

FACT SHEET

CHILDREN (UP TO AGE 21) ENTITLEMENT TO SERVICES

The “Early and Periodic Screening Diagnostic and Treatment” (EPSDT) federal law is an entitlement to medically necessary services for children (up to age 21) who need services to correct or ameliorate the child’s physical or mental conditions. These provisions would apply to children with behavioral or emotional disorders who need intensive services to correct or ameliorate their condition. These provisions would often apply to children who are autistic, developmentally disabled and children who have a mental illness.

FREQUENTLY ASKED QUESTIONS:

Q. Do the children have to qualify for Medicaid?

A. Yes, and if the child is under the age of 18, then family income is considered. However, if the child is 18 years or older (18-20), then family income is not considered and then you only look at the child’s assets and income.

Q. Is my child, who I adopted through DCFS eligible for intensive home based or residential treatment through EPSDT as part of the subsidy agreement regardless of my income?

A. Yes.

Q. Can the State have a “Waiting List” for this program?

A. No. Every child who has a medical need for these services must be served.

Q. If my child has Medicaid and is on the PUNS list waiting services, is he or she legally entitled to immediate services?

A. Yes.

Q. If my child has Medicaid and has been denied and ICG-Illinois Care Grant for intensive community based or residential treatment, can he receive these same services immediately through EPSDT?

A. Yes.

Q. If a child qualifies for funding at age 18 and since the EPSDT program ends at age 21, will the child lose ongoing services?

A. Courts have ruled that if the child still needs the services, then the Americans with Disabilities Act (AD) requires the State to continue to provide these services.

TO DO LIST FOR PARENTS WITH A DISABLED CHILD

1. Get your child's name on the State of Illinois "Waiting List" for services even if you don't need services now. (Waiting list is formally called PUNS—"Prioritization of Urgency of Need for Services") (State of Illinois wrote on January 4, 2008 that one of the factors for families getting funding for services is "length of time on the PUNS database")
Contact your local Pre-Admission Screening Agency / Independent Service Coordination Agency to get on "Waiting List."
-Will, Kankakee, Grundy County—Service, Inc. 815-741-0800
2. What Services are Available For Your Child (outside of the school system) from the State of Illinois because of your child's disability? Contact your local Screening Agency / Service Coordination Agency listed above.
 - A. Children's Services—including but not limited to, personal support; respite; behavior intervention; therapies; modifications for home, vehicle and adaptive equipment; and residential.
 - B. Adult Services—including but not limited to, personal support; day programming services; residential; respite; behavior intervention; therapies; transportation; and modifications for home, vehicle and adaptive equipment.
(All programs for developmentally disabled children and adults are Medicaid funded and if your child has more than \$2,000 or inherits money, then he/she may have to spend down all the funds to pay for the services.)
3. Your Child should not have more than \$2,000 in their name including any custodial account or bonds held by you.
4. Establish a "Special Needs Trust." Your disabled child will be the beneficiary of the trust and the funds in the trust can exceed \$2,000 and all the funds will not count as your child's asset by Social Security and Medicaid.
-Your Will would not give money directly to your disabled child but would give the money to the "Special Needs Trust."
-Life insurance beneficiary and retirement fund beneficiary would not be the disabled child but would designate the "Special Needs Trust" or your Estate, so that the monies would flow to the Trust.
5. At age 18, apply for SSI (Supplemental Security Income). Your child may be eligible for approximately \$674 per month.
-Your child's payment will be reduced 1/3rd if you do not charge your child rent for food and shelter costs.
-Your child will not be eligible for SSI if he/she has more than \$2,000.
6. On or before age 18 consider Guardianship for your child.
-Does your child need assistance making decisions affecting their health, personal welfare and financial matters?
7. Special Education—know that your child is entitled to appropriate educational services from the school district up to the age of 22.
-Includes life skills and transition services to prepare your child for the real world and function with as much independence as possible.

GUARDIANSHIP WHEN THE DISABLED CHILD TURNS 18

In Illinois, the law considers a “disabled person” to be a person 18 years or older, who because of mental retardation or mental illness, or physical incapacity or developmental disability, is unable to fully manage his or her own personal or financial affairs in a safe manner and is therefore in need of a guardian.

The court may appoint a “guardian of the person” or a “guardian of the estate” or appoint both a “guardian of the person and estate.” A guardian of the person refers to the authority of the guardian to make decisions concerning the person and physical care of the “disabled person,” including health care decisions and living arrangements. A guardian of the estate refers to the authority of the guardian to handle the money, property, bills and other financial affairs of the “disabled person.”

Frequently Asked Questions:

Q. What happens if I don't obtain guardianship over my disabled adult son or daughter?

A. With respect to medical care, sometimes doctors and hospitals will accept the consent of the parents, but this does not always happen. With respect to living and social arrangements, if a “friend” or “stranger” persuades the disabled person to socialize or live with them, generally law enforcement will honor the desires of the disabled person if there has been no guardian of the person appointed. Without appointment of a guardian, all the parents can do is try to persuade their adult child to choose differently.

Q. If my developmentally disabled adult son or daughter gives me “Power of Attorney,” will this avoid the need for guardianship?

A. No. Many parents have incorrectly been told to get “power of attorney” from their disabled child. In order for a power of attorney to be valid, the person granting or signing the power must have the legal capacity to consent and fully understand what he or she is doing, which generally does not exist for a person who is developmentally disabled. Even assuming that the developmentally disabled person is high functioning and has some capacity to consent, that person would also have the right to cancel or revoke the power at any time in the future.

Q. If I am appointed guardian, will I be responsible to pay the disabled person's bills out of my funds?

A. No. You are not responsible to pay any debts from your own assets.

SSI BENEFITS

DEVELOPMENTALLY DISABLED ADULTS (18)

Supplemental Security Income (SSI)

SSI is a federally financed and administered, needs-based program, which guarantees a national minimum income level for the aged, blind, and disabled with limited income and resources.

Every developmentally disabled person should apply for SSI when they turn 18 years of age. Most 18 year old developmentally disabled persons will satisfy the tests for limited income and resources. Because the developmentally disabled person is an adult (18), the income and resources of his or her parents are not considered. Eligibility for SSI will be based on the income and resources of the developmentally disabled person.

FREQUENTLY ASKED QUESTIONS:

Q. How much will the developmentally disabled adult receive in SSI benefits?

A. Effective January 2009, the maximum SSI payment for an eligible individual is approximately \$674 per month.

Q. Why do some developmentally disabled persons receive approximately 1/3rd less than the maximum SSI payment?

A. The current living arrangements of the developmentally disabled person will be a factor in determining the amount of his or her SSI monthly payment. The developmentally disabled person can get up to the maximum payment if he or she is living in someone else's household (i.e. parents) as long as he or she pays for his or her food and shelter costs. If the developmentally disabled person is living in someone else's household and does not pay his or her food and shelter costs or pay only part of their food and shelter costs, then the SSI monthly benefit may be reduced up to 1/3 the maximum amount.

Q. What resources or assets can a developmentally disabled person have and still qualify for SSI?

A. Generally, to get SSI, the countable resources or assets must not be worth more than \$2,000 for an individual. Resources are case and things the person own and can turn into cash. Examples of resources are bank accounts, property, stocks and bonds.

Q. What happens if the developmentally disabled person's resources or assets are transferred in order to get under the \$2,000 limit?

A. If the resources of the developmentally disabled person are transferred or given away or sold for less than it is worth, the disabled person may be ineligible for SSI up to 36 months.

Q. Can the resources or the assets of a developmentally disabled person be placed in a "Special Needs Payback Trust" and still qualify for SSI benefits?

A. Yes. By putting the assets into a "Special Needs Payback Trust" these monies will not count towards the \$2,000 limit on assets which a disabled person is permitted to have and still qualify for SSI. It is very important to have an attorney who has experience in this area to draft this

type of Trust or otherwise an improperly drafted Trust may disqualify the person for SSI benefits until that Trust is exhausted.