

Spokane County Parent Coalition

Transition from School to Adult Life

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The following article provides some general information for parents of children in special education who will be leaving the public school system in the near future. This can be a very difficult time for families and it seems to sneak up and clobber you over the head before you even realize it is coming.

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The frustrations that families may face during this phase in life are many. There are likely to be circumstances beyond your control as maybe there should be. Your child, who is now a young adult, might be struggling for independence and control. There might be limits that threaten the perfect plan you have come up with. There may not be resources where it is perfectly obvious there should be. Through this trying time, everyone will learn, and you will become a better person if you just persist.

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This is only a brief collection of thoughts and advice from a variety of sources. We all have individual situations and this information, as a whole, may not apply to everyone. I will bet that if you take the time to read this, you will learn something useful and at least find a general direction of where you need to go next.

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Realize as a parent that these are emotional times. As any of our children grow up, there are times when we realize as a parent that our children are becoming their own person with likes, dislikes, and their own view of the world. This is sometimes hard to accept with our typically developing children and is complicated further when we have a child with special needs and/or developmental disabilities.

Continue to receive school services until age 21. If appropriate. This is very important for young adults with significant disabilities. People are not eligible for employment or community access supports from DDD until 21 years of age. DVR will provide short-term services and supports before the age of 21. There are innovative ways to serve young adults 18-21 yrs. old who are still enrolled in public school. Young adults can have part time employment or attend courses in the college setting while still being enrolled in public school. If your child wants to graduate with his peers, they can go through the ceremony with their class but not actually

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graduate, and still receive services from the public school until the age of 21 if you set this up in advance. If your child turns 21 after August 31, they are entitled to the whole next year of public school.

IEP must address transition at age 14. Federal IDEA Law and Washington Administrative Code. Transition needs must be identified at age 14 and transition services must be provided starting at age 16. This is a good time to attend resource fairs, visit employment providers, ride public transit, question casemanagers, and brainstorm options with your child to become more informed. You should also be informed of the transfer of rights from you to your child at least one year before age 18.

Learn about supports available for adults. Resource fairs, High School Transition Coordinator, School Districts, DVR, DDD, Adult and Aging Services, Home and Community Services, County DD Boards, Independent Living Centers, Parent Coalitions, and other advocacy and parent groups should have knowledge and information about adult services. Other adults with disabilities and their families can also be a great resource.

Self Determination, Independence. Self-directed IEP's and transfer of rights at age of majority (18 years of age) unless a guardianship is in place. This means that the child does have the right to make their own decisions automatically at age 18. Plan for adult life early and encourage independence at a young age.

Start thinking about and planning for transition as early as possible. The federal IDEA law says transition needs must be addressed when your child is 14 years old. This does not mean you should wait until this point to think about what will happen when your child gets older. Develop a vision for your child as early as possible. This vision, when broken down into yearly goals becomes very helpful in developing IEP's for your child during his or her school years.

Guardianship. This concerns adults 18 and older, which may not be able to make decisions on their own. A guardianship allows another person to be a decision maker for a person who is judged to be incapable of making decisions for themselves. This is a legal issue that can be handled by an attorney and a decision made by a judge. There are various levels of guardianship that can be considered. A guardianship can be total or partial (examples of partial guardianship could be medical decisions only or financial only, etc.). Again, consider the abilities of your child and do not just assume that they cannot make their own decisions. Remember, you cannot be present at all times and your child may very well outlive you. Think of these things early in life and

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encourage as much independence as possible. Legal guardianships generally cost between \$700-1500 if handled by an attorney. If the individual or family is considered low income, under \$2,000 in resources, they might be able to get court costs and Guardian Ad Litem fees waived by the court which will reduce the overall cost.

Social Security. SSI is federal program that provides assistance to people with disabilities and their families. There are income guidelines that may make your family ineligible when your child is under 18 and living at home. When your child reaches age 18, your income is no longer considered and that might make the individual eligible for financial assistance and/or health benefits. This assistance can help in planning for the future. Remember, if at first you are denied, try, try again. Don't take "no" for an answer the first time. There are statistics that show only about 40% of original applications for SSI are approved, only 10% approved after the first appeal, but about 85% are approved after the second appeal process.

Sexuality. This is something that most parents don't even want to talk about. As parents we have fears that our son or daughter may be taken advantage of or may not understand what they are doing. At the same time, there is a level of independence and personal choice that our adult children may exercise. This is hard enough to face with our typically developing children and complicated further with an adult son or daughter with developmental disabilities.

Choice of Employment and Community Access Providers: In Spokane County, people 21 years of age or older with developmental disabilities and their families are able to choose an agency they would like to provide them with employment or community access services and supports. You can also change agencies in the future or negotiate for more services if you wish. This is a program funded by DDD but there are waiting lists for this service.

Employment. Work for working age adults. Employment should be encouraged and considered as it is for anyone else. Consider the possibilities for your child, not the downfalls. Employment leads to independence, relationships, and inclusion within the community. There are several different options for employment supports: Individual Employment, Group Supported Employment, and Specialized Industries.

Try DVR first. Short term employment supports. If this is all the assistance you need, that is great. DVR can be involved as early as 14 years of age to help with transition planning. You can still be on a waiting list at DDD while receiving services and supports from DVR. You can re-open your DVR case if circumstances change. There

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have recently been changes in how DVR provides services because of limited funding. Please refer to "Order of Selection" information that is included.

Community Access. People with more significant disabilities or other circumstances may not be able to work. Community Access is not offered by DVR and not from DDD until 21 years of age. Community access offers activities during the day other than employment. These activities can lead to community involvement, relationships, independence, volunteer opportunities, and even employment in the future.

Transition Funding from Legislature. Since 1989, the Washington State Legislature has provided funding for students who were graduating from high school for employment or community access programs. This funding has continued and is still available today. Even with this effort, there are still many young adults on waiting lists for services. If you approach DDD or DVR for assistance, mention the transition funding for graduating seniors, it just might help.

Get name on DDD waiting lists ASAP. Your DDD casemanager can add your child's name to the DDD waiting list for employment and community access programs as early as 17 or 18 years old. It may take years for your child to receive services so the sooner their name is on the list; the sooner they will receive services in the future. If you have been denied services in the past, don't think that means forever. Things do change.

Encourage school districts to become more informed of what is available in the community for young adults with disabilities. Some school districts are just now realizing their obligation to plan for students in Sp. Ed. that will transition from public school to adult life. Anything that you can do to assist your school district with this task not only affects the success of your child, but also others coming up after your child. Maybe you can bring information that you have received to the school or target a specific teacher to educate. Learn together.

Consider post-secondary education if appropriate. This could include Community Colleges, Trade Schools, or other Vocational Training. If people with disabilities are going to be successful and independent, then continuing education and training might help the individual pursue a career and obtain a job that pays a livable wage with benefits. Doesn't this sound better than working part time for minimum wage at a job the person may have little interest in? Focus on abilities and possibilities, not weaknesses. If this is an option for your son/daughter, you will want an evaluation and/or assessment not more than a year old when you approach a college, university, or trade school.

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Living situations. This is a struggle for some families. As parents, we worry about the safety of our children. The fact that your child has disabilities may compound this issue even more. Many families just accept that their child will live with them for the rest of their life. In reality there are many options for a young adult with disabilities to live as independently as possible in the community. There are levels of care available from total assistance to owning your own home, with a whole spectrum in between. Consider these options because once again, your child may very well outlive you and then what will happen? There are long waiting lists for these services from DDD.

Health care. For people with disabilities, this is a very important issue. Health care might even be the biggest issue and expense in many people's lives. The rate at which people with disabilities are unemployed, or only work part time reduces the possibility that they might be eligible for health insurance from an employer. Medicaid is an alternative for medical coverage for these people and financial eligibility for this program can actually be a disincentive to becoming employed full time. There is progress being made toward eliminating barriers to employment for people with disabilities and a Medicaid sliding scale - buy in program is one of those ideas.

Financial Planning. Special needs trust funds, wills, and long-term care. These are all issues that take intense planning and foresight. Financial planning may again involve the services of an attorney to make things legal to protect you and your son/daughter. If you do not plan for the future of your child, someone else will, and there is no guarantee that they will even know your child and look out for their best interests. This can also save a lot of stress and emotional toll on other members of your family.

Focus on the future: possibilities, dreams, realities, and outcomes. This is the magical key to transition. If you are thinking about the future and taking steps toward it while your child is young, it may not sneak up on you and catch you unprepared. Making quick decisions during a crisis may not be what is best for anyone in the future. Take your time and make decisions that consider everyone's best interests.

Communicate with other families. This is a huge resource of information, knowledge, and infinite wisdom. You might feel very isolated and think you are the only one who has ever gone through such a difficult time, but I guarantee, there are others who have gone before you. You need to seek out those experienced trailblazers who can show you the road and save you a lot of time and frustration. Many times this is not very difficult because of the advocacy groups and parent organizations that now exist. Ask your child's teacher or casemanager if they know of someone who has graduated recently that you could contact.