

# Ask the Expert: Tips for Adults Advocacy in the Legal Realm

By Ed Wilcenski, Special Needs Planning Attorney



Advice from an attorney well-versed in issues related to disability will often be necessary in developing special needs trusts, establishing guardianship, or appointing financial and health care agents, and in protecting government benefit eligibility.

## What are the most common legal issues faced by people with disabilities?

By far the most common issues are access to services and the need for continued advocacy after children reach the age of majority. While children are in school, many services are provided through the school district, and parents have the legal right to make decisions for their children.

Once a child reaches the age of 18 and ages out of the school system, services are no longer guaranteed, and parents are no longer legally entitled to make decisions for their children (nor are they legally entitled to access medical and financial information without the child's consent). At that point, we look to establish (and/or protect) eligibility for Supplemental Security Income and Medicaid programs, and we consider the need for guardianship or the appointment of an agent through a power of attorney or health care proxy.

Remember that many individuals with Spina Bifida are fully competent and able to make their own medical and financial decisions, but they still appreciate the continued assistance and advocacy that parents will provide as they transition into adulthood. Ensuring that the parents have the legal ability to speak with health care providers, government agencies, and financial institutions can make this advocacy much more successful.

## How can adults be good legal advocates for themselves?

Successful advocacy in any area always involves good information and communication.

For example, individuals with disabilities who are mentally competent should have a basic understanding of the eligibility rules that govern those programs that provide ongoing support in the community (with Medicaid being one of the most important, as it funds many services that would not be available through a primary health insurance program). This knowledge will enable them to identify for themselves changes in their life situations that may affect their benefits. It will also enable them to take part in many important decisions, especially those that involve money, as many programs are "means tested" (meaning they provide benefits to those whose income and financial resources meet certain requirements.)

Many individuals with disabilities work and accumulate assets, but need the support of means tested benefit programs in order to make employment possible—these programs can fund transportation, personal care assistants, and service coordination. Individuals can often protect their income and assets and still participate in many of these critically important programs, often through the use of special needs trusts. By understanding how these trusts operate and how they can be used to help protect assets, individuals with disabilities can be active participants in the management of their financial affairs.



Good communication can also be important in those cases where individuals with developmental disabilities are unable to be their own best advocates. Often the parent or other person involved in day-to-day care has become intimately aware of what works and what doesn't, preferences, and little things which may have impact on quality of life. At some point, the parent and primary caregiver will no longer be able to provide the same level of advocacy and assistance and someone else may have to step into the role of advocate. Good record-keeping and communication with those who will step in help smooth that transition. Parents should consider writing a "letter of intent" to help document these important issues.

### **What resources are available in the area of legal advocacy?**

The Internet provides access to a wealth of information—so much so that it can be overwhelming and often intimidating. And what you find on the Internet may not be specific to your particular location or program, so use it with caution.

National Web sites such as those offered by government agencies are good places to start. They can provide the general picture, but when you need specific information it is best to contact someone in your community who knows the local situation well. The national Web sites can often direct you to local resources.

Legal advice from an attorney well-versed in issues related to disability will often be necessary in developing special needs trusts, establishing guardianship, or appointing financial and health care agents, and in

protecting government benefit eligibility. The Special Needs Alliance (SNA) is a great resource for finding such an attorney with experience in this area. The SNA is a national, nonprofit organization of attorneys committed to helping people with disabilities and their families. Membership in the SNA is by invitation only, and the majority of these attorneys are themselves family members of individuals with disabilities. Access their Web site at [www.specialneedsalliance.org](http://www.specialneedsalliance.org).

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