



Your Special Needs Planning Checklist

Establishing lifetime care for a child with special needs requires careful planning. Taking the first step is much easier when you are prepared and know the important aspects of a successful plan.

Plan for expenses while understanding the benefits and possible impacts.



Gather estimates of your out-of-pocket expenses, including fixed costs for nursing and therapy, transportation, special education, any home modifications and specialized computer equipment needed for learning.



Understand available government benefits like supplemental security income (SSI), Medicare and Medicaid and know what your child is entitled to. There are restrictions and financial requirements to consider. A helpful list of available government resources can be found at <https://www.usa.gov/disability-services>.



Build your retirement fund. This will help ensure your retirement savings don't get depleted because of caring for a child with special needs. You will need to have reliable income for when you are no longer able to work.



Check your beneficiary designations. In order to preserve your child's Medicaid and SSI benefits, it's important your child is not named as beneficiary on any financial savings vehicles, including life insurance policies, IRAs, annuities and 401(k)s. Consider the potential negative impacts of monetary gifts or an inheritance from family or friends on your child's benefits.



Use careful consideration before establishing a 529 plan or any custodial accounts for your child with special needs. Similar to beneficiary designations, you don't want these accounts to negatively impact your child's eligibility for Medicaid and SSI benefits.

Think through estate planning and legal considerations.



Ensure all of your legal and financial records are organized and located in a safe place and paperwork is up to date. This information is helpful to have on hand and readily available for planning purposes.



Find an attorney who has experience in working with families who have loved ones with special needs. There are many things to consider when planning for the future care of your child when you can no longer care for them. Setting up a special needs trust, establishing guardianship guidelines and power of attorney for your child are a few key areas where you will need an attorney's help.



Review your will or make one with an attorney if you haven't done so already. A will is a legal document detailing your wishes regarding your assets and dependents after your death, including your guardianship instructions for your children. You should consider a special needs trust for assets passing to your child.



Determine the appropriate asset distribution plan among all of your children.



Communicate your plan to avoid well intentioned family members leaving assets directly to your child with special needs.



Create a letter of intent. This document helps ensure that your child's future caregiver knows their functional abilities, daily life routines, interests, and particular likes and dislikes. Be sure to update on a yearly basis.



Complete an advance directive for your child. An advance directive is a legal document that states a person's wishes about receiving medical care if that person is no longer able to make medical decisions because of a serious accident or injury. In the case of a child with special needs, an advance directive gives an individual (such as a parent or guardian) the authority to make medical decisions for a child that is unable to make their own decisions.