



Special Needs Planning Benefits All Siblings

This edition of the Voice is written by [Benjamin A. Rubin, Esq., LLM](#), a partner in Rubin Law, with offices in Buffalo Grove, Chicago and Old Orchard, Illinois. The firm focuses exclusively on serving the families of children and adults with developmental disabilities, intellectual disabilities and mental illness. Having a brother with autism, among other significant disabilities, has profoundly shaped who Benjamin is today, including the type of law he chose to practice.

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Having a sibling with special needs almost always has a profound impact on an individual. It has the potential to affect every major life decision they make—where to attend college, what job to accept, and even whom to marry. The repercussions can ripple through the generations, affecting their children as well. Siblings, who may not remember a time when family dynamics weren't shaped by a brother or sister's disability, have a different perspective from their parents.

The biggest impact, which is almost universal, is a sibling's understanding of their future responsibilities. They know that, at some point, they'll assume a more active caregiving role, since it's likely that their brother or sister will outlive their parents. The tasks they'll be taking on depend in large part on the special needs planning that's been done by their parents. While it can be difficult for them to begin preparing for a time when their child with special needs doesn't rely on them, it's crucial that they do so. Otherwise, the parents' illness or death could cause a crisis affecting the entire family. When parents begin special needs planning early, they contribute to the independence, financial security and peace of mind of *all* their children.

Financial Security

Government benefits such as Supplemental Security Income (SSI) and Medicaid often provide the financial foundation for a loved one with special needs. However, both programs are needs-based, requiring beneficiaries to have minimal income and assets. In order to supplement the coverage they provide, parents should seriously consider establishing a [special needs trust \(SNT\)](#), which can hold funds for the child's benefit without affecting their eligibility for such programs.

Even if an SNT will not be funded until the parents' deaths, it's important to explain to the other siblings how this financial planning will protect *them* financially, as well, since they will be less likely to be burdened with expenses on behalf of the child with special needs.

Fair funding

Many parents struggle with how to equitably divide their estate among their children, especially when funds are short and one child has a much greater need for financial support.

One potential solution is to [fund the SNT with life insurance](#), leaving the rest of the estate to the other children. Another possibility is to establish within the parents' estate plan a minimum amount to be left to the SNT, before dividing the estate equally among siblings. Again, it's important to communicate intentions to family members in order to avoid misunderstandings.

Residential Living

[Where a child with special needs will live](#) is central to their quality of life, and it's not a decision to leave to chance. Where will they thrive? How will that choice affect the rest of the family? There are long waiting lists in many states for placements in supported residences.

It's very different to plan for a future where a sibling will be living along with you, your spouse and children, rather than in a community setting, with customized supports that you monitor. Doing so years in advance, and revisiting the decision regularly is a good idea.

Having a special needs sibling can also affect dating. When should you bring up the fact that you have a brother or sister with special needs? On the first date? Maybe you should, because if you're looking for a life partner, why waste time with someone who won't embrace this significant aspect of your life and future responsibilities? It is not uncommon for the sibling to become divorced due to the stress put on the marriage when an adult brother or sister with significant special needs moves in after the death or illness of caregiver parents.

When my parents carried out a plan for my brother to live a full life in the community, the transformative impact was immeasurable. He currently lives in a CILA (Community Integrated Living Arrangement), commonly referred to as a group home, with three other individuals and staff. He has gained independence and social experience. And when I met my wife, I could tell her with confidence that while my brother would be a very important part of our lives, he would have his own life, and we would never be required to have him reside with us.

Perhaps most importantly, my parents can be truly devoted grandparents to my children, as well as to my sister's children. If my brother were still living at home, their time and attention would be constantly divided. With my brother living successfully in a group home, our children get to enjoy some exclusive attention from my parents that my sister and I rarely received. For that I am truly grateful.

Decision-Making

Making personal and financial decisions for someone else is an enormous responsibility. While siblings are often asked to become trustees for an SNT, this can get complicated. They may not have the knowledge and skills needed to manage government benefits, make investment decisions, pay the trust's taxes and handle reporting requirements. They may be unable to devote the necessary time, given other obligations. Or, while they may initially agree to the role, a marriage or job relocation could alter their situation. It could even strain their relationship with the beneficiary, since they might be put in the position of denying requests for trust distributions. In many cases, a corporate trustee, [with the sibling\(s\) overseeing performance in the role of trust protector\(s\)](#), could be preferable.

If the individual with special needs has the capacity to understand and sign a legal document but may need help making financial or medical choices, [a healthcare advance directive and/or financial power of attorney](#) should be arranged once they reach the age of 18 (21 in some states). While this should be done even if parents are living, the eventual role of siblings should be considered. In cases of significant disability, it may be necessary to name a [guardian](#) to oversee the individual's welfare.

In such circumstances, it may be a good idea to split responsibilities if there are multiple siblings who can be called upon. Perhaps one could handle personal and medical issues, while the other manages finances. Perhaps one could be guardian, the other the SNT trustee. Taking a team approach can help siblings maintain balance in their own lives.

Conflicting Emotions

It's inevitable that parents' time will be disproportionately devoted to the sibling who has the most needs. In my role as president of [Supporting Illinois Brothers and Sisters \(SIBS\)](#), I often hear of conflicted emotions with regard to a brother or sister with disabilities. Siblings are often fiercely protective, but at the same time, they may ask, "Why must they always take center stage?" So, at times, they also feel jealous and resentful. Growing up, they are often much more mature than their peers, due to dealing with "adult things" from a very young age.

As a result, some siblings experience depression and other mental health problems. It's important for siblings to "unpack" those intertwined emotions, and therapy can help. It's

usually better to deal with those issues as a child or teen than to wait until adulthood, when a spouse and children may be affected.

Young siblings need “respite” as much as their parents do. Even family vacations can be stressful. Whether it’s a weekend away or a day’s special treat, children need one-on-one time with a parent.

Disability affects all family members. By beginning special needs planning early, parents can reduce uncertainty and stress, while enabling *all* their children to lead more independent lives.

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