



Developmental Diversity Program

Transition Handbook

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What do we mean by *Transition*?

Transition refers to the process during which a student prepares to leave school and enter the adult community. This change process can also mean becoming involved with new service systems outside of the school. Transition presents important challenges for both parents and students that experience disabilities. As young people face a number of choices about careers, living arrangements, and social life, for individuals who experience disabilities, these choices and decisions can be complicated by the need for additional support.

How can Parents Help with Transition?

There are many ways that parents can help to make sure that their child's transition is as smooth as possible.

Set goals

Include your child in setting goals for the future and make sure that their school program prepares them to meet those goals. Transition is a great time to gain as many independent work and living skills as possible.

Encourage gradual independence

Parents are not always going to be around. Begin now to encourage independent travel, self-care activities, money management and decision-making. A person who experiences a disability may always need support, but they may gradually gain independence through learning new skills and experiencing new things.

Gather information

Read up on issues such as guardianship, healthy expression of sexuality, and driving. Decisions about these matters will have to be made based upon the person's level of independence, competency, the family's values, and the resources available to help with each issue.

Familiarize yourself with the adult service system

Parents need to become informed about all the available programs and the eligibility criteria for each one. Your child's Services Coordinator can help you navigate these systems.

Build self-esteem

Show through your actions that you believe in your child's future. Teach them skills that you would teach any child who is getting ready to go out into the

world: how to do laundry, make a simple meal, and sew on a button. If you have confidence in your child, they will learn from that confidence.

Encourage social integration

Friendships are an invaluable form of natural support, and participating in community life can encourage the development of skills for independence.

Gain work experience

It is important for individuals to gain experience in work situations. This should be addressed at the IEP meeting and incorporated, when appropriate, into the IEP. Parents, along with the school/transition program, VR, employment providers, and Services Coordinator, can assist throughout the process of preparing for work and finding jobs. Work experience can help youth learn important skills such as personal hygiene, punctuality, reliability, and work ethic. For more information about preparing for employment, please ask your Services Coordinator for a copy of the **“Planning Your Way to Work” handbook**, or view it online at:

http://ocdd.org/index.php/ocdd/employment/category/planning_my_way_to_work_transition_guide/

Provide opportunities to manage money

Individuals should be paid for the work they do – and with money comes the need to manage and budget finances. If appropriate, the individual should be taught money management skills through activities such as planning and completing shopping trips using their own money, while also learning about budgeting. For parents, it is important to be aware of alternatives for individuals who may need support with handling their finances (see the chapter on “Money Matters” for more information).

And most important of all...

Dare to DREAM and let your visions shape the future

Don't allow available services, current skill levels, achievement tests and IQ scores to be the primary determining factors about the future.

For parents, transition means letting go. The issues surrounding transition are complex and loaded with emotional significance. However the more information that parents have, the easier it is to make wise decisions.

For more information, visit: <https://www.peakparent.org/>

Overview: Guide for Parents

Turning 18 – Transition to Adult Services

Benton County Developmental Diversity Program

Eligibility for Developmental Diversity Services

By age 18 (for intellectual disability, age 22 for developmental disability), eligibility as an adult for services needs to be established, even if the individual has been eligible as a child. The Developmental Diversity (DD) program may request updated testing and can work with schools and parents to accomplish this. Eligibility for children is considered *provisional* and can change. Adult eligibility is considered *permanent*. For some developmental disabilities, testing can be done prior to age 21. If you have questions, you are welcome to contact your Services Coordinator or the eligibility specialist (see the contact list at the back of this handbook).

School Services

If a child earns a modified high school diploma, they are eligible to receive school services through the school year in which they turn 21. After age 18, most students will receive transition services through the schools to help them learn skills for living and working in the community. They are still entitled to a full school day.

Guardianship

Parents are considered natural guardians of their children until age 18. When people turn 18, they are legally considered adults and become their own legal guardian, unless a court has found them to be “incapacitated” and designates another person to be the individual’s legal guardian. Parents continue to have a role in helping and supporting adult children to make informed decisions, but when children turn 18 and legally become adults; they have the responsibility to decide what is in their best interests, which services to accept or reject, and to sign papers giving consent to sharing information or receiving services. Parents will not be able to sign for them, unless they have been designated legal guardians by the court.

The DD program encourages working closely with parents and family members to help the now adult child make good decisions, access appropriate services and supports, and participate in individual planning. Parents may still have a great deal of influence with their children even if they are not legal guardians.

Guardianship does remove rights from an individual and should be considered carefully. If it is appropriate for your child, you may consult with a lawyer or the courts.

Most adults with developmental disabilities are their own guardians and though they may need support with decision-making, they usually do not need a substitute decision-maker. The role of a substitute decision-maker (guardian) is to make the decision that the individual would make for themselves if they had the capacity to make the decision. Most adults turn to other trusted people to help and support them in their decision-making. People can need support with decision-making without needing a substitute decision-maker. (For more detailed information on guardianship, as well as alternatives, see the chapter on “Guardianship”).

Supplemental Security Income (SSI)

SSI is a financial benefit administered through Social Security that individuals may qualify for based upon having a certain level of disability and a certain level of income. Most children served by the DD program have a qualifying disability and may or may not qualify as children depending upon the family income. When the child turns 18, Social Security looks only at the individual’s income, not the family income for eligibility.

It is a good idea to call SSI to set up a 1st appointment after one’s 18th birthday

You can apply through the Social Security office and your services coordinator can assist you with the process. If your child is found eligible, they will receive a monthly payment for income support.

Your child may engage in paid employment and still receive SSI. The SSI check may be decreased depending upon the amount of paid work an individual performs, but they will always have more income by working than if they do not work. There are many protections in place so that an individual does not lose benefits by working. Your services coordinator can help direct you to a benefits advisor.

If your child is found not to be eligible for SSI, they have the right to appeal the decision. If the appeal is successful, SSI will be awarded as of the date the individual applied and a back payment will be made.

If a child already receives SSI and OHP, SSA will initiate the adult eligibility process when they turn 18.

Oregon Health Plan (OHP)

If an individual receives SSI, they are also eligible to receive health insurance through the Oregon Health Plan, which is Oregon's version of the federal Medicaid program. If adult children have private health insurance through their parents or other sources, they can maintain their private insurance and have OHP as secondary insurance which may cover things not covered by the primary insurance.

Many of the services provided by the DD program; including vocational programs, residential programs, and support services, are funded through Medicaid so it is beneficial to establish eligibility for Medicaid if one would like to access other services in the future.

To access OHP, individuals need to make an appointment with either the Disability Services Office or the Benton County OHP enrollment worker. Your Services Coordinator can assist you with the process.

Adult Support Services (Brokerage)

Adults (over 18) who live independently or in their family homes may choose services from either the Benton County DD Program or from one of two adult support services agencies, also known as brokerages. The two brokerages that serve Benton County are Integrated Services Network and Mentor Oregon Mid-Valley Brokerage.

Brokerages have Personal Agents that perform work similar to the Services Coordinators in our program. Referral for support services is through your Services Coordinator.

Individuals served by the DD program can be referred to support services any time after their 18th birthday. Individuals may choose to be referred to a brokerage at any time. People served by brokerages may choose to return to the DD Program at any time. (For more information see the chapter on "Support Services through Brokerages").

Employment/Vocational Supports

There are several opportunities to receive support in finding work, including school transition programs, vocational rehabilitation (VR), summer work experience, and vocational programs that offer job coaching and similar services.

One focus of the transition programs through the schools will be on learning job skills and having work experiences. Individuals may also receive services

through Vocational Rehabilitation (VR) if they want to work in the community. VR services are time limited. They are intended to help develop an appropriate job situation and provide job training. It is not intended as long term support on the job. They will help access long term employment, but not temporary work like a summer job.

The DD Program and brokerages may be able to provide long term or short term support as needed. Support may include whatever an individual needs to be successful in a job, including transportation to and from work. There are several vocational service providers available to choose from to provide long-term on the job support.

For people who are still eligible for school services, summer work programs are available to provide an opportunity for young adults to learn work skills and have a variety of work experiences in a small group environment. Your Services Coordinator can help you access these programs. (For more information see the chapter on “Employment”).

Residential Supports

As our children become adults, they often prepare to leave the nest. Adults with developmental disabilities may live independently in the community or sometimes they need varying levels of support. Some individuals may be able to live on their own with very little or no support. Other individuals may need additional support coming into their homes. Still others may need specialized shared living arrangements (foster homes, group homes) or more intensive support in the home. Regardless of the living situation, it is important that individuals have choice, independence, and support to keep them healthy and safe. It is important to discuss future needs and hopes with your Services Coordinator or Personal Agent to develop appropriate plans.

Individuals who plan on renting an apartment or house either alone or with others, may need help paying the rent. The Linn-Benton Housing Authority administers rent subsidy programs such as Section 8 to help individuals with low incomes afford housing. Through these programs, rent payments are a percentage of income and the program pays the difference to the landlord. Waiting lists for these programs can be quite long and it is good to apply early. It may take as long as 18 months to two years to get housing assistance.

There are also housing developments that are subsidized and as long as an individual lives in a particular housing complex, the rent will be subsidized, but

if they move to another apartment, the subsidy will not travel with them. A Section 8 voucher will travel to any housing in the United States that accepts it.

Individuals with disabilities typically have the same desires for independence and leaving the family home as everyone else. It is not unusual for young people to live in homes with other people when they first leave the family home. The system of residential support is designed to give individuals with disabilities the same opportunities at independence and community involvement by providing the additional support people may need.

Even after our children move out on their own, parents and family still play an important role in their lives. Visits and on-going participation in activities and planning meetings is encouraged no matter where your child lives.

Counseling, Skills Training, and Socialization

The Benton County DD Program offers a variety of services to help individuals transition to adulthood. If individuals have more significant difficulties, we also offer individual and group counseling and psychiatric services through the Benton County DD Program. Your Services Coordinator can assist you with accessing these services. Additionally, there are social and recreational opportunities through Special Olympics, The Arc of Benton County, the Corvallis Parks and Recreation Department, IMPACT, and other community groups. (Talk to your Services Coordinator or stop by the Benton County DD office to get a full list of activities).

Register to Vote

When individuals turn 18, they are eligible to vote. Our community is strongest when all members have a voice. People who represent the developmental diversity of our community are encouraged to participate in all aspects of community life, including voting.

Register to vote online at: <https://secure.sos.state.or.us/orestar/vr/register.do>

Helpful Information about your Child

1. List of things that always makes _____ happy:
2. Food likes and dislikes:
3. TV/music likes and dislikes:
4. What would they miss in their room if it wasn't there:
(Comfort items like fuzzy slippers, favorite blanket, light on, etc.)
5. List sounds, noises, people, situations and/or objects that they like and/or dislike:
6. Are there any emotions/behaviors that are associated with any situation?
(i.e. Loves parades but is afraid when candy is thrown)

7. What prompts or reminders are needed to accomplish everyday tasks? (i.e. bathing, dressing, getting into a car)

8. What can they do independently?
(i.e. make bed, do laundry, put in a video?)

9. List any allergies (food/medication):

10. Anything else you can think of that would further help others understand your child's needs?

11. Comments/Concerns you would like others to be aware of:

Transition Planning

Transition is a process that helps you define goals that will take you from high school to adulthood. These goals are based on your strengths, preferences and interests. It includes planning through the Individualized Education Program (IEP) and should document all the supports and services you need to make a smooth and productive transition out of school. It might also include a description of supports that you may need after graduation.

When does transition begin?

Transition planning typically begins between the ages of 16 and 18. Your IEP should include a transition plan with goals that address activities and services like community training, employment skills, etc. If you have graduated with a modified diploma or certificate of attendance or have not yet graduated, you can continue to receive transition services until the school year in which you turn 21 is completed. However, once you graduate with a regular diploma, you are no longer eligible to receive transition services.

What things should be included in my transition plan?

The transition plan should address your goals or vision of what you will be doing after graduation based on your preferences and interests in the following areas:

- Employment
- Community participation and mobility
- Recreation and leisure
- Post-secondary training and other learning opportunities
- Independent living

The transition plan should be meaningful to you and help you move toward your adult goals. The transition plan will identify what the school will do to achieve these goals and will identify other agencies who will also be involved now and in the future.

Your ISP can help you build the IEP around some of your transition goals. This will also help you and your family think about services you might need through your county DD program. Make sure to consider the accommodations and/or assistive technology (devices that help you with tasks, like computers) that you might need for the courses you are taking or for a potential job.

Who is involved in transition planning?

Your IEP team helps you lay out your transition plan. The school district will invite your team to meet and plan. This can include you, your family members, teachers and other professionals (therapist and specialist), your transition teacher, your Services Coordinator, Vocational Rehabilitation Counselor, and school guidance counselor.

You might wish to invite others who know you well enough to contribute to this process, like friends, teachers, providers, church or spiritual leaders.

How is Vocational Rehabilitation (VR) involved in my transition planning?

The school district should invite a representative from VR to your IEP at least once in your senior year or before if the team feels it would be helpful. The school district, VR, and your Services Coordinator will work together with you to envision what supports will be used to get and keep a job that matches your interests and skills, either before or after graduation. The school, VR and your services coordinator have the responsibility to coordinate the transition planning and provide you with information on how this works. (See the chapter on “Employment” for more information about VR).

Employment

Some people might tell you that you can't work because you have not done so before or because they think you would lose essential Social Security benefits. This is not necessarily true. Your Services Coordinator can help you pursue your employment goals.

Students with disabilities can go to work and get paid in a community job. Making this successful transition requires decisions, planning, and cooperation between you and your team. You have choices to make. Whether you want to test out new jobs, develop a career, or just earn a paycheck, there are many options available to you for employment in your community.

You may not need assistance in getting and keeping a job, or you might require more help like:

- Learning about the responsibilities of having a job;
- Needing a coworker or coach to teach you about your job and then you can do it yourself;
- Requiring devices to assist you in performing some work duties;
- Having tasks adapted or modified so you can complete them; or
- Getting some planned regular "extra support" from a coworker or coach to help make sure you can keep doing your job.

The goal is paid community employment where most of your coworkers are persons without disabilities, the job matches your interests and abilities, and you receive long term support to be successful on the job.

You, your Services Coordinator, school staff, and a Vocational Rehabilitation (VR) counselor will become partners to achieve employment.

No matter what kind of employment you choose to pursue or what supports you need to work, your desires, strengths, interests and abilities should drive the process.

How do I get started?

Talk to your family, teacher, and Services Coordinator about wanting to work. These are the people who can help you change your person centered plan (IEP, ISP) to achieve this goal. Your Services Coordinator will share information with you and help you make an appointment with agencies that can help you to go to work. Agencies like VR, and employment providers are important resources for

you and may form an employment team with you. They may help you to complete an Employment Person Centered Plan and participate in community based work assessments or other activities to help identify your work interests and support needs at an employment site.

How can I figure out what kind of job I want?

Your Services Coordinator, VR Counselor, school, and employment providers can work with you to help you think about:

- Experiences you've had that have given you skills to use at work
- Your strengths, gifts, capacities and abilities
- Specific information on what you need to be successful at work
- Challenges and support strategies
- Resources
- What work settings fit you
- Names of people who can assist with the employment process

Everyone has help in getting a job. Sometimes it is an easy process and you won't need much help from others, but other times you might need a customized approach to finding one. That is what job development is, and each member of the employment team will help with this.

A job developer focuses on your skills, interests, and abilities in order to seek out the job that is the right fit for you. You may have a particular need or special skill that gives your job developer the opportunity to be very creative in their approach, matching you to the employer and the job they want done. Your family and close friends can be especially helpful in supporting your job search and helping you deal with problems as they arise.

Employment Services available through Employment Providers

Discovery

If you need more information to help you figure out what you want to do for your career, you may request to be referred to a service called Discovery.

This is a short term service where you will explore employment through work experiences, informal interviews, and other activities designed to explore your interests and strengths. This may include a visit to your home, several different community settings, and may include arranging volunteer or work experience

opportunities in order to search for the type of jobs that best match your interests and strengths.

Employment providers that offer Discovery services will create a Discovery Profile with the individual. The Discovery Profile is the result of meetings with the individual one-on-one as well as with their team, and through going out into the community with the individual and identifying their strengths and passions. Once a Discovery Profile is complete, the provider will work with a Job Developer to brainstorm ideas of jobs that would be a good fit for the individual.

Talk to your Services Coordinator or Personal Agent for more information about accessing Discovery services.

Employment Path

Employment Path services provide learning, volunteer, and work experiences for individuals preparing to get a job. The goal of Employment Path is for an individual to develop general employment skills that may be used in an integrated job. *These services can only be accessed after the completion of school.*

Employment Path services are time limited and are outlined in your ISP, which means they can only be used until your goal has been met. Specific goals will be written into your ISP and will be reached through an ongoing person-centered planning process.

Talk to your Services Coordinator or Personal Agent for more information about accessing Employment Path services.

Job Development

A Job Developer identifies job opportunities in the workplace where your skills match what the employers need. Job Development may include support with the application and interview process, and visits with potential employers. If you have completed Discovery, your Job Developer can use your Discovery Profile to find the best job options for you.

Talk to your Services Coordinator or Personal Agent for more information about accessing Job Development services. You may be able to access Job Development through VR.

Small Group Supported Employment

Small Group Supported Employment opportunities are services and activities where the group (fewer than 8 people) works as a crew or workgroup. Through Small Group Supported Employment, people have regular opportunities to interact with the community and obtain valuable skills that can be applied toward their career goals in the future. The purpose of Small Group Supported Employment is to help someone eventually get individual integrated employment.

Talk to your Services Coordinator or Personal Agent for more information about accessing Small Group Supported Employment services.

Job Coaching

Once you have obtained an individual integrated job, Job Coaching is available to help you learn the new tasks and support your transition into your new job. Job Coaches can assist in teaching new skills if you are moved to a new position or are seeking promotion. They can help you build relationships with your coworkers, learn about the rules of the business, and support you in being successful at work.

Talk to your Services Coordinator or Personal Agent for more information about accessing Job Coaching services.

Additional resources

I Work We Succeed – Employment First

www.IWorkWeSucceed.org

Employment Success Stories

<https://www.oregon.gov/DHS/EMPLOYMENT/EMPLOYMENT-FIRST/SUCCESS-STORIES/Pages/index.aspx>

Oregon Office of Vocational Rehabilitation Services

<http://www.oregon.gov/DHS/vr/index.shtml>

SSA Worksheet (to help gather and organize information)

http://www.ssa.gov/disability/disability_starter_kits.htm

Vocational Rehabilitation Services

In addition to the services you receive through your County DD program, Vocational Rehabilitation (VR) Services are designed to help you meet your employment goals by assisting you in preparing for, finding, and keeping a job. Vocational Rehabilitation provides short-term services to people with disabilities, and The Oregon Commission for the Blind provides vocational rehabilitation services for persons who are blind or who have visual impairments.

Services can include some or all of the following: the development of an Individualized Plan for Employment, assessments, job development, job coaching, assistive technology, school (college or technical school), work clothes, worksite accommodations, tools and more.

Some individuals need both (1) short term services to get and learn a job and (2) long term support to keep a job. This is called supported employment. The resources that may be used in partnership with VR to help a person with disabilities keep a job could include:

- An individual's county DD program or brokerage
- Social Security Work incentives
- Natural Supports through coworkers

How do I know if I am eligible for VR?

In order to be eligible for VR services, the rules say you must:

- Be an "individual with a disability," meaning a person who has a physical or mental impairment that constitutes or results in a substantial barrier to employment and can benefit from VR services to achieve an employment outcome.
- Require VR services to prepare for, secure, retain, or regain employment.

If you receive Supplemental Security Income (SSI), Social Security Disability Insurance (SSDI) or Social Security for Disabled Adult Child (SSDAC), you are presumed to be eligible for VR services. Bring your determination letter from Social Security Administration office or a copy of your check to your VR Counselor. They will also need some background information about you and your disability to determine if you meet eligibility based on the laws they must follow.

What is an Individual Plan for Employment (IPE)?

Each person is unique and therefore requires an individualized approach to reach their employment goals. You, your Services Coordinator, and VR counselor will

work together to establish your goal and identify the services that are necessary for you to achieve and maintain this goal.

You and your employment team will write your Individual Plan for Employment (IPE). Although your IPE is separate from your Individual Support Plan (ISP), these plans should fit together and complement one another.

How do I hire a job developer or provider agency?

Finding someone who will help you with the job search is a key to success. Your Services Coordinator or VR Counselor can assist you with names of individuals and with the interview process if needed.

Can I use the VR system if I am already receiving services from another agency?

Yes, if you want to achieve community, competitive or supported employment. VR will not and cannot help someone who wants sheltered employment. Even if you are receiving services from another agency (state or private), you can receive services from Vocational Rehabilitation. VR may be able to provide or fund services that you do not already receive. If you are receiving services from more than one agency, it is important to let your VR counselor know this so you can talk about how your services will be coordinated. You will want to work with all the agencies to make sure that the services you receive complement each other and that you and your team work together toward the same goals.

What are some other services available to me?

Disability Rights Oregon

620 SW Fifth Avenue, Portland OR 97204 503-243-2081, 1-800-452-1694

<http://www.disabilityrightsoregon.org/resources/3-brochures/>

General Disability Resources

www.disability.gov

Social Security Administration

www.socialsecurity.gov

Social Security Red Book on Work Incentives

<http://www.socialsecurity.gov/redbook/>

Benefits Planning

Benefits planning helps you understand how your Social Security or other benefits could be affected by earning an income. You may be eligible to take advantage of work incentives, which are special rules that let you work, earn money and still keep your public benefits. The goal of benefits planning is to help you make informed decisions about working and the possible outcomes of the decisions you make.

Why do I need to know about benefits planning?

It is important to know about the work rules and work incentives, and to think through how they can help you reach your employment goals. You want to be confident that going to work will increase your quality of life, and getting accurate information about benefits and working is critical to reaching that goal.

When should I consider benefits planning?

The best time to meet with a Benefits Planner is when you are thinking about going to work, you have been offered a job, or you are already working and have the potential to earn more money. Since some of the earning thresholds that affect your benefits change each year, it's also a good idea to touch base with a Benefits Planner annually. It is important to make sure you are making decisions about work based on accurate information and to discuss any changes in work that may impact your benefits.

Who can help me with benefits planning?

Vocational Rehabilitation (VR) can refer you to Work Incentives Network (WIN) advisors. Disability Rights Oregon (DRO) also provides benefits planning for free. The Benefits Planner will help you navigate through the maze of rules and help you think through each Work Incentive to identify those that could help you.

Benefit Planners will work one-on-one with you to:

- Provide information about how wages will affect each type of benefit
- Identify Work Incentives that fit your situation
- Provide tools and assistance in reporting income and requesting Work Incentives
- Help you earn more money

Disability Rights Oregon

620 SW Fifth Avenue, Portland OR 97204 503-243-2081, 1-800-452-1694

<http://www.disabilityrightsoregon.org/need-help/planning-for-work>

Money Matters

Special Needs Trusts

Also known as a Supplemental Needs Trust, the purpose of a Special Needs Trust is to provide a means of supplemental support to enhance the quality of life for a person receiving government assistance, without jeopardizing the benefits they receive. A Special Needs Trust can be a private trust drafted by an attorney, or a pooled trust wherein a single “Master Trust” is used to serve many individuals. Both private and pooled trusts must be drafted so that the trust is irrevocable, and that available funds are used only for the sole benefit of the beneficiary. A pooled trust may only be established and administered by a non-profit organization.

Administration of a Special Needs Trust must follow strict guidelines set forth by state and federal agencies in order to maintain eligibility for public benefits for the beneficiary of the trust. This applies to both pooled and private trusts.

About The Oregon Special Needs Trust (The Arc Oregon)

The Oregon Special Needs Trust (OSNT) is a pooled trust in which funds are pooled for investment and trust management purposes. However, each beneficiary has his or her own subaccount, which is individually monitored and managed.

Visit The Arc Oregon for more information about the Oregon Special Needs Trust:

thearcoregon.org/what-we-do/osnt/trust-overview/

ABLE Accounts

1. What is an ABLE account?

ABLE accounts are tax-advantaged savings accounts for individuals with disabilities and their families. ABLE accounts allow individuals with disabilities to save up to \$100,000 without the assets counting against their federal and state benefit’s asset limits. ABLE accounts were created as a result of the passage of the national Stephen Beck Jr., Achieving a Better Life Experience Act (ABLE Act) of 2014 and the Oregon Senate Bill 777.

2. Why the need for ABLE accounts?

Millions of individuals with disabilities and their families depend on a wide variety of public benefits for income, health care and food and housing

assistance. Eligibility for these public benefits (SSI, SNAP, Medicaid) require meeting a means or resource test that limits eligibility to individuals who report more than \$2,000 in cash savings, retirement funds and other items of significant value. Savings up to \$100,000 in ABLE accounts will not affect an individual's eligibility for SSI, Medicaid and other public benefits.

3. Am I eligible for an ABLE account?

The ABLE Act limits eligibility to individuals with significant disabilities with an age of onset of disability before the age of 26. If you meet this age criteria and are also receiving benefits already under SSI and/or SSDI, you are automatically eligible to establish an ABLE account. If you are not a recipient of SSI and/or SSDI, but still meet the age of onset disability requirement, you could still be eligible to open an ABLE account if you meet Social Security's definition and criteria regarding significant functional limitations and receive a letter of certification from a licensed physician. You need not be under the age of 26 to be eligible for an ABLE account.

4. Are there limits to how much money can be put in an ABLE account?

The total annual contribution by all participating individuals, including family and friends, for a single tax year is \$14,000. The amount is tied to the gift tax limit and may be adjusted periodically to account for inflation. The total limit over time that can be deposited in an Oregon ABLE Savings Plan account is currently set at \$310,000. The first \$100,000 in an ABLE account is exempted from the SSI \$2,000 individual resource limit. If and when an ABLE account exceeds \$100,000, the beneficiary's SSI cash benefit would be suspended until such time as the account falls back below \$100,000. It is important to note that while the beneficiary's eligibility for the SSI cash benefit is suspended, this has no effect on their ability to receive or be eligible to receive medical assistance through Medicaid.

5. Are there tax advantages to ABLE accounts?

Yes. Investment earnings grow tax-deferred and qualified disability expense distributions come out federally tax-free. In addition to federal tax benefits, there are state tax benefits for Oregonians. Contributions to ABLE accounts with beneficiaries under the age of 21 are deductible for Oregon income tax purposes up to annual limits that are indexed annually for inflation. For 2016, the deduction is \$4,620 for taxpayers filing jointly and \$2,310 for single filers.

6. Which expenses are allowed by ABLE accounts?

A "qualified disability expense" means any expenses related to the eligible

individual's blindness or disability which are made for the benefit of the individual who is the designated beneficiary, including the following expenses: education, housing, transportation, employment training and support, assistive technology and personal support services, health, prevention and wellness, financial management and administrative services, legal fees, expenses for oversight and monitoring, funeral and burial expenses, and other expenses.

7. Can I have more than one ABLE account?

No. The ABLE Act limits the opportunity to one ABLE account per eligible individual.

8. Will the Oregon ABLE Savings Plan offer options to invest the savings contributed to an ABLE account?

The Oregon ABLE Savings Plan will offer qualified individuals and families multiple options to establish ABLE accounts with varied investment strategies. Each individual and family will need to project possible future needs and costs over time, and to assess their risk tolerance for possible future investment strategies to grow their savings. Account contributors or designated beneficiaries are limited, by the ABLE Act, to change the way their money is invested in the account up to two times per year.

9. How is an ABLE account different than a special needs or pooled trust?

An ABLE Account will provide more choice and control for the beneficiary and family. Cost of establishing an account will be considerably less than either a Special Needs Trust (SNT) or Pooled Income Trust. With an ABLE account, account owners will have the ability to control their funds. Determining which option is the most appropriate will depend upon individual circumstances. For many families, the ABLE account will be a significant and viable option in addition to, rather than instead of, a Trust program.

Visit Oregon 529 Savings Network for more information:

<http://www.oregon529network.com/faqs/able-savings-faqs/>

Representative Payee

Some individuals with disabilities receive government, military and other benefits. They usually receive these benefits by check made payable to the recipient. Many individuals with developmental disabilities can manage this money. However, others may need support with money management or may be vulnerable to exploitation by others.

The administrator of these benefits, such as the Social Security Administration (SSA), may sometimes assign a representative payee for a recipient of these benefits. This payee receives and distributes the benefits when the individual with intellectual disability cannot manage the check. In some cases, family members serve as Representative Payees. However, in many instances non-governmental organizations (i.e., public guardian offices, clubhouses, or even for-profit companies) serve as Representative Payees. The payee must regularly account to the benefit's administration on the use of the benefit check, and is liable to repay money if it is mismanaged.

The decision to assign a representative payee to someone is usually based on non-legal documents such as a doctor's report. Contact your local SSA office or administration office of other benefits for more information on the representative payee system. For more information, go to SSA's web site www.ssa.gov/payee

Power of Attorney

Power of Attorney is a legal document that permits a decision maker (agent) to make decisions on behalf of another person. It is most frequently used for financial management, and cannot be used for medical decisions.

Conservatorship

A Conservatorship is a formal method of managing and protecting the income and assets of an individual. Conservatorship is appointed and supervised by the Probate Court.

Support Services through Brokerages

What are Support Services for Adults?

Support Services for Adults with developmental disabilities are individually designed supports that assist a person with developmental disabilities to live in their own home or with family or friends and fully participate in community life, including work. These services are different from Comprehensive Services, such as residential services, group homes, and foster homes, which may provide 24 hour support. Support Services are available through support brokerages.

What is a Support Brokerage?

A Support Brokerage (or Brokerage) is an organization that helps an adult with developmental disabilities develop an individualized plan for community living and access supports to implement the plan. Oregon has regional brokerages throughout the state. You have the right to choose whether you would like to receive services through your county DD program, or through a brokerage.

What happens if I decide to access services through a brokerage?

Once you are referred to a brokerage in your area, a Personal Agent (the brokerage equivalent of a Services Coordinator) and others of your choice will help you plan for the services you need and build a budget to pay for these services. After the brokerage authorizes the plan, you can begin the process of hiring someone to provide your supports. The brokerage will assign a Personal Agent to you, but you can request a different PA if you feel your needs would be better met by someone else.

How will my Personal Agent help me?

Your Personal Agent will use a person-centered planning process to help you, and the people close to you, identify your support needs. The PA will help you figure out how to get your goals and needs met and what resources are available to you, including unpaid natural supports. All of this is written into a plan called an Individual Support Plan (ISP). Your Personal Agent makes sure your support needs are addressed in your plan. They will write the plan with you, but it will be your plan, and you will decide what it includes. You have the right to change

your plan whenever you need to or want to.

Your Personal Agent will also help to make sure your plan is carried out as you expect. They will help you coordinate all the resources you need for your plan. These resources may include private funds, community resources and public benefits, such as housing or food stamps.

Your PA will not make decisions about you or for you, but will help you, as needed, make your own decisions. Once you get the funding for your services, you will employ people, organizations or agencies to deliver your services. Your Personal Agent can help you find these people.

Who will provide my support services?

Your Personal Agent will help you through the process of identifying, choosing and hiring one or more providers. Your PA will also help you understand how to manage your providers.

You can be quite creative in designing supports to meet your personal needs.

Here are some typical supports you might purchase through providers:

- Assistance with daily living skills (cooking, eating, cleaning)
- Help and instruction with personal care (bathing, dressing, grooming)
- Increasing communication skills (expressing yourself, using technology, reading skills)
- Budgeting assistance
- Transportation
- Support to participate in your community
- Employment supports
- Respite care for your family members that provide you help
- Behavioral support

Who will provide my support services?

You are in control of your budget and provider selection. Your Personal Agent assists you in making informed and cost effective decisions and choices from

among qualified providers. You will interview potential providers and choose the one that best meets your values and needs.

What resources are available to help me be an employer?

For detailed information on hiring employees, please review the Domestic Handbook and Domestic Policy Handbook. This can be downloaded at: <http://www.sdri-pdx.org/customers/index.html>.

What else can a brokerage do for me?

A brokerage will help you learn to make informed decisions about your plan and services. You will learn how to talk to providers about what is working and not working in your plan, and how to change your plan and services as needed.

The brokerage is expected to monitor service quality. One important way they do that is through an annual Customer Satisfaction Survey. You are asked to respond to a series of questions about how satisfied you are with the services of the brokerage. You are asked if you are getting the types of support you need to do what you want to do.

A brokerage will serve as your fiscal agent, which means it will help you manage your Support Service funding. A fiscal agent helps keep track of funds used, pays those people or agencies you hire to provide services, and handles the tax responsibilities that you may have as an employer.

Please talk to your Services Coordinator for more information about Brokerages, or if you are interested in receiving services through a Brokerage.

Guardianship

Guardianship is an important issue for individuals who experience developmental disabilities and their families and caregivers. We offer the following information as a primer on guardianship and Arc programs. For more information, contact Kathy Bullard, The Arc of Oregon Guardianship, Advocacy, and Planning Services (GAPS) Representative for our area at 503-910-9671 or kbullard@thearcoregon.org

Guardianship

In Oregon, parents are recognized as the natural guardians of their children until the children reach the age of 18. At that time, parental natural guardianship ceases by law, *whether or not the children have a disability*. Any person attaining the age of 18 is recognized as a competent adult by law, and remains so unless found incapacitated by a court of law.

Without the court's determination that an individual is incapacitated, the individual retains all their constitutional rights and is responsible for making their own decisions. These rights include the rights to decide residence, consent to or reject medical care, sign a contract, marry, and make lifestyle choices.

Determining Incapacitation

A person can be found to be incapacitated under Oregon Revised Statute (ORS) if they are an adult whose "...ability to receive and evaluate information effectively or to communicate decisions is impaired to such an extent that the person presently lacks the capacity to meet the essential requirements for the person's physical health or safety. 'Meeting the essential requirements for physical health and safety' means those actions necessary to provide the health care, food, shelter, clothing, personal hygiene and other care without which serious physical injury or illness is likely to occur."

Determining the Need for a Guardian

Whether or not an individual needs a guardian depends on many factors. Perhaps the most significant is the individual's ability to give informed consent. Informed consent is a person's agreement to allow something to happen, based on full disclosure of the facts needed to make the decision

intelligently. Many persons with developmental disabilities are capable of independently making, or significantly participating in, many decisions that affect them. The imposition of guardianship can greatly reduce or eliminate this freedom to participate by transferring decision-making powers to the guardian.

Even those persons who are apparently unable to make significant decisions on their own may not require guardianship if they have trusted support from family, friends or interested others who are willing and available to counsel them.

Unless they are totally incapable of giving input to decisions that affect them, persons with developmental disabilities are likely to benefit from assistance and counseling which is less formal than guardianship. This allows them to retain their essential civil rights while still benefiting from the guidance of those who care.

It is important to remember that persons with developmental disabilities are capable of increasing their potential throughout their lives, particularly if they are allowed to do so in ways which are least restrictive to their personal liberties. For the vast majority of individuals, this means living in a supportive community environment where they are able to learn from a variety of social situations. This learning process may provide a knowledge base sufficient to decrease the need for guardianship.

Frequently Asked Questions about Guardianship

What is Guardianship?

A guardian is an individual or organization named by an order of the court to exercise any or all powers and rights over a person who has been determined to lack the ability to make and then act upon personal decisions on their own behalf. The court grants the guardian the authority to make decisions, which may include:

- medical treatment
- residential placement
- education and vocational needs
- other issues

Guardianship for an adult can be awarded only through a court of law. It is a court-approved, legal relationship between a competent adult called

a "fiduciary" or "guardian" and an incapacitated adult called a "protected person" (formerly called "a ward"). Guardianship is subject to the supervision of the court. Under Oregon law, ORS 125.300 (1), guardianship is to be used for an incapacitated person only "... as is necessary to promote and protect the well-being of the protected person. A guardianship for an adult person must be designated to encourage the development of maximum self-reliance and independence of the protected person and may be ordered only to the extent necessitated by the person's actual mental and physical limitations."

Further, ORS 125.300 states, "An adult protected person for whom a guardian has been appointed is not presumed to be incompetent. A protected person retains all legal and civil rights provided by law except those that have been expressly limited by court order or specifically granted to the guardian by the court. Rights retained by the person include but are not limited to the right to contact and retain counsel and to have access to personal records."

Guardianship is a legal way to assist the person indefinitely or until they are no longer incapacitated. It should be considered only after less restrictive alternatives have been evaluated and determined not appropriate to meet the person's needs.

For some people, the following less restrictive options may offer appropriate support (alternatives to guardianship are discussed more thoroughly beginning on page 23):

- Appointing their own Health Care Representative (covered in ORS 127.505-127.660)
- Having a Health Care Representative appointed by the individual support plan (ISP) team under the Oregon Administrative Rules (OAR 309-041- 1500 to 309-041-1610/available only to someone living in a 24 hour residential facility or receiving supported living services*)
- Having a representative payee or conservator appointed
- Offering different support services
- Assigning someone as advocate

For other individuals, either a limited or full guardian may be needed for

most decisions. There are some decisions, however, such as consent to sterilization, which cannot be made by a guardian (ORS 125.320) under any circumstances. (See Restrictions on Guardianships)

Who needs a Guardian?

The fact that a person has a disability does not automatically dictate a need for guardianship. The test for determining the need for guardianship focuses on the ability of the person to make decisions and to communicate decisions once made. Making incorrect or ill-advised decisions on a periodic basis is not the test. Rather, it is an inability to engage in the decision-making in the first place which is important.

An individual may need guardianship services if they cannot make sound decisions about where to live and work, how and when to seek medical care or other professional services, how to properly care for dependents or how to purchase items such as food and clothing.

Questions to consider:

- Does the person understand that a particular decision needs to be made? Does the person understand the options available in any decision?
- Does the person understand the consequences of each option?
- Is the person able to properly inform appropriate parties once the decision has been made?

Why a person may need a guardian:

There may be different reasons why an individual with a developmental disability may need a guardian. Some common reasons are:

- The person cannot adequately manage personal assets. Someone is needed to ensure the assets are secure and used for the intended purpose.
- The person needs medical care or other services that will not be provided unless there is a clear understanding about the person's legal capacity to consent to treatment or services. Health and service providers are becoming more concerned about liabilities when providing services to someone who may not have the capacity to make an informed consent for services.
- Parents or siblings cannot get access to important records or provide other help without guardianship. As a legal adult, a person with

developmental disabilities must often give consent for the release of health and other records to parents or others. Health and service providers unsure of the person's ability to give consent may require documentation of the person's legal capacity before allowing access to records without the person's consent. (Note: The recent implementation of the federal law, the Health Insurance Portability and Accountability Act, or HIPPA, creates new and significant penalties for health care providers and others who release records without approved consent of the patient or client.)

- An individual with developmental disabilities may require the help of an advocate—someone who has a legal status or relationship to that person.

How do I determine if my child needs a guardian?

In many cases, there are no easy answers to this question. In addition to considering your child's decision-making competency, a parent should consider medical needs, residential issues and need for advocacy assistance. Individuals with similar abilities may require different levels of intervention and assistance, depending on their family involvement, living situations and available supports.

Questions for parents to consider when determining the need for a guardian:

- What is your child's ability to understand questions and communicate answers?
- Does your child have a sense of consequences? Given support and objective assistance, can he or she make a decision based on knowledge of the situation?
- Can your child express personal wishes and preferences? Are they living in a residence where these preferences are respected?
- Does your child have a sense what is needed for their own well-being?
- What are the medical needs of your child? Can they understand basic treatment decisions? Will medical professionals accept their signature for consents? Will you have difficulty obtaining necessary medical information?
- Have you considered less restrictive alternatives?

What are the types of Guardianship?

There are three types of guardianship recognized under Oregon law:

1. temporary and emergency guardianship
2. limited guardianship
3. full guardianship

1. Temporary and Emergency Guardianship

A temporary guardianship is limited to a specific purpose and for a time period of up to 30 days (with a 30-day extension possible). This may be used in an emergency medical or dental situation if less restrictive means are not available.

The notice of a proposed temporary guardianship must be given or sent to the same list of people and in the same manner as for non-emergency guardianship proceedings. The notice must be given at least two days *prior* to the appointment of a temporary guardian unless the court finds that there is immediate and serious danger that requires the immediate appointment of a guardian.

A petition requesting an *emergency* temporary guardianship must specify why there is immediate and serious danger to the life or health of the proposed protected person and that the welfare of the proposed protected person requires immediate action. The court may waive the usual required notice before the appointment is made for an emergency guardianship. The notice is then required within two days *after* the appointment is made.

The court will appoint a visitor who will conduct an interview with the proposed protected person within three days and write a report within five days after the appointment of a temporary guardian. The court will hear any objections within two working days after the date the objections were filed.

The appointed temporary guardian has access to those records and information that are related specifically to the purpose of the temporary guardianship. The temporary guardian must report to the court as to what action(s) they have taken when the guardian's duties are completed, the temporary appointment expires, or the court orders the termination of the appointment.

A temporary guardian who becomes a permanent guardian (*through additional legal action*) may include this information in the first annual court report.

2. Limited Guardianship

Filing for a limited guardianship is a legal process for a guardian to be appointed to act on behalf of a protected person in areas such as where the person lives (including in or outside of Oregon), medical care and treatment, or other areas that the court has specified.

It is generally accepted that limited rather than full guardianship should be used to the maximum extent possible. For example, a court will limit the guardian's authority to health care decision-making if a protected person needs assistance in making health care decisions, but not in making decisions about where they work or engage in leisure activities.

3. Full Guardianship

A full guardian has full, decision-making authority. A guardian can determine, for example, medical care and treatment; and where the protected person lives and works. Under ORS 125.300 (3), however, **a protected person retains all legal and civil rights not specifically limited by the court, including the right to contact an attorney, the right to have access to personal records, and the right to vote.** There is no competency requirement for voting in the State of Oregon.

Additionally, if a protected person resides in a facility licensed by the State of Oregon (such as a group home serving persons with disabilities), that individual's guardian is ensured the rights identified under Oregon Administrative Rules and ORS 430.210. The guardian, for example, may become a member of the Individual Service Plan (ISP) team.

What is the process for obtaining a Guardianship?

The following information describes the process for limited and full guardianships. Refer to previous information under "Types of Guardianship" for a brief summary of the procedures for temporary and emergency guardianships. Costs for obtaining a guardianship may vary a great deal depending on filing fees, the court visitor's fee and legal fees. The Arc recommends that a petitioner consult an attorney who specializes in guardianship.

Steps for Obtaining Limited and Full Guardianships

1. Filing the Petition

A petition to the court must be filed in the county where the respondent (the proposed protected person) lives. The assistance of an attorney is most often enlisted in the preparation of a guardianship petition. The attorney does not need to be located in the respondent's county. However, it may be more convenient and less costly if the attorney practices in the county where the proposed protected person lives. The petition must specify the request to appoint a guardian. It must include information such as:

- Name, age, and address of the respondent
- Name, age, and address of the petitioner
- Name of the proposed guardian
- Treating physician's name(s)
- Care provider(s)
- Factual information that supports the request for the guardianship
- Any limitations of the guardian's powers

The petition should include a statement as to whether the proposed guardian has had any past criminal convictions, cancellation of any occupational licenses, or bankruptcy proceedings. The future guardian must also indicate whether they intend to place the respondent into a mental health treatment facility, a nursing home, or other residential facility. *(After the guardianship appointment, the guardian must still file a statement informing the court of any intention to make a placement into one of these facilities if the need arises at a later date.)*

The petition also includes a general description of the estate of the respondent, sources and amount of income. If the proposed guardian seeks to exercise any control over the estate of the respondent, there is additional information that is required. ORS 125.055 details the information that is to be included in the petition

2. Serving Notice

After the petition is filed with the court, notice must be delivered to the proposed protected person stating that a petition for the appointment of a guardian has been filed. The notice must be presented so that the person receiving it can understand it, printed in

14 point type, and it must be served at least 15 days before the final date for filing objections to the petition.

The notice will include the name, address and telephone number of the petitioner or the person making the motion and their relationship of the petitioner to the respondent. Additionally, the notice will include a statement where objections may be made or filed and the deadline for making an objection. If a hearing has been set, that information will also be included. A copy of the petition must be enclosed. Additional requirements regarding this notice can be found in ORS 125.070.

The notice must be sent to others entitled to receive notice at least 15 days before the final date for filing objections to the guardianship petition. Others entitled to receive notice include the following:

- The spouse, parents and adult children of the proposed protected person
- The person or persons most closely related to the proposed protected person if there is no spouse, parents or adult children
- Any person living with the proposed protected person and interested in her/his affairs or welfare
- Any person already nominated or appointed to act as a fiduciary (such as a conservator) by a court of any state
- Any trustee of a trust established by or for the proposed protected person
- Any person appointed as a Health Care Representative under ORS 127.505-127.660
- Anyone acting under a power of attorney from the proposed protected person
- The Department of Veterans Affairs if the proposed protected person is receiving money through that government agency
- Any other person the court requires to be notified

Objections to the petition may be either written or oral. (The designated way to present an oral objection will be defined by each local court.) Anyone not on the original list to receive future notices may inform the court *and* the proposed guardian in writing that they would like to receive copies of future filings in this case. The request

to the court must include name, address, phone number and payment of any applicable fees.

3. The Court Visitor

The court will appoint a third party, called a visitor. The visitor must not have any personal interest in the case, must have training or expertise to evaluate the abilities and needs of the named person and may not be the one to serve the guardianship notice to the proposed protected person.

The visitor will interview the proposed guardian, the proposed protected person, and any others with relevant information. Within 15 days of the court visitor appointment, a written report is to be submitted to the court with recommendations regarding the appropriateness of guardianship and the suitability of the proposed guardian. Additional time may be allowed to file the visitor's report at the discretion of the court. Anyone (including persons on the list of those entitled to receive notice) wanting a copy of the visitor's report must file a *specific* request for a copy.

The court considers the information contained in the petition and the visitor's report to determine the following:

- Whether the proposed protected person is incapacitated in the areas outlined in the petition
- Whether the appointment of a guardian is necessary
- Whether the proposed guardian (identified in the petition) is qualified and willing to serve
- Whether any limitations should be placed on the guardian
- Whether there is a need for further evaluation

Fees for the court visitor vary from county to county. In Multnomah County there is a set fee, but in many other counties, the visitor's fee is determined by an hourly rate.

4. After the Court Visitor

If there are no objections and the court decides that the respondent needs a guardian and that the proposed guardian is the best one, it will write the guardianship order appointing the fiduciary or guardian. A hearing will be held if the court feels it does not have enough information, the information conflicts, or there are objections filed.

At the time of the hearing, evidence will be presented to the judge. The proposed protected person can request an attorney from the court. Both sides can call witnesses and bring evidence. The judge will then decide if the proposed protected person needs a guardian, who will be the guardian, and the guardian's specific responsibilities.

5. After the Appointment of a Guardian

After determining the need for guardianship and the qualifications of the nominated person, the court will make a guardianship order that defines the restrictions and powers of the guardianship. A copy of the order must be attached to the Letter of Guardianship issued by the court. ORS 125.310 specifies the format to be used. The court may require that the guardian post bond. Be sure to let the individual's Services Coordinator know about any changes in guardianship, and be prepared to provide a copy of the Letter of Guardianship.

Once the judge signs a guardianship order, it remains in effect indefinitely, or until the protected person or other interested party successfully petitions to have the guardianship terminated, the judge terminates the guardianship, or the guardian (with court approval) resigns. *The exception is temporary guardianship, which lasts 30 days with a possible extension of an additional 30 days.*

A judge may remove a guardian *without* a petition with the determination that "the best interests of the protected person would be served by termination of the proceedings." (ORS 125.090 [2] [e]) It may be possible that a protected person continues to be incapacitated, that the current guardian is not serving in the protected person's best interest, and that the judge terminates the guardianship.

At any time after the appointment of a guardian, the court may appoint a visitor. The visitor may perform any duty that they would have performed at the time the guardianship petition was originally filed.

This could include interviewing people, examining records, reporting to the court in writing, and being present at any hearings.

A guardian may resign at any time with the approval of the court. If the guardian resigns or is removed, a successor guardian may be

appointed, unless the protected person successfully shows, in the same proceeding, that they are no longer incapacitated.

6. When a Guardian Dies

A guardian may inform the court through their Last Will and Testament (also known as a testamentary nomination) who they wish to be guardian following the testator's (guardian's) death. In Oregon, the courts give special consideration to the person testamentarily nominated, although the person ultimately selected must be both willing and capable of serving and must be found by the court to be fit to serve.

Who may be Guardian?

Any person at least 18 years of age, who is able to make informed decisions, who has not been convicted of a serious crime, and is acceptable to the court, may be named guardian of an adult with disabilities. The court may also appoint an agency, public, or private fiduciary.

What are a Guardian's responsibilities?

1. Except as limited in the court order, the guardian has custody of the protected person and determines where they live. ORS 125.315 (3) states before a guardian may place an adult protected person in a residential care facility or mental health treatment facility, the guardian must file a statement with the court informing the court the guardian intends to make the placement. A copy must be given to the protected person, and anyone else entitled to receive such notices, indicating the manner in which the protected person may object to the proposed move.

If the protected person lives in a nursing home or residential facility, a notice must also be sent to the Long Term Care Ombudsman. If the protected person lives in a mental health treatment facility or a facility for individuals with developmental disabilities, the notice must be sent to the Oregon Advocacy Center, which is the system in Oregon that is designated to protect and advocate for the rights of individuals with developmental disabilities and/or mental illness. For more information regarding this notice, consult your attorney or the Oregon State Statutes.

2. The guardian provides for the care, comfort and maintenance of the protected person and as appropriate, arranges for his or her training and

education. The guardian shall take reasonable care of the protected person's clothing, furniture, and other personal effects unless a conservator has been appointed.

3. Subject to certain statutory restrictions, the guardian may authorize medical decisions on behalf of the protected person. The guardian should seek to carry out the wishes of the protected person, or if they are not known, the guardian should act in the best interest of the protected person. A guardian may not authorize sterilization of a protected person.
4. The guardian may make burial and funeral arrangements. Pursuant to ORS 97.130, the guardian may control the disposition of the remains of the protected person and subject to the provisions of ORS 97.954; the guardian may make an anatomical gift of all or part of the protected person's body.
5. The guardian may receive nominal sums of money on behalf of the protected person to pay for care, support and education of the protected person. The guardian must take care not to become involved in financial conflicts of interest. The person's funds may not be used to pay the guardian for providing services or to pay legal fees and court costs pertaining to the guardianship unless previously approved by the court.
6. A guardian must make an annual report to the court within 30 days of the anniversary date of the establishment of the guardianship. Copies of this report must be given to the protected person and any other person/agency entitled to this report. This report and further details may be found in ORS125.325.
7. The guardian must promptly notify the court if they have any change in name, residence, or post office address.

Are there restrictions on guardianship decisions?

The Court has the discretion to grant a guardianship with restrictions. In that case, the appointed guardian's authority is limited to the areas that the Court outlines as necessary. Some decisions that the Court may decline to include in the appointment of a guardian's authority are: living arrangements, consenting to medical treatment, hospitalization or institutionalization, participation in lawsuits, property management and real estate transactions, payment or collection of debts, or creation of a will.

If a surgery is necessary for medical reasons that may result in sterilization, this procedure must be reviewed by the Oregon Advocacy Center before consent can be given. In some cases, two medical opinions may be required.

The Court looks at each individual's unique situation and tries to impose only those conditions that are absolutely necessary to maintain that individual's well-being. As stated earlier, a guardian may not authorize sterilization of the protected person.

Some individuals require assistance with both personal care and estate management. In Oregon, the primary responsibility of the guardian is to provide consent for issues such as medical treatment and living situation. A Conservator can be appointed the responsibility of managing some or all of the property and/or income of the ward.

Guardianship is a long-term engagement between the Court, the appointed guardian, and the protected person. The court may modify, revoke, or terminate the guardianship if the protected person's situation changes, including revocation of the guardianship if the protected person's ability to make and communicate decisions is demonstrated to the court.

What are the standards for a good Guardian?

The guardian is responsible for promoting independence and assisting the individual to continue to grow toward taking charge of his or her affairs. Decisions made on the protected person's behalf should be based on his or her preferences as much as possible. In addition, the guardian has implicit responsibility to protect the protected person from exploitation, abuse, and neglect.

In the early 1990s, the National Guardianship Association (NGA), a newly formed group of professional guardians, advocates and others, adopted a code of ethics and standards of practices to help guide professionals and parents on issues that guardians face, and how to respond to these issues in the day-to-day role of a guardian. These standards have been continually reviewed and updated, and today comprise 24 different standards covering areas such as informed consent, confidentiality, conflict of interest, and self-determination. While many of these standards may be more germane to professional guardians, family members may want to review these standards, which may help provide guidance in undertaking the role of guardian.

For a copy of the NGA's Standards of Practice from their Web site go to www.guardianship.org

Are there alternatives to Guardianship?

Before pursuing guardianship, family members should first consider using less intrusive measures. For example, someone who lives alone and has trouble managing money may not need a legal guardian. The person may only need a restricted bank account and the occasional visit of a case manager, family member or other trusted person for help in budgeting money and paying bills.

Alternatives to Guardianship include:

- Representative Payee
- Joint Bank Account
- Trust Account
- Conservatorship

These do not always carry the "legal weight" of guardianship. Instead, they may only legally protect the person or property to a limited degree, or are non-legal services or options that may meet the individual's needs instead of legal guardianship. It is a good idea to consult with a knowledgeable attorney experienced in disability issues to make sure alternate plans do not inadvertently jeopardize government benefits or create other legal problems.

Representative Payee

Some individuals with disabilities receive government, military and other benefits. They usually receive these benefits by check made payable to the recipient. Many individuals with developmental disabilities can manage this money. However, others may not have good money management skills or are vulnerable to exploitation by others.

The administrator of these benefits, such as the Social Security Administration (SSA), may sometimes assign a representative payee for a recipient of these benefits. This payee receives and distributes the benefits when the individual with intellectual disability cannot manage the check. In some cases, family members serve as Representative Payees. However, in many instances non- governmental organizations (i.e., public guardian offices, community mental health centers, clubhouses, or even for-profit companies) serve as Representative

Payees. The payee must regularly account to the benefit's administration on the use of the benefit check, and is liable to repay money if it is mismanaged.

The decision to assign a representative payee to someone is usually based on non-legal documents such as a doctor's report. Contact your local SSA office or administration office of other benefits for more information on the representative payee system. For more information, go to SSA's web site www.ssa.gov/payee

Joint Bank Account

Most banks can assist with creating a bank account to help manage money. For example, benefit checks can be directly deposited and certain bills automatically paid. It may also be possible for spending money to be sent regularly to the individual from his or her account. A joint bank account can help an individual manage money and prevent excessive expenditures.

Power of Attorney

Power of Attorney is a legal document that permits a decision maker (agent) to make decisions on behalf of another person. It is most frequently used for financial management, and cannot be used for medical decisions.

Trust Account

Setting up a trust may protect money or other property from being overspent or mismanaged. A carefully written, restricted trust may provide financial protections that relieve the need for other legal protections such as guardianship.

Conservatorship

A Conservatorship is a formal method of managing and protecting the income and assets of a minor or a person who is incapable. Conservatorship is appointed and supervised by the Probate Court.

Health Care Representative

A health care representative is a person that is appointed to make medical decisions for another individual. The legal form documenting this appointment must be updated annually.

Considerations for Parents

There are a number of factors that may lead parents or others interested in the welfare of adults with developmental disabilities to seek guardianship. Perhaps the most common for parents is the desire to establish some control over their adult child's life. They may feel that their child is incapable of acting responsibly, or they may wish to exert what they feel is a positive influence over their adult child.

Unfortunately, this is not always a valid or even an effective reason for establishing guardianship. Although legal authority is established upon the appointment of a guardian, the legal mechanism in itself cannot prohibit the protected persons from acting as they please.

Another common reason for establishing guardianship is to create substitute decision-making authority in case the protected person is unable to give informed consent. Consent is generally considered to be valid only if it is given by someone capable of recognizing the potential ramifications of his or her decision.

This dilemma often arises in medical situations in which physicians and other health care professionals are placed in the legally sensitive position of treating a person of questionable capacity and asking for informed consent. Some physicians, in this situation, will accept consent only from an adult, legally empowered by appointment as guardian, to provide substitute consent on behalf of the individual. The appointment of a Health Care Representative either by the individual or by the ISP team may be desirable and/or preferable over the expense of obtaining a guardianship. (The laws governing the appointment and responsibilities of a Health Care Representative are contained in ORS 127.505-127.660 for a self-appointed Health Care Representative and OAR 309-041-1500 to 309-041-1610 for an ISP team appointed Health Care Representative.)

Parents may also seek guardianship in order to control their offspring's finances. They may fear the potential of an unscrupulous person taking advantage of them. They may also be concerned that they may make unwise purchases without fully realizing the consequences. Financial protection alone is generally an insufficient motive for establishing guardianship due to the protected person's loss of fundamental rights.

If an individual's assets consist primarily of payments from Supplemental Security Income, Social Security, or other sources of governmental support, a

representative payeeship might be most appropriate. This is a mechanism that authorizes one person to receive payments allotted to another person who is deemed incapable of handling them properly. The Social Security Administration, Veterans Administration and some private pension plans have created payee provisions. Under payeeship, a person is not declared by the court to be incapable of handling his or her property. The person remains legally capable of controlling all of his or her property and assets, except those subject to payeeship.

Other parents may petition for guardianship to gain increased authority to demand better and more appropriate services for their daughter or son. This may or may not be an effective strategy, depending on a number of factors outside of the guardianship itself, such as the overall relationship between parents and service providers. Guardianship does allow access to a protected person's records, and that fact alone may be a driving force for parents to seek guardianship.

Stories

(Note: Names have been changed to protect confidentiality)

Choosing to be a Guardian for Medical Reasons

Janet and Cliff always knew they would file for guardianship for their son, Thomas, because he had on-going medical needs, in addition to his developmental disability. He had a seizure disorder that required medications and frequent neurological appointments. He also had scoliosis, allergies, asthma, sinus and ear infections, and seemed to be more susceptible to colds and viral infections than their other children. Since he was non-verbal, these illnesses were often difficult to diagnose and required close monitoring and creative problem solving. They had a good working relationship with his physician, but since he saw several specialists, they were concerned that maintaining access to his records and directing his medical care would be impossible without legal guardianship.

As Thomas approached 18 years of age, Janet initiated the process with an attorney. She was surprised to learn of the fees and court costs, and felt they could not afford the process at that time. Since Thomas had no immediate medical needs, and his pediatrician still played a major role in providing his medical care and making referrals, she and Cliff decided to wait until they saved some money for this legal process. Three years later,

they began the guardianship process with an attorney recommended to them.

Janet felt the process went smoothly and since there were no objections, they never even saw a judge. She said the court visitor was friendly and recognized that Thomas couldn't make independent decisions and would always need someone to advocate on his behalf. As she recalls, the entire legal procedure took about two months. She said there were several things they did to save time and attorney expenses. Knowing they would need a statement from their son's physician explaining his disability and need for guardianship, she asked Thomas's pediatrician to write a letter documenting his needs. She also had a psychological evaluation from the school and had discussed their decision to pursue guardianship with his teacher weeks before they contacted the attorney. She knew they would have the support of all involved.

The one thing Janet cautions parents however, is that they remember to file the annual guardianship court reports on a timely basis. "It's a relatively easy form", she explained, "and there have never been any questions concerning it after filing it with our probate department. But if you're not careful, you could overlook the date and forget to send it in. We have made sure October 20 is one of those dates we never forget—sort of like April 15."

Choosing to be a Guardian for a Daughter

Mark has been a single dad since his daughter was 8. "Sophie and I have always been close and although I'd like her to be as independent as possible, I'm her dad and know her better than anyone else. When she needs someone to help her out or make sure she's doing ok, I'm going to be that person." What concerned Mark most as Sophie entered her teen years, was that people sometimes assumed she understood more than she actually did. He said it was as if she had all the right answers, but never really got the questions. "If you stop and ask her what she means, she gets frustrated, and you realize that she's putting phrases together that she's heard from everyone else."

As her peers grew up, Sophie wanted to share their experiences and that caused some tensions at home. Every parent has protective parenting instincts, and as Mark says, "When you have a teenage daughter with a disability, you can get anxious about even daily routines." Eventually she

settled into a job at a sheltered workshop and their lives took on a predictable, steady pace. That all changed when Mark began experiencing health problems and realized he couldn't always be Sophie's care provider. He also began accepting the fact that she needed her own life, separate from him. She eventually moved into a group home, giving her 24-hour support, but also a sense of being on her own.

Soon after Sophie moved, Mark decided to contact an attorney about guardianship. He wanted to make sure that even though his daughter lived half way across town, and spent most of her week with other people, he would still be included on her team and would be responsible for major decisions. As he put it, "I didn't want to take anything away from her, but I knew she couldn't even tell a doctor what her symptoms were if she got sick. And I knew she would go along with just about anything people wanted."

Initially there were a few staff members that questioned why Mark would pursue guardianship. They saw it as a threat to Sophie's self-determination. But most of the team members acknowledged that Sophie really couldn't make independent decisions; she was easily influenced by others, and was not able to form opinions without people offering their own first. They also knew that Mark tried to balance what was in his daughter's best interest, with what he thought she would want for herself. Sophie didn't fully understand the implications of having a guardian and didn't object to her father's new role. She simply saw him as her father, someone she trusted and looked forward to seeing every weekend.

Choosing not to be a Guardian

James is an adult with Down Syndrome. He lives in his own suite on the third floor of his family home. He takes public transportation daily to his job in the hospital cafeteria where he has been the busboy and dishwasher for 12 years. Dorothy and Tom, James' parents, have not pursued guardianship for their son. James takes his parents' advice about his own medical care, finances, and recreational opportunities. However, while James is involved in making his own decisions and has a basic understanding of his own health needs, it is Dorothy who makes his appointments and coordinates his care. She acknowledges there may come a day when medical professionals may be reluctant to share information with her, due to a recent privacy act and hospital regulations. As long as James is able to sign

consents allowing them to receive information, guardianship does not appear to be necessary.

If the time comes when James might move out of the family home, into a supported living environment, Dorothy would reconsider the need for guardianship. It is questionable whether James can make informed decisions for himself and she feels others easily influence him. In that case, to ensure that she will be informed about issues in his life and continue to play a decision-making role, guardianship may prove to be the best solution.

“Guardianship involves a court process that doesn’t seem appropriate or necessary in our case,” Dorothy said. She is also concerned how he would perceive this legal procedure. “I want to preserve my son’s dignity.”

Dorothy and her husband began addressing James’ future planning needs when he was young. They took steps to provide for his financial support and, now that his siblings are older, know his younger siblings will step forward to advocate on his behalf.

Choosing to be a Health Care Representative

When Ray and his twin sister, Kay, were born in the 1940s, children with developmental disabilities in Oregon were frequently sent to Fairview Training Center. Ray’s parents kept him at home and raised him with their other children. He had two older sisters, but was particularly close to his twin, Kay, who was not disabled.

Their mother was instrumental in the founding of an agency that provides residential services for individuals with mental disabilities. Ray moved to this residential program in 1986 after his mother’s health began to fail.

Although their mother wanted Kay to assume guardianship of Ray after their mother’s death, the rest of the family had mixed feelings about this decision. Instead, they chose to be joint advocates.

As he aged, Ray became medically fragile, which required a move to a home offering more individual care. This was a difficult time for Ray, because he was very attached to his previous staff and had received excellent care. Even if she had been his guardian, Kay realized she could not have kept Ray in the same home, so she supported him in his new environment and worked with his team to ease his transition. As Ray’s health needs increased, it became evident he needed someone to provide

legal consents for medical treatment. She became his appointed Health Care Representative (HCR), which gave her the legal right to be informed of his condition, involved in making decisions, and the legal authority to sign medical release forms.

“I always felt that my sisters and I were heard and respected by the medical community,” Kay said. “My role was to let the medical support teams know who Ray was, his likes, and dislikes.”

Kay was a constant in Ray’s life until his death in 2003. Together with her sisters and Ray’s Individual Support Team, she made decisions based on his best interests, and to the best of her ability, what he would have wanted for himself.

Terms & Definitions

Conservatorship – A formal method of managing and protecting the income and assets of a minor or a person who is incapable. Conservatorship is appointed and supervised by the Probate Court.

Court Visitor – A person appointed by the court under ORS 125.150 for the purpose of interviewing and evaluating a respondent or protected person and the person seeking guardianship.

Developmental Disability – A disability attributable to autism, cerebral palsy, epilepsy and/or other neurological condition which requires significant support to manage day-to-day activities.

The disability:

- originates before the individual is 22 years old, except in the case of intellectual disability, which must be manifested before age 18 and,
- has continued or can be expected to continue, indefinitely and,
- constitutes a substantial handicap to the ability of the person to function in society or,
- results in significant sub-average general intellectual functioning with concurrent deficits in adaptive behavior which are manifested during the developmental period

Individuals of borderline intelligence may be considered to have an intellectual disability if there is also serious impairment of adaptive behavior. (Oregon Administrative Rules)

Fiduciary – A guardian or conservator appointed under the Oregon Revised Statutes or any other person appointed by a court to assume duties with respect to a protected person. (ORS 125.005)

Health Care Representative – A Health Care Representative can make medical decisions and sign consent forms. Health Care Representatives are either appointed or self-appointed, depending on the individual's decision-making capacity. Each has requirements and regulations.

Appointed Health Care Representative – OAR 308 041 1500 through OAR 309 041 1610 provides for the appointment of a Health Care Representative for making "health decisions for incapable individuals in situations where there is concurrence by the ISP team regarding the individual's incapacity, the identity of the Health Care Representative and significant health care decisions." The

protected person must be an adult with a developmental disability who lives in a facility or home licensed as a 24-hour residential service.

Self-appointed Health Care Representative – ORS Chapter 127 states, “A capable adult may designate in writing a competent adult to serve as attorney-in-fact for health care.” This document is effective when it is signed, witnessed and accepted as required by the Oregon State Statutes and when the capable person becomes incapable. The Statutes also state a capable adult may execute a health care instruction as defined in ORS 127.531. This form of an advanced directive gives instructions to the Health Care Representative and must be signed and witnessed as required.

Incapacitated – “A condition in which a person’s ability to receive and evaluate information effectively or to communicate decisions is impaired to such an extent that the person presently lacks the capacity to meet the essential requirements for the person’s physical health or safety. ‘Meeting the essential requirements for physical health and safety’ means those actions necessary to provide the health care, food, shelter, clothing, personal hygiene and other care without which serious physical injury or illness is likely to occur.” (ORS 125.005)

Informed Consent – A person’s agreement to allow something to happen based on full disclosure of the facts needed to make the decision intelligently.

Individual Support Plan (ISP) – The written details of the supports, activities, and resources required for the individual to achieve personal goals. The general welfare and personal preferences of the individual are the key consideration. The individual and their team are responsible for developing the individual plan of support.

Individual Support Plan (ISP) Team – The individual, the case manager, the individual’s legal guardian, representatives of all current service providers, advocate or others determined appropriate by the individual receiving services. The team assesses personal choices and preferences, significant health care, mental health or behavioral needs and safety and financial skills. If the individual is unable or does not express a preference, other appropriate team membership shall be determined by the ISP team members. (OAR 309-41-405)

Oregon Administrative Rule (OAR) – A compilation of the administrative rules of Oregon state agencies, compiled, indexed, and published by the Secretary of State's Office.

Oregon Revised Statute (ORS) – The codified laws of the State of Oregon. The ORS is published every two years to incorporate each session's new laws. The most recent version of the ORS will have the date of the most recent Legislative session. If an ORS and OAR are in conflict, the ORS overrides the OAR.

POLST – Physician Orders for Life-Sustaining Treatment is a document designed to help health care professionals honor the end-of-life treatment desires of their patients. The document is a physician order form that follows patient wishes and treatment intentions. It is not intended to be completed by the patient or the patient's family. It is not an advance directive, which in Oregon must follow statutory wording. For more information, go to www.ohsu.edu/ethics

Protected Person - Effective January 1, 1996, “a person for whom a protective order (such as a guardianship or conservatorship) has been entered.” ([ORS 125.005](#)) Prior to January 1, 1996, “a minor or other person for whom a conservator had been appointed or other protective order made.”

Testamentary Nomination – The nomination of a guardian in a Last Will and Testament.

Links

Oregon Administrative Rules - <http://arcweb.sos.state.or.us/banners/rules.htm>

National Guardianship Association - <http://www.guardianship.org>

Resource List

ABLE Act/Savings Account

<http://www.oregon529network.com/faqs/able-savings-faqs/>

About The Oregon Special Needs Trust (The Arc Oregon)

thearcoregon.org/what-we-do/osnt/trust-overview/

The Arc of Benton County

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

Benton County Developmental Diversity (DD) Program

<https://www.co.benton.or.us/health/page/developmental-diversity-program>

Cornell Transition from School to Work PDF

http://www.ilr.cornell.edu/EDI/publications/PPBriefs/PP_4.pdf

Corvallis Parks and Recreation

<http://www.corvallisoregon.gov/index.aspx?page=56>

Disability Rights Oregon

<http://www.disabilityrightsoregon.org/need-help/planning-for-work>

Employer's Guide (For Employers of Personal Support Workers (PSWs))

<https://apps.state.or.us/Forms/Served/se9046.pdf>

Employment Success Stories

<https://www.oregon.gov/DHS/EMPLOYMENT/EMPLOYMENT-FIRST/SUCCESS-STORIES/Pages/index.aspx>

FACT Oregon Transition to Adulthood

<http://factoregon.org/family-support/transition-adulthood/>

General Disability Resources

www.disability.gov

Integrated Services Network (Brokerage)

<https://www.ccsww.org/home-page/people-disabilities/isn-support-services-brokerage/>

Linn-Benton Housing Authority

<http://www.l-bha.org/>

Mentor Oregon Mid-Valley Brokerage

<http://www.mentororegon.com/>

National Guardianship Association

<http://www.guardianship.org>

National Institute of Mental Health (NIMH)

<https://www.nimh.nih.gov/index.shtml>

Oregon Administrative Rules

<http://arcweb.sos.state.or.us/banners/rules.htm>

Oregon Council on Developmental Disabilities

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

Oregon Health Plan (OHP) Help Desk

<http://bentonlinnhealthcenters.org/>

Oregon Home Care Commission (Supports for Employers and Personal Support Workers (PSWs))

<http://www.oregon.gov/DHS/SENIORS-DISABILITIES/HCC/Pages/index.aspx>

Oregon ISP

<http://oregonisp.org/>

“Planning Your Way to Work” handbook

http://ocdd.org/index.php/ocdd/employment/category/planning_my_way_to_work_transition_guide/

Register to Vote

<https://secure.sos.state.or.us/orestar/vr/register.do>

Representative Payee Information

www.ssa.gov/payee

Senior and Disability Services

<http://www.ocwcog.org/seniors-disability/>

Social Security Administration

www.socialsecurity.gov

Social Security Red Book on Work Incentives

<http://www.socialsecurity.gov/redbook/>

Special Olympics (Susie Peters)

<http://www.soor.org/Sub-Page.aspx?Name=Benton-County&PID=89>

SSA Worksheet (to help gather and organize information)

http://www.ssa.gov/disability/disability_starter_kits.htm

Steps to Success (For Employers of Personal Support Workers (PSWs))

<http://www.oregon.gov/DHS/SENIORS-DISABILITIES/HCC/Pages/Steps.aspx>

Vocational Rehabilitation

Corvallis Office: 541-757-4131

Institute for Community Inclusion and Getting the Most from the VR System

<http://www.communityinclusion.org/index.php>

Employment Providers

Provider	Phone	Website
Collaborative Employment Innovations (CEI)	(541) 224-6503	http://ceiworks.org/
Cornerstone	(541) 752-9724	http://www.cornerstoneassociates.com/
Work Unlimited	(541) 753-5204	http://www.workunlimited.org/
Bridges/Quest	(541) 207-3750	No Website
Benco	(541) 753-5040	http://bencocorvallis.com/
Hendrickson	(541) 929-4299	No Website
Home Life	(541) 452-8026	http://homelifeinc.org/
RISE	(503) 371-3586	http://riseservicesinc.org/oregon-cat/
Alternative Services, Inc. (ASI)	(541) 967-8557	http://asioregon.org/
Blue Sun	(541) 207-3212	http://www.bluesuninc.com/
Supported Employment Services	(541) 967-3040	http://www.supportedemploymentservices.com/

Benton County Developmental Diversity Contact Information

Benton County Developmental Diversity (DD) Program	(541) 766-6847	https://www.co.benton.or.us/health/page/developmental-diversity-program
Services Coordinators		
Jennifer Beck	(541) 766-6245	
Julie Cervantes	(541) 766-6160	
Chrissy Cliburn	(541) 766-6746	
Dawn Harbach	(541) 766-6148	
Gloria Kim	(541) 766-6162	
Susan Mentzer	(541) 766-6895	
Holly Noble	(541) 766-6636	
Patti O'Bannan	(541) 766-6161	
Susie Peters	(541) 766-6196	
Fabiola Sandoval	(541) 766-6159 - English/Spanish	
Rachel VanDerlip	(541) 766-6341 - English/Spanish	
Other Benton County DD Contacts		
Amy Bonnett (Quality Assurance Coordinator, Adult Abuse Investigator)	(541) 766-0142	
Erin Bowers (Eligibility Specialist, Quality Improvement Coordinator, Adult Abuse Investigator)	(541) 766-6130	
Andrea Brush (Quality Assurance Coordinator, Adult Abuse Investigator)	(541) 766-6236	
Carrie Forty (Quality Assurance Coordinator, Foster Home Licensor)	(541) 766-6395	
Joseph Leykam (Counselor)	(541) 766-6151	
Jaime Sarabia (Office Coordinator)	(541) 766-2104 - English/Spanish	
Jasper Smith (Program Manager)	(541) 766-6158	

