

Getting Started Guide: Youth 6-18

Overview	1
Concerns	2
Where do I start? Evaluations	3
Your child's doctor	4
Special Education Department	4
Deschutes County IDD (Intellectual/Developmental Disability) Services	4
Eligibility	5
Special Education	5
Deschutes County IDD Services	5
After Eligibility Determination	5
Special Education	6
Deschutes County IDD Services	6
Case Management	6
Personal Support Worker (PSW)	6
Community First Choice State Plan (K-plan)	7
Respite Care	7
Vocational Rehabilitation (VR)	7
Social Security	8
Eligibility	8
ABLE Accounts	8
Medicaid	9
Residential Options	9
Foster Care	9
Residential Care	9
Low-Cost Housing	10
About the Author	10

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 6-18 suspect that your child has a learning challenge, developmental delay, or another condition that impacts their learning or functioning, 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.

Depending on age, evaluations may be conducted by your doctor, school district, county, or an independent private assessor. Evaluations through the school and the county are free; however, a doctor or an independent assessment generally requires payment from the family.

Good to Know: *There are three evaluation paths: **medical, educational, and mental health.** 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.*

- *A **medical** evaluation is made by medical experts who assess your child, and provide a diagnosis that can drive treatment services and be used for insurance claims.*
- *An **educational** evaluation is typically led by the school district's Special Education department, and is used to determine eligibility for educational services to help your child (birth - high school graduation or age 21) receive a fair and appropriate education, as*

they prepare for their future. The special education plan is called an IEP (Individualized Education Plan).

- *A **mental health** evaluation is performed by a licensed mental health professional, such as a therapist, psychologist, or psychiatrist. They assess and diagnose the child, then develop a treatment plan that may be helpful in accessing services and supporting other treatment plans.*

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.

Special Education Department

In addition to speaking with your child's doctor, you can contact your child's general education teacher to discuss if your child is demonstrating a need to be considered for a special education evaluation. You can also contact the Special Education Coordinator at your child's school, or the Deschutes School District's Special Education Department at (541) 355-1060 to request an evaluation for your child. The evaluation will determine if your child is eligible for special education services. See the section below called *After Eligibility Determination* for more information on what those services could include.

There is no cost for the evaluation unless the family chooses a private evaluation. If you choose a private evaluation, confirm first with the Special Ed coordinator if they accept private evaluations, and whether the school requires specific evaluations or tests.

The IEP process can be complicated, with lots of unfamiliar acronyms and terms. It's important that parents participate and advocate for their child, especially at IEP meetings. Make time to

learn about the process and prepare for the meeting. A great place to start is at FACT Oregon. You can call them for help, and look at their website for IEP and special education resources [here](#). Be sure to check out FACT's Tool Kit in English and Spanish to help parents prepare for an IEP meeting. In Central Oregon, CODSN offers local peer support and special education guidance [here](#). See [Support and Advocacy](#) for more information on FACT Oregon and CODSN.

Deschutes County IDD (Intellectual/Developmental Disability) Services

To see if your child is eligible for County IDD services, start by calling the number below, or head to the Deschutes County eligibility page [here](#). 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. 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.

Eligibility

Special Education

In Oregon, eligibility for special educational services is determined by each school district or educational service district (ESD).

For a child (age 5 to 21) to qualify for an Individual Education Plan (IEP), several conditions must be met. First, the child must have a disability that falls under one of the categories covered by IDEA (note that a diagnosis doesn't guarantee eligibility). Then, the child's disability must have an adverse impact on the child's educational performance. Last, the child must need specially designed instruction as a result of his/her disability to make progress in general education. If a child does not meet eligibility for an IEP, the child could be offered a 504 plan. More information on IEPs and 504s can be found [here](#).

After you request an evaluation from your child's school or school district, and you sign the Consent to Evaluate form, the school's IEP (Individualized Education Plan) team will evaluate your child to determine if your child is eligible for services. The team will look at all areas of your child's development, and will include at least two professionals who will observe and evaluate your child. Parents or caregivers should be involved in this process. Teams will likely request medical information, including hearing and vision information, to rule out any sensory impairments.

The timeline for determining eligibility is mandated by law. For Special Education departments in Oregon, once a parent signs the form giving consent to evaluate your child, the school is legally required to complete the evaluation within 60 school days (not calendar days). Please note that timelines are different for birth to 5 year olds.

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 and assessments. An Eligibility Specialist gathers and reviews medical and educational records, if available, to determine eligibility. In some cases, a new evaluation may be needed. These are provided by an outside assessor and may have a waitlist.

As with Special Education, there are laws mandating the timeframe for the evaluation process. For Deschutes County IDD Services, the eligibility team has 90 calendar days from receiving a signed application and release of information to make a determination of eligibility. If additional testing is required, the process can take longer.

After Eligibility Determination: Services

Once your child's educational team makes a decision on eligibility, a variety of services and support will be available to them.

Special Education

If your child is determined to be eligible, the special education lead person will work with your family to create an IEP (individualized Education Plan) for your child, and to coordinate services. These services could include accommodations and modifications, aids and services (for example, speech therapy, occupational therapy, physical therapy, and/or specific therapy for learning differences).

If your child has already received support from HDESD's Early Childhood Special Education, the previous service coordinator will lead a hand-over process to a new service coordinator. Different services become available when your child enters kindergarten, and eligibility for services might change as your child develops.

Deschutes County IDD Services

If your child is eligible, the County will assign a Service Coordinator to your child. The Service Coordinator will provide case management.

Case Management

For children birth – 18, 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](#).

As your child nears 18, the Service Coordinator will assist your family with the transition from school services to adult services. Once your child reaches age 18, brokerage services become available as an alternative to county services for case management. In Deschutes County, [Full Access High Desert](#) is the current brokerage. For more information, see Adult Getting Started Guide [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 case manager (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 the disabled child.

Good To Know: *Direct Support Professional (DSP) is the same role as a 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.

Vocational Rehabilitation (VR)

VR Youth Services helps match individuals with disabilities with employers and employees throughout the state. If your child is between the ages of 14 – 21, they can start to explore employment through the pre-employment transition services (Pre-ETS). These services offer a range of job search skills, including career counseling, interest assessments, job shadows, and more.

VR eligibility requires a series of assessments (yes, more assessments!) and is not a quick process. Once eligibility is determined, VR will provide support for youth as they prepare for employment.

For more information on VR youth services, including a request form, look [here](#). A general overview of VR is found [here](#).

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 often qualify for SSI. 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 [Abilitree](#) in Bend will put you in touch with a Social Security Advocate who can help apply on your child's behalf. Even if you chose to apply on behalf of your child without the help of an advocate, Abilitree can help explain the process and what mistakes to avoid.

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 allow individuals to put additional money aside without it impacting SSI eligibility.

An [ABLE account](#) plays a very helpful role in maintaining proper income levels. It provides a tax-free savings account where disabled individuals can deposit additional funds, which can then be used to pay for qualified disability expenses. *"The law aims to ease financial strains faced by individuals with disabilities by making tax-free saving accounts available to cover qualified disability expenses."*

Young children below the age of 18 can open an ABLE account with parent permission, if they meet requirements. What the money may be spent on and how much may be kept in an ABLE account often 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 start.

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.

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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

IEP - Individualized Education Plan

IFSP - Individualized Family Service Plan

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

PSW - Personal Support Worker

SSI - Social Security Supplemental Income