



The Top 5 Things to Know When Your Child With Disabilities Turns 18

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The 18th birthday of a child with special needs marks the beginning of significant changes regarding the benefits and services they can receive. In the United States, most children who turn 18 become adults in the eyes of the law, which means they are legally responsible for their choices and actions. If you or your child has been receiving various state and federal services, benefits, and accommodations, it's essential to understand what those changes are. We've put together the top five issues that are helpful for you to know.

1. Decision-Making: Who is Responsible for Making Decisions about Your Child's Health and Welfare?

Once an individual turns 18 or, in some states, 19, they are presumed to have the capacity and ability to make their own health care and financial decisions. This means that parents no longer have the authority to make these decisions for their child or even to be involved in these decisions without the express consent of their child. In some cases, a child may have sufficient capacity to execute a power of attorney (most frequently a parent) once they turn 18. The power of attorney is allowed to do things for the newly turned adult, such as apply for benefits, open a bank account, help the individual with their decision-making or make decisions on the individual's behalf when appropriate. Court involvement is not required to become a power of attorney but does require that the individual requesting one understands the document that outlines this arrangement.

If the individual does not have the capacity to execute a power of attorney, then a guardianship proceeding may be necessary. Court involvement is required to obtain guardianship. In most states, the court will decide if a person lacks the capacity to care for themselves or make decisions regarding their own care. Parents should not assume that their child cannot make their own decisions and should not assume that as the parent of a child with a disability, they will be able to act as they always have in making decisions. Instead, it is important to consult an experienced attorney to determine what is in the individual's best interest and the best way to offer protection and as much independence as possible.

2. Changes in SSI Services Eligibility

Supplemental Security Income (SSI) is a federal government program that provides cash assistance to low-income individuals who are disabled, blind, or elderly and have limited income (i.e., money earned from work, received from other sources, and receiving free food or shelter) and few assets. SSI is a cash program. Every eligible individual gets the same amount of money each month regardless of the nature of the qualifying disability, the level of their needs, and the city and state where they reside. SSI eligibility rules form the basis for most other government program rules.

For those 18 and over to be eligible for SSI, there must be a medically determinable physical or mental impairment (including an emotional or learning problem) that:

1. Results in the inability to do any [substantial gainful activity](#); and
2. Can be expected to result in death; or
3. Has lasted or can be expected to last for a continuous period of not less than 12 months.

If your child received SSI benefits before their 18th birthday, you can expect the standards under which they receive them to change. Before 18, the Social Security Administration (SSA) attributes part of both parents' (legal guardians') income to their child's resources to determine their child's eligibility. Upon the child's 18th birthday, [the parents' income is no longer considered when determining the means-based eligibility limits.](#)

Therefore, **many people with disabilities who did not qualify as a minor will qualify for SSI as an adult** because only the adult applicant's income and assets are being used to determine their financial eligibility.

3. Education Transition

If your child is being educated through your state public school system, in most states, they will be working toward either receiving a diploma or certificate upon graduation. Beginning in 9th grade and throughout your child's time in high school, during your IEP meetings, you should be discussing with your child the best course of action to pursue. If you both determine that your child will pursue a diploma, they may then choose to pursue continuing education through college, university, or trade programs. Often these institutions can provide accommodations for students like in their IEP if the student qualifies.

If you and your child decide that they should pursue a high school certificate, depending upon their level of capacity and need, the child may be able to continue in a transitional

program in their high school even after they complete their senior year. These programs typically focus on life skills, including financial literacy, social engagements, employment preparation, and similar activities. Most children in this program are permitted to remain in the program until the end of the school year in which they turn 22 years of age (or 21 in some states).

Finally, some children may choose to seek employment after high school. Your local Vocational Rehabilitation Services provider should also be involved in the IEP meeting and will be able to guide your child through the process of seeking employment.

4. Supports in Living Arrangements

Once a child with a disability turns 18, they may choose or qualify for different living arrangements depending on the services they already receive. For example, if your child is receiving therapy services at school, where will they receive these services once they transition out of school? This could be through a [Medicaid Waiver](#) or private insurance.

Qualification for respite services may look different as well. If your child is limited to a specific number of hours of care each week, the hours may be sufficient if your child is in school for much of the day. However, the hours may be insufficient if your child is no longer eligible for public education. Also, programs in your area may require participation at times that are not workable for your child if they continue to live at home. It is essential to understand all of the benefits and options available to your child before deciding living arrangements and services after they complete high school.

5. Financial Protections

It is important to consider financial protections for a person with disabilities as early as possible. You do not need to wait until your child is close to turning 18 to start this process. You can begin protections by considering a special needs trust and updating your estate planning documents, so an inheritance does not terminate your child's governmental benefits. Other ways to protect your child's income and resources are through an ABLE account and a Representative Payee for Social Security. Once your child is no longer in the educational system, these two protections can become particularly helpful.

ABLE accounts allow an individual to maintain some income and resources above the amount typically allowed for recipients of governmental benefits to help them continue to receive those benefits. It can also allow your child the opportunity to have some financial independence and learn to manage their own finances without the risk of significant financial losses or abuse. There are limits on how much can be deposited into an ABLE account each year and on what the funds from the account can be used. ABLE accounts

are also a good tool when used in combination with a Special Needs Trust to provide financial protection and independence for your child.

The Social Security Administration (SSA) will determine who will serve as the payee for your child's Social Security benefit. SSA may decide that your child is able to serve as their own payee or may appoint a Representative Payee for your child. This decision is made with the Social Security representative assigned to your child's application. It is important that a Representative Payee not commingle their assets and your child's Social Security Benefits. Therefore, a separate bank account in your child's name will be necessary for them to receive their benefits.

The top five changes we listed are meant to serve as a starting point in navigating your journey as an adult or parent of an adult with disabilities. For more information, please check out the resource links below or contact the [Special Needs Alliance](#) for help finding an attorney that can guide you.

National Guardianship Association: <https://www.guardianship.org/>

Social Security Administration, SSI information: <https://www.ssa.gov/ssi/>

Medicaid – Link to State Profiles: <https://www.medicaid.gov/state-overviews/state-profiles/index.html>

ABLE National Resource Center: <https://www.ablenrc.org>

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