



All Grown Up»

What to consider when your child with special needs turns 21—and is no longer a child. **By Samantha Neudorf**

As parents, we hope for our children to grow up and—difficult though it may be for us emotionally—fly the coop to live on their own as full-fledged, independent adults. But if you have a child with special needs, these concerns may run deeper, and that goal may seem elusive or even impossible. That is why parents should start to consider what happens to their children with special needs, no matter how young they may be, well before they turn 21.

The first thing to consider is what your child with special needs will do after completing high school. Will she go to college? Will he attend a vocational school? Will she live on her own? These are all conversations you should be having now. Here are some points to consider when planning the future for your child with special needs.

Obtaining Guardianship

If your child has health issues, you may want to consider applying for guardianship, because once your child with special needs turns 18, you as the parent may not have access to his health care information because of HIPAA: the Health Insurance Portability and Accountability Act of 1996. Under HIPAA, patients older than 18 have their own rights to privacy for their medical records, meaning parents or caregivers do *not* automatically have the right to this information. One way to work around this, if your child is unable to take care of himself,

is to obtain guardianship—which means, essentially, that you will retain legal responsibility for your child even though he is of age to be considered an adult.

Bernard Krooks is an attorney and founding partner of Littman Krooks, a law firm that specializes in elder law and special-needs planning, with offices in Manhattan and White Plains. Krooks advises that parents start to apply for guardianship by the time their child is 17 years old because the process could take longer than six months.

The guardianship process involves petitioning the court. Parents begin by filling out an application to certify that their child does indeed have a disability, and a doctor must submit a form to verify this. The application must also specify why the child with special needs is not able to care for himself. Then there will be a hearing in front of a judge, which is why it may be valuable to hire a special needs attorney to assist in the process.

Krooks also suggests setting up a special needs trust to create a supplementary source of funds to pay for everyday necessities that government benefits will not cover, such as services that are not covered by Medicaid.

“The reality is what the government gives you is decreasing due to fiscal constraints,” Krooks says, “so it’s very important to have a special needs trust to pay for things that help improve the quality of life of somebody with disabilities.”

Pursuing Higher Education

Under the Individuals with Disabilities Education Act, children are entitled to free and appropriate public education by federal law, and schools must provide them with an education through 12th grade. The IDEA covers 13 kinds of disabilities, including autism, deafness, orthopedic impairment, and visual impairment.

As a part of the IDEA, children with special needs will receive an Individualized Education Program, which is a document that specifies what your child's disability is and how the school will support her. The IEP will specify how the child is doing in school, educational goals, and transition planning to prepare him for life after high school.

In order for a child to move on to college, she will need a regents diploma if she went to high school in New York, and will have to undergo psychoeducational testing to analyze the mental processes that might affect her educational performance. Once a child takes this test, he can apply to college and the school will provide the proper accommodations when taking exams.

Lara Bakshi, special needs and special education attorney and founder of Bakshi Law in Manhattan and West Islip, strongly advises that, if they are able to, children with special needs either receive a higher education or pursue a vocational program.

"The most important thing for a child with special needs is to be able to interact with their peers that are not special," Bakshi says.

Bakshi suggests that a child with special needs attend a small liberal arts college because it will be more structured and less overwhelming than a large university.

If he decides to attend a vocational school, programs such as the Boards of Cooperative Educational Services, which has 37 locations across New York state, are popular choices. There are programs, such as Career and Technical Education to learn how to operate different machineries.

Littman Krooks, among other companies, employs people with special needs in its office to help with administrative tasks, including making photocopies, filing paperwork, and helping with shredding and scanning documents.

Deciding Where to Live

The other big question to consider is where your child with special needs should live because she will technically no longer be a child after turning 21. Krooks says that parents tend to keep their children at home, but the problem is it's not preparing them to live independently.

"Statistically speaking, the parents will predecease the child," Krooks says. "Years ago, children with special needs did not have a normal, typical life expectancy, but now many kids, even with Down syndrome and other special needs, are able to live a full or close to full life expectancy."

Parents should therefore consider helping their child with special needs find a place to live in proximity to his doctors, he says. Krooks suggests finding a specialist who has worked in the area for a long time and to establish a relationship with the doctor throughout the child's lifetime.

"The sooner you plan for this, the fewer things that you'll be unprepared for along the way," Krooks says.