

# Special Needs Planning Beyond the IEP and Age 22

Caregivers who want to plan for the financial future of their adult dependent over the age of twenty-two who has special needs often have different issues to consider than caregivers of younger dependents. Special needs planning is sometimes very different for caregivers who have dependents in these two age groups.

For many caregivers with younger dependents receiving special education services, the nature of the disability, interventions, ultimate prognosis and outcomes may still be uncertain and unknown. Caregivers may try different therapies, educational and treatment modalities, and be very proactive in trying to positively impact their dependent's abilities. These caregivers often do not know what type of long-term care support their dependent will need and whether or not that they will be able to function independently. They do not know how all their hard work, therapy and doctors' visits, and advocacy efforts will pay off for their dependent in the long run. Caregivers of younger dependents are very hopeful for positive outcomes, adaptations, and results.

Whereas caregivers of older dependents may have a clearer sense of their dependent's capabilities, the supports they may require, and what the future may hold for them. By age 22, most caregivers have a solid understanding of their dependent's skill levels and future possibilities. Caregivers usually know whether they will go onto college, their employment opportunities, Activities of Daily Living (ADL) skill level, and interpersonal skills and competencies. They know whether or not their dependent will be self-sufficient, need government benefits, can live alone, or will need supplemental assistance and support to be provided by caregivers or loved ones through special needs planning efforts.

Caregivers of both younger and older dependents may need to calculate just how much money is needed to supplement educational, medical, social, recreational, housing, or vocational services. Government benefits may need to be supplemented through additional planning efforts. Some of these issues are directly related to calculating how much money is actually needed when special education services end at age twenty-two.

After a student's twenty-second birthday, mandated education services are generally no longer provided. The Individuals with Disabilities Education Act (IDEA) of 2004 (<http://idea.ed.gov/>) requires that children with disabilities receive:

1. An initial evaluation to determine if the child has a disability.

2. A free appropriate public education that emphasizes special education and related services designed to meet their unique needs and prepare them for further education, employment, and independent living.
3. Education as close as home as possible in the least restrictive environment with children who do not have disabilities.
4. Supplemental services (such as speech therapy, occupational therapy, or a classroom aide) to complete their education.

Caregivers of dependents with special needs, who turn age 22 and transition from their IEP and special education services into the adult services arena, are faced with many new issues and obstacles. Hopefully, well-designed transition plans were put in place years ago by the educational team and the student successfully transitions to further education or employment. The nature, scope, and severity of the disability will determine whether additional transition, rehabilitation, day programming, medical, or vocational services are needed. Some adults with special needs will continue to receive government benefits such as SSI and Medicaid, while others will not.

Many privately held health insurance policies do not cover students or adult dependents with special needs past the age of twenty-two. Caregivers need to carefully review their health policies and contact their benefits department to determine extended coverage for their dependents over the age of twenty-two. Coverage varies from plan to plan. Some policies do provide extended coverage past age twenty-two, while others do not.

For those persons who do not receive government health insurance benefits, the cost of medical care is staggering. Many states provide supplemental health care coverage for people with special needs over age 22, which may not be tied to SSI eligibility. These supplemental policies may require either an extra premium, larger co-insurance percentages or deductibles. However, many states do not provide supplemental health care policies for adults with disabilities. Caregivers need to check with the social service agency who administers Medicaid in their county or state to determine the level of coverage and services provided in their area, since they can vary from state to state. In addition, many states offer choices between Medicaid providers, and coverages between those plans can vary, as well.

Caregivers of adults with special needs often experience “sticker shock” and large medical bills if their dependent is not receiving government health insurance benefits or if they are not covered under a caregiver’s individual or group health policy. These caregivers should seek out knowledgeable professionals and advocates to help secure needed health care benefits and services for their dependent. There are advocacy organizations in most states that can advise caregivers on health insurance related issues.

Special needs planning, when coordinated with a properly funded special needs trust, can help caregivers plan for the financial future of their dependent with special needs. If structured by knowledgeable special needs professionals, assets can pass to a special needs trust and not count towards the \$2,000 SSI limits for an individual - which means that government benefit eligibility will be maintained and money can be used to supplement the lifestyle of the person for whom the trust was established. The trustee needs to make certain that the money is used for supplemental purposes only.

An important part of special needs planning is to make certain that a mechanism is set up to provide "enough" money to meet long-term needs. Caregivers with dependents under age 22, whose multiple needs are being met through local school systems, may find themselves with additional bills after their dependent graduates from the educational system. Caregivers may find that they now have to pay out of pocket for additional speech therapy, occupational therapy, counseling, physical therapy or other services previously provided under the terms of the IEP. When planning for a person under age 22 with special needs, caregivers cannot forget to incorporate important benefits and services provided by the local school system. Replacement services and costs need to be carefully planned. They will become the responsibility of the caregiver or their dependent after their twenty-second birthday.

Due to the complexity of federal and state laws, you may require a specially trained professional who can work with your other advisors to help you plan for the future of your dependent with special needs.

**[Call Jim Thompson CFP, ChFC, ChSNC, 217 417 5228 for a confidential consultation.](#)**