

Launch: Preparing for the Transition to Adulthood



Dear Parent/Caregiver,

What do you think of when you think of adulthood? For parents of children who experience disabilities, that future may look a little different, as might their role as the parent of an adult experiencing disability. This handbook, along with the *Launch! Preparing for the Transition to Adulthood* training, provides an introduction to adult services, supports, new acronyms, and agencies, but most importantly, it introduces parents to the critically important principle of self-determination.

Your love, care, and concern may never change, but as your son or daughter launches into adulthood, your role will evolve. There is a passing of the baton; you have run your leg of the race. Now you champion, cheer, encourage, and assist your son/daughter as s/he takes off on the next leg. You held true in your pursuit of dreams you had for your son or daughter’s adult life, and in doing so, taught him/her to dream big dreams for the future. You advocated for them, modeling how to be an empowered self advocate.

Not so long ago, the future for an individual experiencing disability was somewhat

We teach our children to dream big dreams for themselves when we begin to dream big dreams for them!

predetermined. Most can think of the stereotypical assumptions of what that might have looked like (i.e. unemployed, sheltered workshop, group home.)

That is no longer the case!

The principle of supply and demand is contributing to changes in our system. Parents dreaming big dreams for their children experiencing disability are intersecting with systems charged with increasing outcomes. The results include higher expectations in school with renewed focus on access to academics and graduating with a diploma.

The Employment First movement states that everyone can work, and changes our formal systems to support and promote jobs in the community. Consumers (i.e., families and individuals experiencing disability) want to live full, enriching lives in their communities, as well as hold jobs that pay competitive wages, and

have a choice in where and with whom they live. Thankfully, those entities that fund and provide transition-related services are responding.

A closing thought... There is a lot of information presented in this booklet and throughout the training. Every effort has been made to present it in a way that doesn't overwhelm, but again, there is a lot to share on preparing for this important milestone. This training and additional transition resources are available on FACT's website (www.factoregon.org). You can also call the helpline at (503) 786-6082 or 1(888) 988-3228 ext. 302, and speak with a support specialist or request a Parent to Parent [P2P] mentor.

Self-determination

noun

- 1. the process by which a person controls his or her own life;**
- 2. Freedom to live as one chooses**

Self-determination

Self-determination is the cornerstone of your son or daughter's transition into adulthood. It is the process by which a person controls his or her own life, regardless of disability. In practice it means that:

- Everyone has a voice
- We presume competence about our loved one experiencing a disability
- We appreciate a need to stretch, take risks, and grow

Listening

It is important to ask questions and listen to our children. This looks different for each of our children. Some might share their hopes and

dreams like a faucet turned on all the way; others might share a drip here and a drip there. There may be others who need additional supports to speak their minds. Those supports might include augmentative communication, a picture chart, yes/no questions, or a facilitated person-centered plan that captures what is important to them in a way that s/he can then use to share with others. But key is the commitment to listen to the person experiencing a disability.

Presuming Competence

Presuming competence is a purposeful action; a commitment made to presume that an individual is competent to have opinions, thoughts, and insights that should be heard, respected, and honored. Culture, stereotypes, and years of focus on what someone cannot do can result in artificial ceilings. An example of this is relying on concepts like a "developmental age": in other words, if your son or daughter hasn't progressed passed X, Y, or Z milestone by a certain age, s/he never will, and therefore, is pegged at that age forever. Regardless of how one does on any assessment, presuming competence includes treating and supporting a person in such a way that honors his or her real age.

Dignity of Risk

Too often, we remove risk from the lives of individuals experiencing disability in the name of safety. In doing so, opportunities to stretch and grow are also removed. At a time when there is a

"Nothing About Me Without Me!"

- People First rally cry

lot of talk about increasing independence, we fail to allow opportunities for personal growth. Self-determination includes deciding to attempt new things, like a job in the community or moving out on one's own. In our new role during the transition period, we can help identify supports that promote growth with minimized risk.

IEP's, ISP's , IPE's... Oh My!

The Individualized Education Plan [IEP]:

- Determines what special education looks like for your son or daughter, and
- Is driven by education goals identified by the IEP team, as laid out in the Individuals with Disabilities Education Act [IDEA].

For students eligible for county developmental disability services, they may also have an Individual Support Plan [ISP] which will determine Medicaid-funded services and supports necessary to make progress toward home and community-based goals, such as increased independence and employment.

In addition, you have the Individual Plan for Employment [IPE] when you are working with vocational rehabilitation [VR] for support finding a job. It, too, is based on employment goals identified in the IPE, and results in identifying necessary supports to be used. Each will be further explained later in the booklet, but it is important to know that **individualized goals drive each of these plans,**

Student's Name: _____ Date: _____ School District: _____

Transition:
Appropriate, measurable post-secondary goals based upon age-appropriate transition assessments related to training, education, employment, and, where appropriate, independent living skills:

Course of study (designed to assist the student in reaching the post-secondary goals):

Agency Participation: If the representative from any other agency likely to be responsible for providing or paying for transition services did not attend, document the information received for consideration in planning transition services.

Graduation:
 Anticipated graduation date: _____
 ___ with regular diploma
 ___ with alternate document (describe) _____

Transfer of Rights:
 The student has been informed of his/her rights under Part B of IDEA that will transfer to the student at the age of majority. ___ yes
 Date student was informed _____

The district must also provide written notice of the transfer of rights to the student and the parent when the student reaches the age of majority.

Transfer of rights is the formal notification to the student and family that the rights under IDEA transfer to the student at age of majority, which is 18. Notice is to be given to parents and caregivers one year prior. A student can request an education surrogate, which can be a parent, to assist in his or her education-related decisions and participation in the IEP. This request would be made to the IEP case manager.

extended diploma and the alternative certificate do not meet federal requirements for federal financial aid. Preparing a student for the rigorous pursuit of a diploma starts early; do not wait until high school to discuss diploma options! High expectations are important; FACT believes that every student can achieve a diploma!

FAPE in Transition

It is important to remember that the *Free Appropriate Public Education* [FAPE] to which your son or daughter is entitled is what is included in his/her IEP; therefore, it is important to make sure the IEP is well-written and includes goals that clearly lead to where the student wants to be upon completing the transition program.

Knowing that the IEP must be individualized to each student, transition programming can look different for each person, including hours of instruction, access to vocational experience in community, agency partners, and more. Schools must make available the minimum of 990 hours of instruction per school year required for all students, including those in transition programs, but transition programming can include a combination of services like specially designed instruction identified in the IEP, work experience coordinated by a teacher, afterschool volunteer opportunities, other community experiences, or perhaps community college classes or other vocational programs.

Oregon Diploma Options		
Standard Diploma	Modified Diploma	Extended Diploma
24 credits	24 credits	12 credits
Standard grading	Modified grading	Modified grading
Proficiency in Essential Skills	Proficiency in Essential Skills	

Diploma Options

Oregon now has three tiered diploma options and an alternative certificate. It is important to understand the options and identify towards which one you believe your son or daughter will work. The three diploma options include standard, modified, and extended diplomas. Graduates with the standard diploma meet the diploma requirements required for the military; regular and modified diplomas meet eligibility requirements for federal financial aid. The

Keeping the "I" in the IEP

If you haven't already, it is recommended that you watch FACT's online training, *Understanding the IEP: Your Incredibly important Role on the Team* (available at www.factoregon.org), as it provides a comprehensive overview of the IEP process.

Specific to preparation for a transition IEP, let's review two critical components of the IEP:

Present levels is an opportunity to share parent input and concerns which can set the tone for the meeting. In addition to parent input, it is recommended that students introduce themselves at this time using a strength-based one-page profile.

Post-secondary transition goals are also important, as they set the trajectory or path to where the student wants to be after school. It is critically important to have clear, measurable goals.

ADULT SUPPORT SERVICES

Developmental Disabilities [DD] Eligibility

Similar to special education, adult services have eligibility processes to determine who receives services. A special education eligibility alone is not enough to be found eligible for adult services. Likewise, if your son or daughter has already been found eligible for developmental disability services, there is a redetermination of eligibility at 18.

If you think your son or daughter might be eligible for developmental disability services, it is recommended you apply early and not wait until

"Developmental Disability" means a neurological condition that originates in the developmental years, that is likely to continue, and significantly impacts adaptive behavior as diagnosed and measured by a qualified professional as described in OAR 411-320-0080.



they are turning 18. If denied eligibility, you can appeal. Contact your county's Developmental Disability [DD] Services for more information.

Supplemental Security Income [SSI]

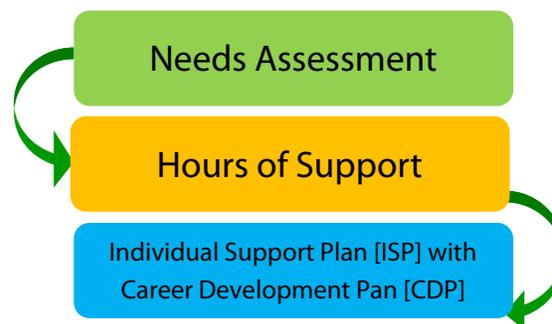
As federal funding administered by the Social Security Administration, SSI makes monthly payments to people experiencing disability who have low income and few resources. You might, in your role as parent of an adult receiving SSI, be identified as the "representative payee." It is an important role with much responsibility. You will receive information about this when you apply. As well, there is a great deal of information available on the Social Security website. Visit www.ssa.gov or your local Social Security office.

Medicaid

Medicaid is the federal funding source for developmental disabilities services through what is called a home and community-based waiver. Parental income is not considered in determining eligibility for Medicaid (for your adult son or daughter); instead, the individual is considered "a household of one." If your son or daughter is already eligible for DD services, your services coordinator can support you in this process. Otherwise, contact your county's Seniors and People with Disabilities Office for information on the application process once s/he turns 18.

Community Choice Options

Adults receiving DD services have a choice in who will provide service coordination. Children up to age 18 receiving DD services receive those services through their local Community Developmental Disability Program [CDDP]. Once 18, the individual has a choice between the CDDP and a local Support Services Brokerage. It is an important decision, so make sure to gather information about both options, ask questions, and support your son or daughter in communicating his/her choice. This is another area where it is often helpful to connect with other individuals and their families to hear what has worked for them. FACT P2P mentors are available if you would like to talk with another parent.



The ISP during Transition

As of this publication, there continues to be a lot of changes underway at the Oregon Office of Developmental Disability Services [ODDS]. You may be hearing the term "K Plan," and have questions to what it means for your family. Implementation of the K Plan, also known as the Community First Choice option, allows Oregon increased access to Medicaid funding, allowing for greater access for families and individuals to supports and services. Work continues on creating a person-centered ISP that supports children and adults receiving DD services. Implementation of the Employment First initiative (covered in next section) has resulted in new energy and a commitment to

True or False:
You lose your SSI benefits if you get a job.

False!

Benefits planning is available to make sure you protect benefits while gainfully working.

Power of Attorney

A power of attorney is a legal document that allows a person to give another person the right to act on his or her behalf. That person is called an *agent*. In Oregon, powers of attorney can only be used for financial decisions.

The way a power of attorney is written is important. The authority can be written to go into effect only when the person becomes incapacitated. A power of attorney can be revoked in writing if the person still has capacity. Because a power of attorney terminates once the person dies, it cannot be used for estate planning.

Representative Payee

When a person gets benefits from the Social Security Administration [SSA], the person receiving funds on behalf of the person experiencing disability is called a *representative payee*.

If the person needs help managing other parts of his or her life, s/he may need to have another decision-making fiduciary established; examples include *a power of attorney, an advance directive for healthcare, a guardianship, or conservatorship*.

HEALTH

Advance Directive: A document of health care instructions explaining what treatments a person would want if/when s/he becomes too sick or hurt to give instructions to doctors. The advance directive is provided to medical staff. The person can choose a health care representative to make health care decisions for him or her.

*Material for this section is taken from Oregon Department of Human Services' *Options in Oregon to Help Another Person Make Decisions—Guardianship, Conservatorship and Other Options in Oregon*, and is available on FACT's website resource page, *Transition to Adulthood*.

You Made It!

There was a lot of information in this booklet, and you made it to the end! Even after finishing this booklet and attending FACT's training, you may still feel "a bit green" about the transition to adulthood process. FACT invites you to visit its website, connect with a support specialist, or request a P2P parent mentor at any time you have a question, want more information, or just want to talk with another parent who has been through the process.

In addition, regardless of how thorough this training and booklet may be, it is not inclusive of every level of detail you may need to help your son or daughter transition into adulthood. FACT has made every effort to include introductory information, but it is acknowledged that every circumstance is different. If you need additional information, please contact FACT at your convenience.

Who We Are

Family and Community Together [FACT] is a family leadership organization for individuals and their families experiencing disability, working collaboratively to facilitate positive change in policies, systems, and attitudes through family support, advocacy, and partnerships.

FACT strives to:

- Strengthen the voice of Oregon families raising children experiencing disability
- Connect families to families
- Provide and promote peer-delivered family support
- Create opportunities for meaningful collaboration

FACT provides:

- IEP trainings and support
- Person-centered plan workshops
- Behavior support trainings
- Natural support trainings
- Advocacy trainings
- Family outings and community activities



FACT- Family and Community Together

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RESOURCES

FACT Helpline:

(503) 786-6082

1(888) 988-3228 ext. 302

support@factoregon.org

www.factoregon.org

Online trainings

One-page profile samples & templates

Person-centered plan facilitation

Transition to adulthood info

...and so much more!



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