

Assistance Programs

Government Assistance

Medicaid

Medicaid is a combined state and federal assistance program for those who are disabled, low income, over sixty-five and blind, or recipients of Aid to Families with Dependent Children (AFDC) or Supplemental Security Income (SSI). Although programs vary from state to state, given the severity of disability of girls with Rett syndrome (RTT), there are often ways to qualify for Medicaid, regardless of the family's income or assets. Your Family Empowerment Representative can help guide you through this process.

In some states, the state may pay private insurance premiums to keep you off Medicaid. Many states have a program called the Health Insurance Premium Payment Program (HIPP). HIPP allows those receiving Medicaid benefits to have private health insurance plans paid for by Medicaid. With HIPP, Medicaid recipients may receive better coverage and a larger network of health care providers is available.

Medicaid Waivers

Medicaid waivers "waive" a family's income so that their children may access medical care through Medicaid. Under the Medicaid waiver programs, the family's income is not counted in determining eligibility; the child's income is used. The child must have limited income and assets. Only children who need a "level of care" that would "normally" be provided in a hospital, nursing home or institution will qualify. This is determined on a case-by-case basis. This allows services to take place in the home or community for some patients who would otherwise have to be hospitalized or institutionalized for care. Medicaid waivers are targeted to individuals with mental retardation or developmental disabilities, the elderly, or disabled. Programs and services can vary greatly from one state to another, but can include medical and respite care. Again, your Family Empowerment Representative can give you information on your State's waiver programs and procedures.

Types of Waivers

The Model Medicaid Waiver removes the income requirements for Medicaid (in most states) and allows services to take place in the home or community.

Regular Home and Community Based Medical Waiver covers services typically covered by Medicaid and additional expenses not usually paid for by Medicaid. If your daughter is under the age of 18, she may be eligible for one of these waivers, which are intended to offer what is needed to keep the child at home.

The State Medicaid Plan Option allows states to provide medical services without permission from the federal government to certain designated categories of children who would otherwise have to be hospitalized or institutionalized. A state plan certifying these categories may be approved and applications are open only to children under the age of 18. This is known as the Tax Equity and Fiscal Responsibility Act (TEFRA) option.

Supplemental Security Income (SSI) is a federal program which provides regular income to individuals with mental or physical disabilities who meet disability and income requirements. Because of the income requirements, many middle income disabled children do not qualify. However, if the child is hospitalized more than thirty calendar days, she is not considered part of the family and can qualify on her own income limitations. Upon discharge from the hospital, SSI is discontinued unless she is part of the waiver program.

To reach the number for your local state Social Security Administration call 1-800-772-1213.

School Programs

Prior to age 3, state programs, such as Early Childhood Intervention, provide therapy and other services to children with disabilities. An early childhood intervention team generally consists of teachers with special education training,

speech and language pathologists, Physical therapists (physiotherapists), occupational therapists, and other support staff, such as music therapists, teacher aides/assistants, and counselors. Services for very young children, from birth through age two, are called Early Intervention or Part C services (so named for where they are described in IDEA). Services are provided based upon an Individual Family Service Plan (IFSP), the plan for special services for young children with disabilities. If you need help finding information on early intervention programs in your area, talk to your child's pediatrician or contact your Family Empowerment Representative.

After age 3, those services are then provided by the local school district. While the school will not provide therapies needed for medical purposes, it will provide that therapy needed to support your daughter's education.

Other Sources of Government Assistance:

- State Programs for Children with Special Health Care Needs
- Genetic Services
- Early Periodic Screening, Diagnosis and Treatment (EPSDT)
- Public School System Requirements
- Section 8 Housing

Other Sources of Support:

- Lions
- Elks
- Kiwanis
- Rotary
- Junior League
- Shriners Hospitals and Clinics