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Planning for Children and Adult Children With Special Needs

Individuals with special needs may have a developmental disorder, such as autism, ADHD, or Asperger's syndrome. They may have an intellectual disability such as Down syndrome. Or, perhaps they have a learning disability such as dyslexia or physical impairments that affect their vision or hearing. People with other serious or chronic health conditions, such as cystic fibrosis or epilepsy, may count as special needs.

The US government combines this group into the overall class of disability. Current data estimates the US population of people with disabilities comprises more than 42 million individuals.

Making plans that address your child's experience while living with physical and cognitive impairments requires careful thought and planning. When looking toward their future, consider your child's ability to make decisions and find the resources they will need. If you can provide for them financially, this will allow them to live on their own to the fullest extent possible.

At the same time, using specific legal arrangements to protect their best interests is crucial. There will likely come a time when you are no longer around or able to help. The foundation for continued care you set today will ensure your child has the best possible chance for a successful future.

Special Needs Planning

Achieving your planning goals begins with understanding the financial implications of your loved one's situation. The top priority is typically providing financial security for your child with special needs. Much of this security will come from government services like Social Security Disability Insurance (SSDI), Supplemental Security

Income (SSI), and Medicaid.

A special needs trust or a life insurance policy can further enhance your child's financial future. Work closely with your special needs planning attorney to incorporate financial resources or gifts into your special needs plan. They can help ensure that your child remains eligible for invaluable government programs. In addition, they are familiar with maintaining all possible avenues of support through legal techniques.

Creating a Support Team

Beyond securing their financial future, as a family, you need to identify your child's support team. First, be sure to select a guardian to make medical or life decisions for your adult child if they are unable to do so. Naming a backup guardian is also common practice.

If there is a special needs trust in place, you must appoint a trustee to oversee the trust. Having a trustee different from the named guardian is an excellent checks and balances system. If possible, involve your special needs child in the discussions and planning process. Individuals living with a disability want a say in who they'd prefer to have involved (or not) in their lives.

Parents may struggle to trust others with the care of their child with special needs as they age. It can be difficult for them to believe that someone else is capable of providing the same level of care. Each family must work out issues and make compromises, keeping the child's best interest in focus.

Professional personal care assistance can relieve the principal care provider, usually the guardian, and give families extra flexibility. Some care options to consider include:

- **Family members** - Many individuals with special needs choose to remain with relatives. Typically, the family knows the child's routines and preferences best. However, this may leave family members serving as unpaid caregivers, putting their earning potential and future at risk. Sharing family responsibility and rotating caregiving may alleviate this problem, yet it may not be ideal for the person with special needs.
- **Personal care professionals** - Known as PCAs, these caregivers are the main method of non-family care. Duties include organizational or housekeeping tasks, bathing, dressing, ventilator or catheter care, and transportation. Although you can hire a PCA through an agency, many families opt to hire and train individuals directly. In either case, proper vetting is a must.
- **Community-based homes and supported living arrangements** - Some adults with special needs are capable of living in group homes. Here, they can live with independence and some support. Care providers who live or work in these settings offer services ranging from medication assistance to decision-making. This living arrangement is typically communal with shared activities,

including meals and social groups.

- **Independent living arrangements** - Many adults with special needs can live on their own with a PCA's support as needed. Some individuals may only require a few hours of PCA care daily to help with morning routines or mealtimes. Others have several PCAs providing 24-hour care in rotation. Sometimes there is an arrangement with a housemate or roommate to provide backup support in exchange for a break on rent.
- **Assistive technology (AT)** - The digital age has given rise to many assistive devices providing greater options for independence. AT allows people with disabilities to control their home environment, take their baseline medical readings, or access the internet.
- **Day programs** - Young adults with special needs may attend public schools until they turn 21. As these young adults transition to adulthood, some day programs provide similar continued education and structure. Such services and programs can help in enhancing their life skills while maintaining social bonds with a community of their peers.
- **Long-term care facilities** - In recent decades, there has been a movement away from care in institutional settings. However, a residential facility may prove to be the best option for certain situations. For instance, there may be limited access to or long waiting lists for community care or other types of support.

Drafting a Letter of Intent

Create a letter of intent (LOI) to help add another layer of protection for your child into the future. An LOI can provide a general overview of your child's life. It might address family history, your child's daily schedule, medical care, education, or public benefits on which they rely. You may also consider including information on the following:

- Employment hopes
- Residential social and religious environments
- Behavior management
- Foods (including any allergies)
- Hopes for their future

You can also explain expectations for your child's final arrangements for funeral services and burial.

Some options for your child's future are only available with additional private funding. However, with the right planning, all children and adult children with special needs can qualify for appropriate life care.

Discuss care options with your special needs attorney as your first step in creating the best plan possible for your child.