



## **Preparing for Tomorrow: What Parents of Adult Children with Special Needs Need to Know**

*This article is provided by SNA member [Lauren I. Mechaly](#), who is Counsel at [Rivkin Radler LLP](#), in Hackensack, New Jersey. She focuses on elder law, special needs planning, estate planning, and estate administration in New York and New Jersey, and assists seniors with long-term care planning and helps individuals with disabilities and their families secure government benefits and community support.*

For parents of children with special needs, growing older doesn't just mean preparing for your retirement and worrying about creaky joints. Ensuring your adult child's future health, happiness, and financial well-being requires preparation, too.

As a special needs attorney with nearly two decades of experience, I've guided countless families through the complex process of planning for the future care of loved ones with disabilities. I am often asked, what will happen to my adult child with special needs when I am no longer able to care for him or her?

If you find yourself concerned about this, you're not alone. It's never too early or too late to start planning for yourself and your child. Here are some key considerations to help you feel more secure and at peace with your child's future:

### **1. Establish Legal Authority**

The first thing I discuss with clients is decision-making on behalf of the child. You'll need to have answers to questions like:

- Who will have the legal authority to make decisions for your child when you no longer can, and what documents need to be put in place to grant that authority?
- If you're currently the guardian, who's next in line?
- Do you have your own legal documents, like a Will, Power of Attorney and Healthcare Proxy, in place?

These aren't easy conversations, but they're vital. I recommend involving your child in the process, to the extent their capacity allows; after all, we're talking about decisions that will impact the rest of his or her life, and input from your child is important in ensuring his or her future needs.

It's also important to note that the degree of legal intervention varies depending on your child's level of capacity. For higher-functioning individuals, we might look at establishing less restrictive options, such as a Power of Attorney and Healthcare Proxy or supported decision-making (which allows the child to make his or her own decisions, albeit with support). For those with limited capacity, pursuing a guardianship may be the only alternative.

## **2. Create a Home for the Future**

Where will your child live when you are no longer able to provide care, decide to downsize, or require long-term care yourself? It's smart to explore residential placement options like group homes and supportive living apartments now, before you are in crisis mode. If your child is more independent, look into modifications and support services that will allow him or her to remain in the family home, with assistance. The key is to start this transition process while you're still around to help.

Remember, this planning process is as much about *empowering* your child as *protecting* them. To the extent possible, we want to foster independence and self-determination, even as we ensure their needs are met.

## **3. Protect Your Child's Financial Security**

Understanding, navigating and making the most of benefits like Medicaid, SSI, and SSDI is crucial. While these benefits may already be in place, it's important to ensure they'll continue seamlessly. Go over your estate plan with your attorney to make sure any inheritance is structured properly, such as through a supplemental needs trust, to protect means-tested benefits.

Keep in mind that the rules around these benefits can change. For example, SSI is currently updating its regulations regarding food expenses, which could impact how the financial support for your child is structured.

## **4. Build a Support Network**

Who will handle day-to-day tasks like managing medical appointments, renewing benefits, or even buying new clothes? The legal guardian isn't the only person for these practical matters, and sometimes that person needs assistance with these tasks, which can be time consuming. I often recommend looking into care managers or advocacy organizations that can provide "boots on the ground" support.

This is especially important if the person you're naming as guardian lives far away. You might need to create a team of support, with different people handling different aspects of your child's care.

## **5. Secure Your Future to Protect Theirs**

Remember, to effectively plan for your child, you need to plan for yourself as well. This includes considering your own estate and long-term care planning.

For example, if you need skilled nursing care, how will you pay for it without depleting the resources you've set aside for your child? It may be worthwhile to look at long-term care insurance or Medicaid planning strategies for yourself. It is just as important to be sure that your estate plan incorporates the right plan for your child so that you do not risk jeopardizing his or her means-tested benefits upon your death.

## 6. Leave a Roadmap: The Letter of Intent

One tool I always recommend is creating a "letter of intent." This isn't a legally binding document, but it is a comprehensive guide to your child's life. It includes everything from their daily routines and medical needs to their favorite foods and activities. This document can be invaluable in helping future caregivers understand and meet your child's needs. And, it makes sure that all important information, like Social Security Number and health insurance information, is in one place.

## 7. Keep Current

Special needs planning isn't a one-and-done process. I recommend revisiting your plan every 3-5 years, or sooner if there are significant life changes. Your child's needs may evolve, your family situation might change, or there could be updates to relevant laws and regulations. Stay in touch with your attorney!

## 8. It's OK Not to Be OK

I always have tissues ready in my conference room, because these conversations can be emotional. Feeling overwhelmed is completely normal! After all, it's scary to think about not being there for your child. But that's exactly why we do this planning. My clients sigh with relief when their estate planning is done, because it provides peace of mind that their child will be cared for even when they're not around.

## 9. Take the First Step

There is not one plan for everyone, and meeting with the right attorney (for you!) is an important first step. There's no one-size-fits-all solution in special needs planning — every family's situation is unique. But the most important thing is to start the conversation. Reach out to a special needs planner who can guide you through the process step-by-step.

Remember, you're not in this alone. While the planning process may seem daunting, breaking it down into manageable steps makes it less overwhelming. Whether you're just getting started or reviewing an existing plan, there's always room to ensure your child's future is well-protected.

**About this Article:** We hope you find this article informative, but it is not legal advice. You should consult your own attorney, who can review your specific situation and account for variations in state law and local practices. Laws and regulations are constantly changing, so the longer it has been since an article was written, the greater the likelihood that the article might be out of date. SNA members focus on this complex, evolving area of law. To locate a member in your state, [visit Find an Attorney](#).

**Requirements for Reproducing this Article:** The above article may be reprinted only if it appears unmodified, including both the author description above the title and the "About this Article" paragraph immediately following the article, accompanied by the following statement: "Reprinted with permission of the Special Needs Alliance – [www.specialneedsalliance.org](http://www.specialneedsalliance.org)." The article may not be reproduced online. Instead, references to it should link to it on the SNA website.

