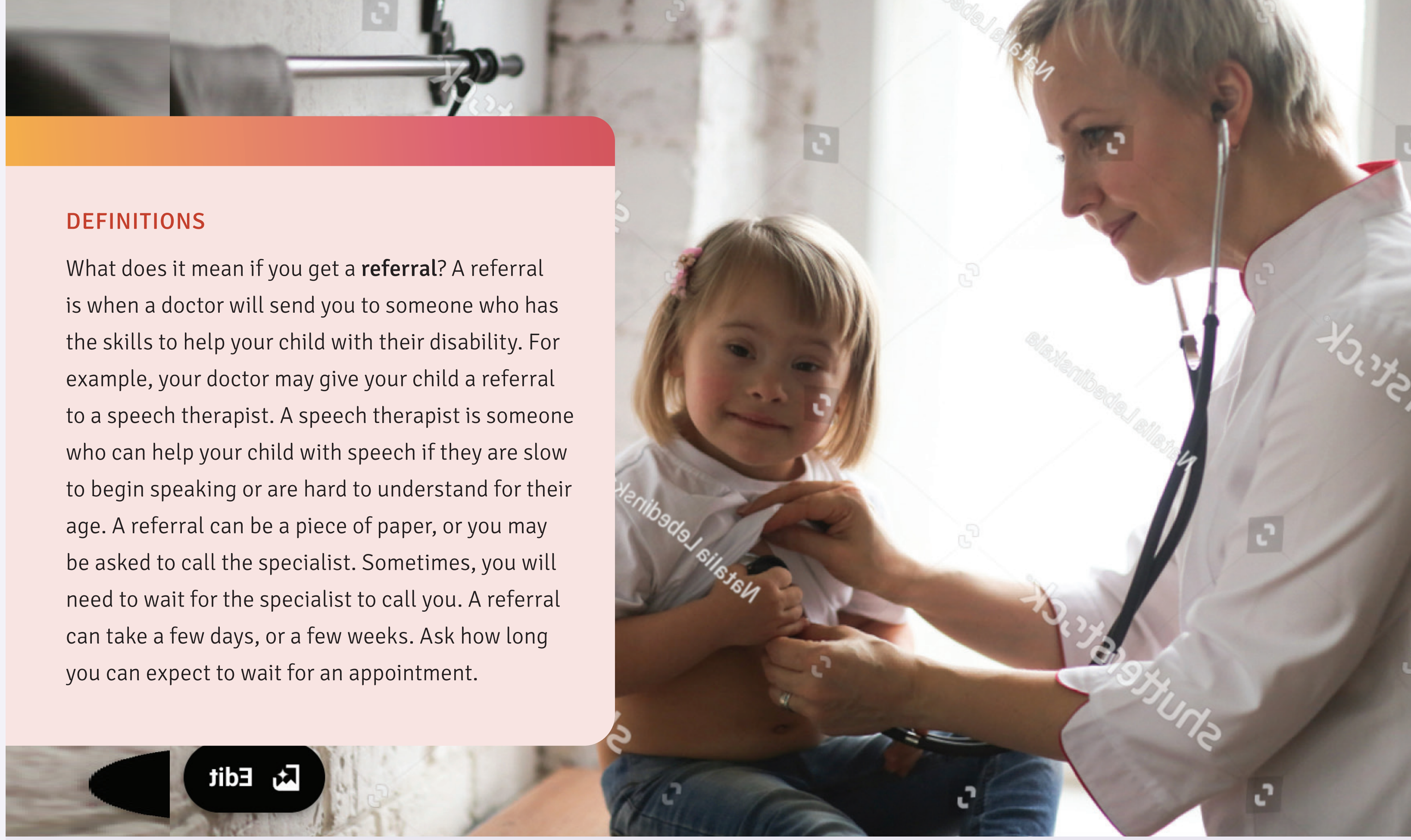
Visiting the doctor often is important for your child's health and wellness. When at your appointment, remember that all people with a disability should determine their needs, or a family should determine the needs of a child. Including:

- ✓ Choosing and setting their own goals
- ✓ Being involved in making life decisions
- ✓ Self-advocating
- ✓ Working to reach their goals

At appointments for babies and children under age 6, you will be asked to answer questions like "Does your baby notice when you are speaking to them? Does your baby have trouble seeing you?" These questions help a doctor know if your child is growing well what their strengths are. They are part of the "Ages and Stages Questionnaire." You will either be asked these questions by a provider, or be asked to answer them while you wait for your doctor.

The Ages and Stages Questionnaire:

- *Shows families and providers where there are specific strengths and skills*
- *Helps families and providers identify where they may be gaps*
- *If your child is not meeting their developmental milestone, such as being able to hold their head up or walk, the provider will refer you to someone to help out*



DEFINITIONS

What does it mean if you get a **referral**? A referral is when a doctor will send you to someone who has the skills to help your child with their disability. For example, your doctor may give your child a referral to a speech therapist. A speech therapist is someone who can help your child with speech if they are slow to begin speaking or are hard to understand for their age. A referral can be a piece of paper, or you may be asked to call the specialist. Sometimes, you will need to wait for the specialist to call you. A referral can take a few days, or a few weeks. Ask how long you can expect to wait for an appointment.

Get the Help You Need For Your Child with a Disability

If your child needs help, the doctor will send you to people called "specialists" who will help you.

1. **Ask your child's doctor to provide a referral to developmental pediatrics.** This person has special skills to help your child if they need extra help whether it's with talking, hearing, walking or more.
2. **Ask them where you can take the referral for help.** Write down the name and phone number of someone you can call.
3. **Call the number the doctor gives you** to get your child special help.

Contact these people if you need help—they can call you back with a translator:

- For children ages 0-6, **Help Me Grow 1 (833) 868-4769** or **email them at hello@helpmegroworegon.org**
- For children over age 6, **Providence Swindells Resource Center at (503) 215-2429**
- For children and youth ages 0-26 **Oregon Family to Family Health Information Center. 1 (855) 323-6744**

Your Care Team

There are all kinds of people who can help you to teach your child everything they need to live their daily lives with strength. They can help your child become independent as much as possible. Some of the names of these people are:

Your Doctor

A Primary Care Provider is the first person you will visit at a clinic to help support your child and tell you all the things you need to know about how they are growing

Care Coordinator/Nurse

helps you to manage all the referrals and specialists you get is a Care

Occupational Therapist

helps your child develop, recover, or maintain the skills needed for daily living and working. They can help your child at school or in the community.

Physical Therapist

help your child with their movement.

A Behavioral Therapist

can help your child with their feelings and emotions and teach them skills and practices to help manage big feelings.

A Speech Therapist

can help if you child has difficulties with communication, eating, drinking and swallowing.

If you need **special food or medicines** for your child, these terms are helpful:

Medical Foods

Equipment provider

Pharmacy

Make sure you right down the names and numbers of all the people you work with so you can keep track of the support network for your child.

The School Visit

While going to the doctor gives you help for your child's body and mind to learn how to be in the everyday world, the schools help your children learn to read, write, do math and more. A disability does not prevent a child from learning. They just need support. The education they receive is called "special education." After you get help at the doctor's, you will need to get help for your child at school when they start to go to school. You can call or visit the school and tell them your child has a disability. You can tell them you need special education, and they will help you create a team to help your child. Before going to the school, review the parents' rights and responsibilities handbook so that you feel confident. You are allowed to bring a support person whether that is a friend, family member or someone else from the community. Remember that there are laws that ensure you are seen and heard as the primary coordinator and advocate of your child's successful learning experience.

Recognize that you are the lead for this team meeting and that you are a partner developing the plans and methods, so it is important to bring notes or outline of your perspectives and wishes. Remember that these individual plans should begin with a statement of the strengths, talents and likes of your child to be used as the building blocks supporting their challenges in learning.

These are the names of people who will help you:

- **Principal**
- **Teacher**
- **School Nurse**
- **Special Education Coordinator**
- **Family Advocates**

Here are some places that can help you:

- **FACT Oregon** helps families understand the steps to helping a child with a disability. **(503) 786- 6082**
- **Help Me Grow** is a free and confidential family support line that provides seamless access to community services. You can call them at **1 (833) 868-4769** or email them at **hello@helpmegroworegon.org**
- The **Oregon Department of Education** can help answers about any school district. You can email them at **ode.specialeducationquestions@ode.oregon.gov** or by phone at **(503) 947-5600**. Make sure to include your child's school district to help them connect you with a staff member who can help.

TIPS FOR PARENTS

- ✓ You may have to call more than once
- ✓ The process can take a long time
- ✓ You will be assigned a services coordinator. Keep their information handy.

Developmental Disability Services

You can also get help from an office called Developmental Disability Services.

You will get a **Developmental Disabilities Case Manager** who will meet with each person to review their current situation, identify needs, and make referrals for essential services.

They do the following:

- Work and advocate for you
- Meet, assess your child's needs and help you understand and access available services and supports
- Create an Individualized Service Plan (ISP) to help your child lead a happy, healthy and fulfilling life
- Connect you with community provider agencies
- Monitor, provide resources and assist with your child's health, safety and ISP implementation.
- They will provide you with a case manager who should meet with you often to help with services
- If you need anything to help your child, they can help get it for you. For example, you might have a child who is visually impaired that might need a special computer or home or a child might need a wheelchair.

For more information call:

Multnomah County Main Office	Washington County Main Office	Clackamas County Main Office
Office Hours: Monday–Friday, 8am–5pm	**Office Hours:** Monday–Friday, 8am–5pm	**Office Hours:** Monday–Thursday, 7am–6pm
Phone: (503) 988-3658	**Phone:** (503) 846-3150	**Phone:** (503) 655-8640
After Hours Help Line: (503) 988-3646		

The American Disabilities Act

As a parent of a child with a disability, there is a law that will protect them and you called the American Disabilities Act. It is a law the federal government of the United States made to make sure people with disabilities are treated fairly. The ADA prohibits discrimination on the basis of disability just as other civil rights laws prohibit discrimination on the basis of race, color, sex, national origin, age, and religion. The ADA guarantees that people with disabilities have the same opportunities as everyone else to enjoy employment opportunities, purchase goods and services, and participate in state and local government programs.

If you feel like someone isn't treating you or your child with a disability fairly or your child is being harmed or bullied, you can call this number for help:

ADA Information Line: 1 (800) 514-0301 or **1 (833) 610-1264 (TTY)**

- Monday, Tuesday, Wednesday, Friday, 9:30am–12pm and 3–5:30pm ET
- Thursday, 2:30–5:30pm ET

Community Resources

There are many resources in the community to help you.

Providence Swindell's Family Resource Center supports parents and caregivers of children who have special health, behavioral or developmental needs. You can call them at **1 (833) 868-4769** to get connected to family resources.

Oregon Center for Children and Families with Special Healthcare Needs, Family to Family Health Information Center

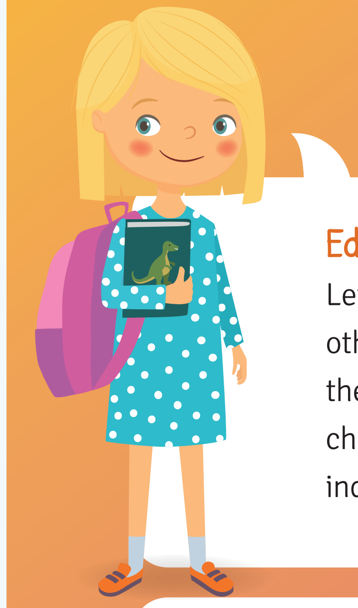
The Oregon Family to Family Health Information Center supports families and caregivers of children with special health needs when navigating complex health care systems. Staffed by parents of children and youth with a variety of health conditions, we provide free one-to-one support, training, and printed materials to families and professionals who serve them. This website houses hundreds of resources for parents, grandparents, and youth.

To speak to an OR F2F HIC Parent Partner call **(855) 323-6744**
or email **contact@oregonfamilytofamily.org**

Notes and Important Info to Remember

IN CLOSING

Hi! Wow! That was a lot of information. We hope all that information was helpful for you. It's very important that we work to support our children and our community. Here are some ways we can be supportive:



Education and Awareness: Let's educate ourselves and others about disabilities, their diversity, and the challenges faced by individuals with disabilities.

Accessible and Inclusive Spaces: Advocate for and actively support accessible spaces, ensuring that mosques, community centers, and public spaces are designed to allow full participation for all, including those with disabilities. Is a sign-language interpreter available for the mosque *khutbah* or lecture for people with hearing impairments? Are community spaces and bathrooms accessible for people who use mobility devices like wheelchairs? Do people with disabilities have an equal opportunity to participate and contribute?

Language Matters: Be mindful of the language we use when talking about disabilities. In Somali, sometimes we are not sure of what the appropriate title is for a certain disability or condition, especially in our native tongue, and we use what vocabulary is available to us. Let's be curious, mindful, and creative when attempting to label a disability. What is the name of the disability? How would the individual like to be referred to?

Supportive Networks: To locate all the resources needed for yourself or for your family, it will take collaboration and support from a team. Ask for help when you need it. Offer help when you can! Do your best to share resources and knowledge with your community.

This guide was created
for you by:

All:Ready

The All:Ready Network was formed in 2018 in the Portland Tri-County region to re-design our early childhood system of care so that race, class and ability are longer predictors of accessing early childhood resources and services that mitigate adverse health experiences. The Network brings over 60 individuals – Birthing People, Culturally Specific Organization Staff, Community Health Workers, Pediatricians, Maternal Child Health Managers and more – together in Child Success Design Projects and Community Gatherings where we create journey maps, identify gaps in service delivery models, create solutions and recommendations and improve touchpoints in the system that will help create more integrated care.

We were formed thanks to the staff at Health Share of Oregon as part of the Early Life Health portfolio and are currently housed within the Early Childhood Team at Clackamas County's Children, Families and Community Connections.

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