

# Getting Started Guide: Youth 0 - 5

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## Overview

It can feel confusing and overwhelming when you notice that your child is developing differently, perhaps more slowly, than other children. You probably have a lot of questions, and are anxious to get answers - and most importantly, to get support for your child.

Please know that many of us have traveled this path with our children and families. We have put together this guidebook to share what we have learned, and what we wish we had known along the way!

**The bottom line:** Your child is unique, incredible, and has so much to teach others. While the path might be bumpy and anything but linear, there will be joy as well.

**You are not alone:** There is support for your child and family, and you will find the right people to guide you and your child as you move forward on your journey.

## Where Do I Start?

There are three basic steps to getting support for your child:

- 1) **get evaluations**
- 2) **determine eligibility for services**
- 3) **if eligible, secure and begin services**

## Evaluations

If you or someone involved with your child aged 0 - 5 (before entering kindergarten) have concerns about your child's development, the first step is to **speak to your child's doctor about getting an evaluation of your child.**

Evaluations help to identify areas of strength and developmental delays, and provide a potential diagnosis. They can also determine what level of support your child needs, and if your child is eligible for services.

**Good to Know:** *There are two evaluation paths: **medical** and **educational**. Typically, they happen separately, which can feel frustrating. Try to be patient and proactive; each process is important to get a better understanding of your child's strengths and challenges, and to access services to support your child's development. There can also be a third evaluation path: mental health, but this is a less common process for young children.*

- *A **medical** evaluation is made by medical experts who assess your child, and provide a diagnosis that can guide treatment services and be used for insurance claims.*
- *In Oregon, an **educational** evaluation for children 0 - 5 is conducted by your local [Educational Service District \(ESD\)](#). The evaluation is used to determine eligibility for educational services to support your child in an educational setting. Although the ESD conducts its own evaluation, it can use information from a medical evaluation, if available, to help with its evaluation and eligibility process.*

*You will hear IDEA (Individuals with Disabilities Education Act) mentioned as you go through the special education process. It is the federal special education law, which gives rights and protections to eligible individuals (birth through high school graduation or age 21) with disabilities. For more information on IDEA in Oregon, look [here](#).*

## Your Child's Doctor

This is the **best place to start**. Your child's doctor can help determine how your child is developing, and identify areas of concern. The doctor will either diagnose your child, or refer your child to a specialist for further evaluation. In Deschutes County, doctors often refer youth who need additional evaluation to the [Programs of Evaluation Development And Learning \(PEDAL\) clinic](#) at St. Charles.

A diagnosis can be important for receiving services and treatment, as well as billing insurance. Medical evaluations with a doctor or an independent private assessment might be covered by insurance, or might require payment from the family. It's a good idea to check with your insurance company first to learn what they cover.

## HDESD Early Intervention / Early Childhood Special Education Program

In addition to speaking with your child's doctor, a parent or guardian can request an evaluation from the High Desert Education Service District Early Intervention / Early Childhood Special Education Program (HDESD EI/ECSE – more acronyms to come!). This is the local entity that handles education services for kids birth - 5 years old. Someone who is familiar with your child (a doctor, teacher, family member, etc.) can also make a referral for an evaluation.

**The evaluation is free.** It will help identify your child's strengths and any delays, and determine your child's eligibility for special education services provided by EI/ECSE. To learn more about what the state of Oregon offers educationally to children with disabilities and their families, look [here](#). For specific information on HDESD EI/ECSE evaluations, look [here](#).

→ For children birth - 2 years old, contact HDESD Early Intervention at 541.312.1947, and ask for the evaluation team

→ For children 3-5 years old, contact HDESD Early Childhood Special Education at 541.312.1970, and ask for the evaluation team

## Deschutes County Intellectual/Developmental Disability Services

For young children (birth - 5) who are experiencing delays, contact the [County Intellectual/Developmental Disability \(IDD\) Services](#) to apply for an evaluation. It is helpful, but not required, for children under 5 to have a physician's statement that lists the child's qualifying disability, or an educational evaluation from HDESD EI/ECSE that was done within the past year. It can be difficult for a young child to qualify because they are still developing and being cared for by

adults; this makes it hard to assess adaptive behavior and everyday living skills. Even if your child does not meet eligibility the first time, you can apply later.

To get started, head to the [Deschutes County Eligibility page](#). There you will find [an interactive guide](#) full of helpful information, as well as links to an application, a release of information form, and the contact information for an eligibility specialist. Then you can call the number below. For more information on applying and what the County offers, look [here](#) or [aquí](#) (Spanish).

→ Call Deschutes County IDD Services at 541.322.7554, and ask to schedule an appointment with an Eligibility Specialist. Or you can email [idd.intakes@deschutes.org](mailto:idd.intakes@deschutes.org).

## Eligibility

### HDESD Early Intervention / Early Childhood Special Education Program

As mentioned above, in Oregon, an educational evaluation for children birth - 5 is conducted by your local ESD. The evaluation is used to determine eligibility for educational services to support your child in an educational setting. For more eligibility information, look [here](#).

There are laws mandating the timeframe from referral to determination of eligibility, and these vary based on your child's age.

By law, HDESD EI/ECSE has:

- for birth - 2 years old, 45 calendar days from referral to complete the evaluation and eligibility process.
- for 3 - 5 years old, 60 school days (different from calendar days) from when consent to evaluate is signed to complete the evaluation and eligibility process.

### Deschutes County IDD Services

In the state of Oregon, eligibility for IDD services is determined by each county. In Deschutes County, eligibility is determined through an application process. Once you submit an application and a signed release form, an eligibility specialist will gather and review your child's medical records (such as a physician's statement) and educational records (such as early childhood educational testing), if available. In some cases, a new evaluation may be needed. These are provided by an outside assessor and may have a waitlist.

For Deschutes County IDD Services, the eligibility team has 90 calendar days from receiving a signed application and release of information application to make a determination of eligibility. If additional testing is required, the process can take longer. After Eligibility Determination

# After Eligibility Determination: Services

## Educational Services

If your child is eligible for educational services, they will receive services from either Early Intervention (ages 0-2) or Early Childhood Special Education (ages 3-5). Once children are kindergarten age, the child's school district provides Special Education services to those who qualify.

### HDESD Early Intervention (ages 0 - 2)

Once eligible, a Service Coordinator from HDESD's Early Intervention program will work with your family to develop an Individualized Family Service Plan (IFSP). The plan is a legally-binding document that specifies which services and supports the state will provide to your child. To learn more, check [here](#).

Eligible children receive services in the natural environment, which may include your home or in the community (for example, daycare). Based on your child's IFSP, and depending on which skills are delayed, your child will receive specific services from different specialists. Early Intervention focuses on skills in these areas:

- Physical skills (reaching, crawling, walking, drawing, building)
- Cognitive skills (thinking, learning, solving problems)
- Communication skills (talking, listening, understanding others)
- Self-help or adaptive skills (eating, dressing)
- Social or emotional skills (playing, interacting with others)

When your child nears their 3rd birthday, their Service Coordinator will hold a meeting with your family to discuss the transition from *Early Intervention* to *Early Childhood Special Education* (services available under IDEA, a federal law). If your child continues to meet eligibility, the same or similar services as Early Intervention will be offered as preschool special education services.

### HDESD Early Childhood Special Education (ages 3 - 5)

The Early Childhood Special Education program offers special education services to eligible kids of preschool age, from age 3 through the start of kindergarten. Services can include specially-designed instruction and/or related services such as physical, occupational, or speech/language therapy.

Eligible children ages 3 - 5 typically receive services at one of the Early Childhood preschool sites, or a community site (e.g., private preschool or Head Start).

The team, led by the Service Coordinator, will work with your family to create an IFSP (Individualized Family Service Plan) for your child. If your child had an IFSP for Early

Intervention, a new IFSP will be created when they transition to this program. When your child nears kindergarten age, the Service Coordinator will work with your family to plan the transition to elementary school (see [Getting Started Guide, Ages 6-18](#)). To learn more about Early Childhood services, check [here](#).

## Deschutes County IDD Services

If your child meets eligibility criteria, the County will assign a Service Coordinator to your child.

### Case Management

Case management involves working with a County Service Coordinator (different from the educational Service Coordinator). Your Service Coordinator will help connect your family with services and resources appropriate for your child's specific needs, including K-plan Attendant Care, obtaining and navigating health insurance (such as Medicaid/OHP), referrals to Foster or Residential Care, and planning for the future. They will also assist your family with advocating for your child's needs in school and other areas. For more information, look [here](#).

### Personal Support Worker (PSW)

A PSW, also known as a Direct Support Professional (DSP), provides help with day-to-day living needs for disabled individuals. This may include basic healthcare needs, spending time together in the house, behavior needs, relief care, or physical activities (e.g., bike riding, walking, etc.).

The assessments ordered by your child's County Service Coordinator will determine the number of monthly hours available for PSW assistance.

Various agencies provide PSW services. Please see [here](#) for more information.

Note that parents cannot be paid PSWs for children under age 18. It is possible, through the K-Plan, for extended family members (uncles, aunts, grandparents) to serve as a PSW. However, it's often preferable to use the PSW hours for a non-family member to provide relief to the family. This allows for the family to be a natural support for their child.

**Good to Know:** *Direct Support Professional (DSP) is the same role as a Personal Support Worker (PSW). PSW is the term used by the state of Oregon, while agencies use the term DSP.*

### Community First Choice State Plan (K-Plan)

The K-Plan enables individuals to remain in their homes and be cared for by family members and others as directed by the person in services, Guardian, or designated representative (or family administrator). Based on an assessment called the ONA (One Needs Assessment), a determination is made for how many support hours your child can receive each month to assist with daily living.

Your County Service Coordinator will help facilitate these assessments, which are conducted by a certified ONA assessor. These hours can be applied to an in-home setting, or to supported living if the child is not residing at home.

Once hours are determined, these hours may be used to pay a PSW (Personal Support Worker) or Direct Support Professional (DSP). Parents cannot be paid providers for children under the age of 18.

The plan is funded by Medicaid, so your child is required to have Medicaid; in Oregon, Medicaid is called the Oregon Health Plan or OHP. If your child doesn't have Medicaid, the County Eligibility Specialist or Service Coordinator can work with your family to try to obtain Medicaid through a "Presumptive Process".

For more details, check with your County Service Coordinator or PSW. Further information is available [here](#).

## Respite Care

Respite care enables families to take extended periods of time away from their caregiving duties. Caregivers may request a total of 14 days per year, though there are stipulations around how many hours per week a Personal Service Worker/ Direct Service Professional can work. Contact your County Service Coordinator for additional information.

## Social Security

Social Security Supplemental Income (SSI) is a *"Federal income supplement program funded by general tax revenues. It is designed to help aged, blind, and disabled people, who have little or no income. It provides cash to meet basic needs for food, clothing, and shelter."*

## Eligibility

Eligibility for SSI is based on financial need. The [SSI website](#) provides specific instructions on eligibility and how to apply. Children with disabilities can qualify for SSI, though it can be difficult for young children (0 - 5). Please note that eligibility is based on their parents' income, which must be below a certain threshold.

Need some help? A phone call or email to the team at [ALSO](#) or [Abilitree](#) in Bend will put you in touch with a Social Security Advocate who can help apply on your child's behalf.

## ABLE Accounts

If a disabled child's family has too much income or too much money in their bank account, the child may lose all or some of their SSI eligibility. [ABLE accounts](#) are tax-free savings accounts where disabled individuals can deposit additional funds, which can be used to pay for qualified

disability expenses. The primary benefit of an ABLE account is that it allows disabled individuals to keep additional money aside without impacting SSI eligibility.

Young children below the age of 18 can open an ABLE account with parent permission, and if they meet the requirements. Specific guidelines on what the money may be spent on, and how much may be kept in an ABLE account, can change each year.

Oregon ABLE Savings administers the program in Oregon. Once the child's ABLE account is established, the individual (or the minor child's parents) receives a VISA debit card to use for expenses. Have a look at Oregon ABLE Savings [here](#) to learn more.

## Medicaid / Oregon Health Plan

Generally, eligibility for SSI also comes with eligibility for Medicaid. In Oregon, Medicaid is known as the Oregon Health Plan (OHP). Find more details here on the [OHP website](#).

The team at [Abilitree](#) is very helpful with this process, and is a great first place to contact.

## Residential Options

At some point, a child with an intellectual or other disability may want or need to live away from their immediate family members.

A variety of options are available for children with IDD, including foster care and residential care.

All residential options require a referral from your County Service Coordinator to the Designated Referral Coordinator (DRC), who will assist with finding placement. Ask your Service Coordinator to get the process started. For more information, look [here](#); click on Supports for Children.

### Foster Care

Foster care usually involves a family opening their home to an individual to live with them. The foster care family (also known as a resource family) is trained and certified, and receives payment from the state, based on the resident's assessed level of support.

Foster care homes are licensed by the state, required to maintain a set of quality standards and subject to regular review and evaluation.

Typically, foster homes are designated as either for adults or children, not both. However, a small number of homes may have approved variances to care for adults and children. Look [here](#) for more information.



## Residential Care

Residential Care programs are often run by a nonprofit organization, which provides care and treatment services to children 24 hours a day in a staffed facility.

Residential Care facilities are designated as either for adults or children, not both.

Residential facilities are also licensed by the state and required to maintain a set of quality standards; they are subject to regular review and evaluation.

## Low-Cost Housing

Depending on income levels, families may qualify for financial assistance and reduced rent through Housing and Urban Development (HUD) also known as Section 8. The state of Oregon has further information [here](#).

Resources for housing assistance may also be accessed through [NeighborImpact](#).

***Good to Know:*** *Housing resources change frequently in Central Oregon, so be sure to check in with [DiversabilityVillage.org](#) and your Service Coordinator for the most up-to-date information.*

## About the Author

Mary Elizabeth (aka Mimi) is ridiculously curious and passionate about neurodiversity. She believes that differently-wired individuals have so much to teach us as parents and as a society, if we can slow down and tune in to their unique way of experiencing the world.

She is the mother of two teenage daughters, wife of an adventure-seeking South African husband, and keeper of a very large Golden Retriever.

Mimi is a Parent Partner with the ACCESS Program for Early Intervention/Early Childhood Special Education with [HDESD](#).

## Acronyms & Abbreviations

**DSP** - Direct Support Professional

**DRC** - Designated Referral Coordinator

**ECSE** - Early Childhood Special Education

**EI** - Early Intervention

**ESD** - Education Service District

**HDESD** - High Desert Education Service District

**HUD** - Housing and Urban Development, also known as Section 8

**IDD** - Intellectual / Developmental Disability

**IDEA** - Individuals with Disabilities Education Act

**IFSP** - Individualized Family Service Plan

**OHP** - Oregon Health Plan; the name of Medicaid in Oregon

**PSW** - Personal Support Worker

**SSI** - Social Security Supplemental Income