

Adult Services for People with Developmental Disabilities

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If your child has a developmental disability, you will need to plan for adult supports. Most of the time, a young adult's eligibility for adult supports is determined before he or she graduates. When your child is of transition age (16 and older), the school transition team should include a representative from adult services. The Designated Agency should be involved at least a year before your child is scheduled to graduate in order to plan for funding. However, you don't have to wait for the school to take action. You can request an intake appointment with your local Designated Agency and start the eligibility process at any time. Your child may receive many necessary services through his or her school program, but you may also be eligible for Flexible Family Funding, income-based funds which can be used at your discretion. The following information can serve as a guide as you navigate the new terrain of adult developmental services.

How to apply for Adult Developmental Services

The first step is to contact your local Designated Agency (DA) and ask for the intake coordinator. Designated agencies are non-profit organizations which contract with the Agency of Human Services to provide services, including Developmental Disability Services. The agencies are organized by county or service area.

The intake coordinator will set

The intake coordinator will set up an appointment to meet with you and your child. According to law, the intake person must make the appointment within 5 days of your initial contact. The intake coordinator will gather information to determine whether your child is eligible for developmental services. This process may include an interview, examining school, medical and treatment records, and a review of your child's adaptive functioning level, such as self-care skills, safety awareness etc.

In order to qualify for developmental services, a young adult will need to be (1) eligible by meeting the criteria for developmental disability, and (2) meet a 'funding priority'.

Step 1: Eligibility

Eligibility for developmental services requires that the individual meet the definition of developmental disability under Vermont Law. According to the Vermont Developmental Disabilities Act, a developmentally disabled individual is someone who (1) has an IQ of 70 or below OR is on the autism spectrum, and (2) has adaptive functioning deficits. Your documentation must show that your child's disability existed by the time he or she turned 18. Don't confuse this with the date of diagnosis; it is not uncommon for individuals with autism to get a diagnosis at an older age. What is important is that there were documented signs that would corroborate that the disability existed at childhood (by age 18). Also, note that no measurement of IQ is necessary for individuals on the autism spectrum.

Adaptive Functioning is measured by a questionnaire that is typically filled in by the parent or other caregiver. This form may be somewhat familiar to you if your son or daughter received Personal Care Services. You may recall a questionnaire which asked about how your son or daughter functioned in different situations and level of independence.

Tip

- ✓ Risk and safety are important issues in looking at a young adult's adaptive functioning. While it is important to focus on strengths, now is the time to concentrate on areas where safety and risk are a concern.

Step 2: Meet a Funding Priority

Individuals who are eligible for developmental services must also meet what is called a "funding priority". The funding priorities are found in the System of Care plan, which runs on a three year cycle.

The funding priorities can and have changed from cycle to cycle, thereby widening or restricting entry into developmental services. For example, the Home and Community Based Waiver is now greatly restricted for children after the System of Care plan changed this funding priority in 2001. There are opportunities for public and written testimony when Agency of Human Services (AHS) puts forth drafts of proposed changes for the system of care plan every three years. For this reason, advocacy is extremely important in order to keep developmental services available for people in need.

How are adult services paid for?

In most cases, Medicaid will pay for adult services. If your child is found eligible and meets a funding priority, he or she must be eligible for Medicaid. Otherwise, he or she will be expected to pay for services based on a sliding scale. Some of the programs which provided Medicaid to your child will end by age 18 (Dr. Dynasaur) or age 19 (Katie Beckett).

Tip

- ✓ Be aware that a delay in services may occur until your child is on Medicaid.

For your child to be eligible for an adult Medicaid waiver, he or she must meet the financial eligibility criteria. Financial eligibility includes a low maximum allowable monthly income and a low countable resource limit. If your child holds excessive resources, you might consider a Special Needs Trust in order for him or her to meet financial eligibility for Medicaid (and SSI). A person who receives SSI checks will automatically be eligible for Medicaid.

Budgets

Designated Agencies must budget well in advance in anticipation of need. At times funding may run out due to unexpected circumstances. In that case, your child may be placed temporarily on a waiting list.

More Tips

- ✓ Contact the Designated Agency (DA) by your child's junior year in high school, even if you expect your son or daughter to stay in school until age 22. DAs budget well in advance of when they anticipate a young adult will be entering system. Make sure an agency representative is included on your child's school transition team.
- ✓ Be aware that there is a gap between the ages of 18 and 19 where it is very difficult for an individual to get adult services, even if the person finishes high school. Services are more readily available once the person turns 19. Ask your agency about the Bridge Program, which offers case management on a time-limited basis during this period.
- ✓ Recognize that, unlike special education, adult services are not a federal entitlement. Every state has a great deal of flexibility in how and to whom to provide services for adults with disabilities. As a result, developmental services are frequently targeted for budget cuts. You can help by getting involved

with systems advocacy and attending the public hearings regarding the System of Care Plan and being vigilant of proposed budget cuts at the State House. As a parent, your advocacy can make a huge difference in the lives of many individuals. Your voice counts!

- ✓ If your child is on a multi-year IEP, encourage him or her to stay in a school program until age 22. You may find yourself at odds with the school, which may try to graduate your child once he or she has accrued the required credits. Keep in mind that it is equally important for your child to meet his/her transition goals. Staying in school as long as possible is an extremely important opportunity for your child to continue to learn job skills, academics and independent living skills while under an entitlement program.
- ✓ Remember that disability does not necessarily mean eligibility. Eligibility criteria differ between special education and developmental services. An individual with a significant disability who was on an IEP while in school may not be eligible for developmental services.
- ✓ Determine if your child is eligible for Medicaid. Even if your child is otherwise able to get services, the implementation will be delayed until he/she begins receiving Medicaid benefits. See VFN publication *6 Ways to Medicaid*.
- ✓ Be honest about your child's abilities when asked to complete the functional capacity assessment. The assessment is seeking information on what your child can and cannot do *on his/her own*. Many parents are tempted to 'defend' their child and exaggerate his/her abilities or others may try to minimize his/her abilities. Your responses will be compared to records and responses from other sources.



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Final thoughts

The world of adult services is very different from what your young adult may have been accustomed to in school. There may be far less engagement with typical peers and fewer opportunities to pursue favorite activities (sports, music, etc.) that were part of the school day. Leaving school will require your young adult to adapt to changes in routine, place and personnel. Make sure your young adult is an integral part of the transition planning process. Being actively involved can help him or her adjust more easily. You may find that, while you worry, he or she looks forward to a new phase of life with anticipation. This may be a good point to start letting go a little and not allow your fears and concerns to dampen what can be an exciting time in any young person's life.

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Vermont Family Network (VFN) promotes better health, education and well-being for all children and families, with a focus on children and young adults with special needs.