

Through a Parent's Lens

When a Child Has Special Needs

By **Mary T. Schmitt Smith, CELA**

As a special needs attorney and a Mom of two adult sons with disabilities, I bring an added dimension of experiencing reality in the trenches to my work with clients. Yes, I know how it feels to receive a diagnosis you never anticipated as a parent, to agonize over an IEP, and decide about graduation (or not), and stay up nights worrying about the future. Yet, I've learned a lot from each of my two sons, who are each different individuals. I also know the satisfaction of milestones achieved, whether it was traveling independently on a bus trip to Chicago to see their sister, proclaiming he got the job all on my own, or making his own doctor's appointment to check out an earache.

Even before having children, I started as a special needs attorney helping families of children with disabilities plan for their future. A good friend from law school was a staff attorney for the local Arc, and she would regularly refer clients. For 12 years, I served on the board of the Arc of Oakland County, the sixth largest local chapter of The Arc in the country. The parents who started the Arc were fierce advocates for their children. They were incredibly instrumental in establishing the right to receive a free and appropriate public education (FAPE) and federal funding for special ed services on behalf of children with intellectual and developmental disabilities.

So when my sons, now 32 and 29, respectively, were born, I was familiar with many of the issues that my family would be faced with. Still, nothing really prepares a parent for all the evaluations, the appointments and related therapies. Both my husband and I were fortunate- we finally gave up asking "Why did this happen?" and were able to move on and focus on the real question: What was needed to help each son learn to be an independent individual in this world?

Early intervention services were followed by a stint of developmental kindergarten, then we were introduced to the wide world of special ed, its many acronyms and early inclusion efforts. Our third child is a daughter. Although she does not have a disability, the three siblings are very close. At one point, when they were all attending the same public elementary school, we couldn't figure out why our first grade daughter kept getting into fights on the schoolyard at recess. We learned it was a six-year-old's way of handling the

bullies who were harassing her older brothers. A hard but important lesson about respect and acceptance of differences.

After our sons turned 18, we began navigating the often-frustrating benefit system. Most parents I get to work with are worried about providing long-term financial security for their children, and making the best use possible of public programs increasingly at risk, given budget discussions at every level of government is an important part of special needs planning. Leveraging public benefits with family funds is an essential part of planning. Special needs trusts (SNTs) have become an important tool to preserve their eligibility for means-based programs by allowing us to set aside funds to supplement the needs the government benefits do not provide.

While we learned long ago the importance of advocating on behalf of our sons, we realized that it was just as important that they advocate for themselves, and we've encouraged their independence. Although I may be a representative payee, each writes out checks to pay their monthly bills.

When I offer an SNT trustee workshop at my office, many parents are surprised to learn how many others share their situation. Caregivers can easily become isolated. Burnout is a real danger and marriages can splinter from the stress. While at times difficult, almost impossible, parents really do need to save time for themselves. Respite services are available from community organizations, and support groups families helping other families can be invaluable.

I am only one of many attorney members of the Special Needs Alliance who have family members with disabilities, and our personal experiences inform the work we do. But I have to give credit where it's due: I've also learned a lot from my clients. And a lot from all my kids.

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