

# Insurance Navigation

The cost of health care has skyrocketed to crisis dimensions in recent years, and become a central issue of national policy and concern. Paying for health care (medical services, vision, dental, prescription drugs, therapies, durable medical equipment DME) can be an additional burden to families of children with special needs. For many people, obtaining insurance coverage is a complex process, but it is required in the U.S. and not having insurance could result in both health and financial risks. Once obtained, the insurance may not pay for all of the child's needs. As you consider insurance options, keep in mind all areas of expense to evaluate for your out-of-pocket costs including premiums, deductibles, coinsurance, copays, prior authorizations, in-network vs out-of-network care, and waiver programs. Insurance companies can no longer deny coverage based on pre-existing conditions. To understand, predict, and manage your health care costs, it is helpful to understand your options:

## Types of Insurance Protection

There are a number of different types of insurance protection available. Sometimes the decision is made by your employer, and sometimes you have a choice in selecting healthcare coverage. Often, the type of insurance available is a variation or combination of the following.

- Basic Protection (less coverage, lower premiums)
- Major or Comprehensive Medical (more coverage, higher premiums)
- Disability Insurance (income protection)
- Supplemental Policies (works in combination with primary insurance)
- Secondary insurance (can extend coverage where primary coverage ends, examples could be the 2<sup>nd</sup> parents' private plan or a government-funded plan such as Medicaid)

## In the U.S., there are two major types of health insurance:

- 1 **Private health insurance** (also known as commercial health insurance), which is any health insurance plan privately purchased; often private health insurance is available through an employer
  - **Group Plans:** costs are shared by the insured and employers
  - **Preferred Provider Organizations (PPOs):** services are provided with specific health providers, with an option to see nonparticipating doctors at a higher per visit cost.

- **Self-Insured Programs:** businesses pay all or part of the medical expenses without using insurance. These programs are not subject to state regulation and have very limited legal protection.
  - **Health Maintenance Organizations (HMOs):** groups subscribe to these plans, which provide preventive, ongoing, and hospital coverage, usually with a set fee for service. These plans require that physicians who are members of the HMO are used. This sometimes restricts choice and specialized care. There is usually a small copayment and often a referral from the primary care physician is necessary for specialists.
  - **Individual Plans:** provided by an insurance company, with more restricted benefits than group plans.
- 2 **Government-funded health insurance**, which means insurance benefits provided through a government program such as Social Security, Medicare, Medicaid, the Children’s Health Insurance Program (CHIP), TRICARE (through the U.S. Department of Defense), VA Care (through the U.S. Department of Veterans Affairs)
- Compassionate Allowances are a way to quickly identify diseases and other medical conditions that, by definition, meet Social Security's standards for disability benefits. Rett syndrome is on this list.
  - Medicaid Waivers are state based vehicles to obtain health care services in the Medicaid and CHIP programs for many conditions including people who have intellectual or developmental disabilities. In some states, there are waitlists of years for these waiver programs, and once on a waiver in one state, it does not travel with you if you move to another state.

Visit NORD’s website for more information: <https://rarediseases.org/for-patients-and-families/information-resources/state-health-insurance-information/>

Register for our free RettEd webcast “Planning for a Protected Tomorrow” to learn more about health care options, savings accounts, and income eligibility:  
<https://www.rettsyndrome.org/RettEd>

See the *Rett Syndrome Handbook, 2<sup>nd</sup> ed.*, section seven, Resources: Where To Go For Help