



What to Know When Your Child With Disabilities Turns 22

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On the heels of a child with special needs biggest milestone of becoming an adult at eighteen (18) comes the next and arguably more challenging milestone – life after turning twenty-two (22)*. Last November, SNA member [Margaret Graham Esq.](#) discussed challenges and issues to be aware of when your child with special needs turns eighteen. The most significant topics discussed were decision-making, changes in Supplemental Security Income (“SSI”) services eligibility, living arrangement supports, and financial protections. If you have not considered those topics, please look at [that article](#) for reference.

Education Services Come to an End

While our previous article touched on being aware of education transition, when turning twenty-two, that transition can be one of the most significant for your child and family. Most states’ public school systems will end their required educational services for individuals with disabilities at age twenty-two. Most school systems will offer transition services for those individuals before they turn twenty-two, but it is imperative that planning starts at least two years or more before those services are needed.

Parents need to be aware that a student who is currently receiving services through an Individualized Education Program (IEP) is not automatically eligible for continued adult services when they turn twenty-two (22). In most states, there will be significantly different eligibility requirements for adult services than for special education services. Likewise, having a disability to such a degree that a person is eligible for SSI at age 18 is not a guarantee that the person will also be eligible for adult services. The same is true for young adults under guardianship, meaning establishing guardianship at 18 is not a guarantee that adult services will be available at 22.

To access adult services, a school district may make the referral to a state agency responsible for post-transition services. In most states, that agency is housed in your state’s Department of Human Services. Many states will have a separate Division of Developmental Services and Division of Mental Health Services within the larger human

services agency. The level and quality of transition services high schools provide vary greatly. Parents need to be strong advocates for their young adult children in obtaining information about adult services and pursuing eligibility for such services.

Types of Services for Young Adults with Special Needs

Once your child has turned twenty-two, there are several services to consider when looking at your child's long-term care.

- **Employment or Day/Community Services**

In many states, a local governmental or non-profit agency would help students transitioning out of the school system to establish an adult services plan that will allow the adult to participate in a day program or receive supported employment services.

- **Long-term Housing**

The types of available residential services vary tremendously from state to state and even within a state. Additionally, some states have long waiting lists for residential services. In many instances, a person may be eligible for daytime services (either employment or community services) but not be determined eligible for housing supports until after the parents are unable to provide a home setting

- **Respite Funding**

In some instances, adult services budgets will include a line item for respite services which are intended to allow caregivers to hire additional support persons in an effort to reduce caregiver burnout. Unfortunately, the typically low compensation rates allowed for respite providers may make it very difficult to find people willing to provide respite support.

Special Needs Planning

In many, many instances, the twenty-second birthday of a child with a disability is when it becomes really clear to parents that they need to get their own estate and special needs planning in order. This is true regardless of whether the young adult child is eligible for comprehensive adult services right away, eligible for only limited services, or perhaps not eligible for any benefits beyond SSI. No matter what the public services may be, parents need to plan for when they can no longer provide support to their child – be it financial, emotional, or organizational.

Establishing a special needs trust is the best way to ensure your child will be financially protected. Please refer to this [article](#) for information on types of special needs trust to consider. In addition, parents need to consider other people to name as future guardians or

other supportive roles to provide important assistance after the parents have passed away.

The above topics discussed are meant to serve as a starting point in navigating your transition or your child's transition to an adult looking for assistance with services. For more information, please check out the resource links below or contact the [Special Needs Alliance](#) to help find an attorney who can guide you.

Support Services for Youth in Transition: Youth With Disabilities: <https://www.childwelfare.gov/topics/outofhome/independent/support/disabilities/>

Government and Local Disability Programs and Services: <https://www.usa.gov/disability-programs>

OSEP, Research to Practice Division, Secondary, Transition, and Post-Secondary Team: <https://www2.ed.gov/about/offices/list/osers/osep/rtp-stpst.html>

**Please note that some states will begin the transition to the discussed processes and programs for individuals when they turn twenty-one and not twenty-two.*

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