



What to Do When Your Special Needs Child Turns 18

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Being a parent of a child transitioning from adolescent to adult, can be a time of great pride and accomplishment. However, this same transition can be a time of great anxiety to the parent as the child begins to make life decisions independent of what has been 18 years of mom and dad's wisdom and guidance. The parent of the special needs child not only endures the typical anxiety that comes from this situation, but faces additional challenges as his or her child transitions from juvenile to adult. As a child with special needs ages, his or her support services and public benefits eligibility, among other issues, can change radically. Therefore, it is essential that the parent is attuned to these changes to better prepare for the next phase of the child's life.

The most significant issues the special needs child faces when transitioning from child to adult are financial support, medical coverage, and decision making. Another issue that the parent should address is his or her child's caregiving contingency plan if the parent is no longer able to address such needs himself or herself.

Financial Support and Medical Coverage

When the special needs child attains the age of 18 years, his or her public benefit status can change significantly. Some programs will require a "re-evaluation" of his or her eligibility. Others may provide new, more favorable rules approving benefits for the adult child who had been previously denied benefits prior to age 18.

Before reviewing how public benefits program rules can change for an adult disabled child, it is important to note that not all benefits are needs-based. **Social Security Disability (SSD)**, as an example, is not a needs-based public benefit. An individual can receive SSD, if he or she has enough work credits *or has a parent or spouse who has retired, has died, or is disabled*. In most instances, the same individual will receive **Medicare** two years after he or she begins receiving SSD.

Supplement Security Income (SSI), on the other hand, is a needs-based public benefit program. SSI is a federal program administered by the Social Security Administration that provides a cash benefit for a recipient's food and shelter. Eligibility for SSI, requires that the applicant be blind or disabled and meet an asset and income test. Prior to age 18, an individual's SSI eligibility can include a parent's income and assets. However, after age 18, the individual's eligibility determination will not include a parent's assets and income. For this reason, a child who was ineligible for SSI before age 18, may be eligible after age 18 when parental income and assets are no longer included in the eligibility determination.

For some children, who were receiving SSI before age 18, it is important to also note that the definition of disability under the SSI program changes at age 18. SSI will re-evaluate the individual's disability at age 18. Parents should be aware of the recipient's rights in this process, including the right to have the evaluation performed by the individual's own physician.

Medicaid can become a source of medical "insurance" to the now adult disabled child. Like SSI, Medicaid is a needs-based public benefits program. It provides assistance with health care. Medicaid waivers can also provide assistance with housing, vocational training, and other life skills so that the child can live in a community setting and avoid institutional placement. Medicaid for the disabled has both an asset and income test. The individual also needs to be determined to be disabled. This determination is typically required to be made by *the Social Security Administration*.

Medicaid benefits can also be obtained by working disabled individuals under the **MedWorks** program. MedWorks is a Medicaid buy-in program; that is, an individual can purchase Medicaid coverage if he or she meets program standards. MedWorks eligibility standards are much more liberal than traditional Medicaid standards and the buy-in premiums are usually much lower than traditional health insurance.

Other needs-based public benefits programs that the child may be eligible to receive are Federal Assisted Housing and Food Stamps.

An important concept to note when reviewing the adult disabled child's eligibility for public benefits is the ability to plan to protect assets that may be in excess of public benefits eligibility requirements. Not all assets count toward eligibility limits. Of particular note, is a statutory safe harbor typically referred to as a Special Needs Trust.

A **Special Needs Trust** is a Trust under which the Trustee (person in charge of trust assets) has the discretionary ability to use trust funds for the benefit of the beneficiary. The assets owned by the Special Needs Trust are then exempt under the public benefits program. Trust assets can be used for items and services not provided by a public benefits program or for items superior to that which the public benefits program provides.

An individual under the age of 65 is permitted to fund a Special Needs Trust with his or her own assets provided the Trust is created under and contains statutory requirements. The Special Needs Trust can be the individual's own unique trust or he or she can utilize a "master special needs trust" administered by a non-profit organization. If the child with special needs has funds in excess of a public benefits resource limit, he or she can transfer funds to his or her special needs trust to obtain public benefits eligibility.

Besides Medicaid coverage for health care, the disabled adult child may also be able to receive medical coverage through a parent's health plan. In the alternative, the disabled adult child may also be eligible to receive a subsidized health insurance plan through the health insurance exchange. Fortunately, the Affordable Care Act added to the length of time in which a parent can carry a child under his or her health insurance plan and prohibited denying health insurance coverage to an individual based on a pre-existing condition. The State of Indiana's HIP 2.0, is an amalgamation of insurance provided under the exchange and public benefit and may also be a source of medical coverage for the adult disabled child.

Decision Making

Another issue with the child with special needs transitioning to adult is the limitation of the ability of the parent to make decisions for the now adult disabled child. Under Indiana law, an individual over the age of 18 years is presumed to be able to make his or her own independent decisions unless a Court has found that individual to be incapacitated. Consequently, the parent who has guided medical and personal care for his or her special needs child since birth, may find herself or himself “shut out” of the decision-making process when his or her child turns 18.

One solution is for the parent to petition for guardianship. A **guardianship** is a legal proceeding where a Court finds a person to need assistance and appoints another individual or corporation to assist with or make decisions on behalf of the individual as the Court may direct.

A guardian can be over the individual’s person, estate, or both person and estate. The guardian of the person can make or assist with personal decisions of the individual such as consenting to medical treatment or determining the individual’s living arrangement. The guardian of the estate manages the individual’s finances. It is important to note that a guardian’s powers are quite broad, but they can also be limited to permit the child to attain some level of independence with the least amount of restriction as possible.

There are alternatives to a guardianship that can maintain an even greater level of independence for the disabled child, but still give the parent the necessary authority to assist with medical and financial decisions. A Durable Power of Attorney and Health Care Advance Directive can provide the same authority provided to a guardian. However, the child must have the capacity to sign such documents. A disability diagnosis does not automatically disqualify the child from having capacity, but he or she must understand the nature of the authority provided under the document and the consequences of giving the parent such authority. The Durable Power of Attorney and Health Care Advance Directive can be less expensive substitutes to a guardianship, but in some respects can also be inferior to guardianship. For example, even though the parent is the child’s agent, the child is still the “boss.” Consequently, the child can make decisions independent of the parent-agent. This issue can be troubling for adult disabled children who may be easily susceptible to the undue influence of others. In such an instance, it may be more beneficial to get a Court’s determination of incapacity to protect the child from such malicious influences.

Other Issues and Parent’s Estate Plan

Many disabled children will continue to reside with his or her parents after attaining the age of 18 years, but it is still important that the parent have a contingency plan in place for the child’s housing and life skills in case this arrangement is no longer feasible or greater independence of the child is a goal. In regards to future work and life skills, the Individuals with Disabilities Education Act requires that educators beginning planning for this transition at age 14. This should be the first step in the direction of transitioning from school to work. Other public benefits programs can award disabled individuals who desire to work. The Ticket to Work Plan allows individuals to receive SSD or SSI benefits while training and testing employment opportunities. The Plan for Achieving Self Support program under SSI is a similar program that allows an SSI recipient to set funds aside under a pre-approved plan to achieve future employment.

Not to get lost in the shuffle in the needs of the now adult disabled child and related to housing and work issues of the disabled child, are his or her parents plan in transitioning from being the child's primary caregiver to other supports and services. It is most common for the parent to be the child's primary caregiver long into the child's adult years. However, when a parent begins to suffer his or her own debilitating illness, the ability to continue this arrangement can be greatly hampered. Thus, it is essential to have a contingency plan in place long before the child needs alternative supports.

The parent should first begin by deciding who will become the child's primary decision maker when the parent is no longer able and to ensure that the individual or entity consents to assuming this responsibility. Next, it is important to establish legal documentation nominating this individual or entity and providing detailed instructions for the next caregiver. The nomination of next caregiver typically occurs through the parent's Last Will and Testament or similar document. Meanwhile, it is highly recommended that the parent also prepare his or her own "Letter of Instruction" to the next caregiver. This Letter of Instruction should contain all the things the new caregiver will need to know about the child with as much detail as possible. At the very least, the letter should contain the names, addresses, and phone numbers of all medical providers and key family members. However, the parent should also consider including direction regarding the child's friends, food preferences, preferred recreational activities, etc. Even a miniscule detail such as the child does not like mustard, may be the difference between the child eating a nutritious meal or inexplicably refusing food.

Another key component to the parent's estate plan is to ensure that a protective arrangement for the disabled child's inheritance is established and family resources are allocated according to the desires of the parent. The parent should give particular consideration as to how family resources should be allocated if the parent is in need of long-term care services or one of the non-disabled children are in need of assistance. The parent should establish a special needs trust for the disabled child in his or her own estate plan to ensure that the child maintains valuable public benefits at the parent's death and receives the benefit of the inheritance to increase his or her quality of life. The Trust will cover items not provided by public benefits programs. This Trust is typically independent of any Trust that holds the child's own assets due to differing and often more liberal requirements of the Trust created by the parent.

To obtain assistance in navigating the issues associated with your child's transition from juvenile to adult, please contact us to schedule an appointment at 317-622-8181.

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