

Government Benefits as a Foundation for Special Needs Planning

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Navigating the acronym-ridden maze of government benefits is tough and misconceptions abound. Families may be unaware of the full range of options available to individuals with I/DD, or they may be confused about eligibility, assuming that they have too much income to consider means-based programs.

Most individuals with I/DD can benefit from special needs planning that is informed by an understanding of how government benefits work. Very few people can afford to cover the costs of long-term supports and services (LTSS) for people with severe disabilities. Ranging from cash payments to rent subsidies to employment assistance to residential community living options, public programs can significantly contribute to an individual's ability to live independently within the community.

Although benefits can provide a foundation for special needs planning, there are many important needs that they don't cover and, given budget debates at all levels of government, there's no assurance that current levels of assistance will be sustained in future years. Setting aside funds in a **special needs trust** is a way of ensuring financial security for a loved one with I/DD, while not endangering their eligibility for means-tested programs.

Particulars regarding qualification and administration vary among states, but here's a partial list of important programs for families to research:

Children:

CHIP (Children's Health Insurance Program)- Designed for those under 19 whose family incomes disqualify them for Medicaid but who can't afford private insurance, this coverage generally involves no premiums. Some states charge a modest fee for higher income families.

SSI (Supplemental Security Income)- Cash payments are available for children with qualifying disabilities who are under 18 and whose families meet low income and asset requirements.

Many local **school districts** offer durable equipment, transportation and other forms of assistance for which special education students are eligible till the age of 21. Details differ by location and parents should investigate.

Individuals 18+:

Social Security Child Disability Benefit (CDB) / Disabled Adult Child (DAC) Benefit Individuals who are age 18 or older and experienced the onset of qualifying disabilities before turning 22 may receive benefits based on a parent's Social Security record if the parent is currently receiving retirement or disability benefits or is deceased. The adult child must be unmarried, unless their spouse is a Social Security beneficiary.

SSI Once individuals reach the age of 18, parents' income is no longer considered in determining their eligibility for this program. Cash payments are available for individuals with countable resources of \$2,000 or less (\$3,000 for a married couple). Home and vehicle ownership are exempt, but in-kind support that includes assistance with food, rent and utilities can reduce the SSI benefit amount by one third.

SSDI (Social Security Disability Insurance) This is an insurance program, which provides monthly cash payments to individuals who are unable to work at a substantial level because of a qualifying disability that is expected to last for at least a year or result in death. Benefits are based on prior contributions and employment history and qualification is unaffected by income or asset levels. If individuals are at full retirement age (66 to 67, depending on date of birth) they will receive retirement insurance benefits instead of SSDI. Eligibility is delayed five months from the onset of a disability. Widows or divorced widows with a disability may qualify for SSDI benefits based upon the work record of a deceased spouse or deceased former spouse if they are at least 50 years old.

Medicaid This is the health insurance that in most states automatically comes with SSI. Many other individuals with disabilities may receive Medicaid health benefits to pay for medical care, durable medical equipment, long-term care, in-home caregivers and other residential community living options. Medicaid can pay for premiums, co-payments and deductibles for low income Medicare recipients. Most Medicaid programs are needs-based. Medicaid is operated by the states, so eligibility, services and costs will vary depending on where an individual lives.

Medicare This health insurance is for individuals who are 65+, and those who have been eligible for SSDI or DAC/CDB benefits for 25 months. Medicare is not a needs-based program. Medicare includes hospital insurance and skilled nursing home care (Part A), doctor visits and durable medical equipment (Part B), and prescription drugs (Part D). There is a needs-based Medicare program, Extra Help, that assists low-income individuals with prescription drug co-payments.

Section 8 Housing Vouchers This rent subsidy caps rent at 30 percent of household income. Long waiting lists exist in much of the nation.

SNAP (Supplemental Nutrition Assistance/Food Stamps) EBT (electronic benefits transfer) cards are available for food purchases, with amounts dependent on size of household, income and shelter expenses. Eligibility is based on income and assets, the latter varying greatly among states.

Families can easily become overwhelmed by the complexity of these benefit systems. It is difficult to stay abreast of changing guidelines, given the number of agencies involved and differences among states. Applications are sometimes denied or benefits decreased improperly, resulting in time-consuming appeals. Nonprofit organizations, such as local chapters of The Arc, can often offer useful advice to families, as can special needs attorneys.

Despite the frustration, though, these benefits can provide an invaluable framework for a loved one's special needs planning and financial security. It pays to investigate.

