

As an individual with trisomy 21 approaches the age of emancipation, the following legal support arrangements should be considered and implemented on their 18th birthday.

Power of attorney: A power of attorney allows the individual with trisomy 21 to appoint someone to make decisions for him. With power of attorney, the individual can maintain some control, as defined by the legal document that you create. The power of attorney may be revoked, at any time, by the person who granted it. This may be the best option for more independent individuals.

Guardianship: A designated person is given legal authority to make decisions for an individual that the court decides is “incapacitated.” The court also determines the scope of the guardian’s authority.

Limited guardianship may be appropriate for an individual who is able to make some decisions on his own.

General guardianship may be more appropriate for individuals with more severe intellectual disability.

Representative payee: A person or organization is appointed by the Social Security Administration to receive Social Security funds for an individual who cannot manage his own benefits. The payee uses the funds to pay for the needs of the beneficiary and must be able to show how the benefits were used. The designation of representative payee is necessary, regardless of whether power of attorney or guardianship has been established. Application is completed through your local Social Security office.

Individual Support Plan (ISP): This is a document, created by the Office of Developmental Programs, that provides details about what is most important to an individual with intellectual disabilities. It allows everyone involved in supporting that person to focus on personal preferences, goals, health and safety issues, and functional information. It identifies services that the individual will need to live successfully in the community, delineates roles and responsibilities of providers, and ensures that funds are used in the best interest of the individual.

Waivers are state provided services and benefits, offered in an individual’s own community, that may allow the individual to live more independently and promote community living. This may include support for recreation, educational/vocational opportunities, home assistance with daily living, and transportation. In Pennsylvania, application for waivers are completed through the Office of Developmental Programs. In New Jersey, application for waivers are completed through the Division of Developmental Disabilities.

Achieving a Better Life Experience (ABLE) Act of 2014 allows individuals with disabilities and their families to set up a tax-advantaged savings account for expenses pertaining to their disability. For information by state, see: <http://ablenrc.org/state-review>.

Special needs trust: As part of estate planning, a special needs trust is an instrument that is customized to address the unique circumstances of each family. It allows the beneficiary to remain eligible for need-based government benefits, such as Medicaid and Supplemental Security Income. This allows an individual to maximize both public and private resources to meet basic care needs.