



Political Advocacy by Parents of Children with Disabilities

This issue of the Voice was written by Special Needs Alliance member Lois M. Zerrer. Lois has practiced Elder and Special Needs Law in Springfield, Missouri for over thirteen years and speaks frequently on these topics for Special Needs professionals and families.

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To say that parents of children with disabilities have learned to multi-task is an understatement. Providing for the many personal and care needs of your child on a daily basis can be overwhelming, but advocating for your child is a true act of love that makes the effort well worthwhile.

Caring for your child with special needs often involves more than the daily activities of providing food and shelter. Sometimes you must aggressively advocate with legislators and others in positions of authority to do the right thing for your child and others, an activity that may take you out of your comfort zone. If you are able to be an advocate your advocacy could make a real difference statewide or nationally for your loved one and others.

A personal visit to the U.S. Congress or your state legislature can be effective and enlightening on many levels. You will find that it is invigorating to be in a place where decisions are made that affect thousands or even millions of people. You will be talking with officials and staff who can make a significant difference in the lives of your loved ones. To get the most from such visits, you must be prepared and use the right approach. This article highlights several tips and ideas for being an effective advocate with elected local, state or national representatives.

Tips for Effective Advocates

Several legislators and advocates were contacted for the tips and suggestions that follow. These ideas and tips will help you to be an effective advocate when you contact an elected official.

- 1. Make your contact personal. Your contact will be remembered long after your call or visit if you explain how a legislative proposal will impact your family specifically. Your representative likely will not have first-hand knowledge of your family experience, so make your case personal and less abstract. Tell your story. This will help your representative to recall your knowledge, interest and passion long after your initial contact.*

2. *Be prepared. State the issue in a clear and concise manner. Know the bill number you are advocating for or against and where the bill is in the legislative process. Know who supports your bill and who does not. Have precise talking points ready for those who might be opposed to your side of the issue. Do your research and be truthful.*
3. *Be passionate, not demanding. As Benjamin Franklin reportedly said, “You catch more flies with honey than you do with vinegar.” Advocates who present an impassioned plea in a pleasant, respectful tone will be heard, but those who are strident may alienate the listener. Always be especially polite to office staff, who control and schedule personal time with the legislator. Do not be offended if you are speaking with a staffer instead of directly with the legislator. The staffer is likely to be more knowledgeable about your matter than the legislator, and likely will be the person who prepares a synopsis of the issue and legislation for your representative. Treat the staffer with the same respect and dignity that you would the legislator.*
4. *Follow up. It is essential to follow up after your visit to show the legislator that you are truly engaged with your issue. Don’t send an e-mail to follow up—to stand out, send a handwritten note or letter. Legislators receive hundreds of e-mails a day, which may be appropriate if a vote on your legislation is imminent, but a handwritten letter adds a personal touch. This is a wonderful way to continue to share your story and educate an official. And remember what your mother taught you – “please” and “thank you” go a long way! Thank the legislator for the time and effort spent visiting with you. Offer to be a resource if there are further questions on the issue that need answers. If your advocacy is successful and legislation is enacted supporting your position, again thank the legislator. After the legislation passes, perhaps invite your representative to visit with your organization, or recognize their efforts in another fashion. This can help to establish a long and beneficial relationship with your elected officials.*
5. *Op-Ed letters. Don’t underestimate the value of local advocacy. Writing letters to the editors of local, state or national publications can increase awareness of your cause with a wider audience. The more active discourse that exists on your topic, the better. Elected officials subscribe to services that “clip” articles from local publications, which help to educate the officials and allow them to gauge community opinion. Candidate forums and questionnaires from elected officials can be another outlet to disseminate your opinions.*

Incidentally, one bill that recently passed in the U.S. Senate and is now pending in the House of Representatives is of particular interest to members of the Special Needs Alliance

and many readers of *The Voice*. The Special Needs Fairness Act would allow individuals with disabilities who have mental capacity to establish their own “first-party” special needs trust. (See previous issues of *The Voice* for details on these trusts.) Under current law, such a trust must be established by the beneficiary’s parent, grandparent, legal guardian or a court, but it cannot be established by a competent adult on his or her own behalf.

There are two other bills that recently passed in Congress with critical support from parents and advocacy groups. The ABLE Act allows individuals with disabilities and their family members to set aside funds for disability-related expenses, comparable to 529 Plans for education expenses. The [Disabled Military Child Protection Act allows members of the military with a Survivor Benefit Plan to transfer assets to a first-party special needs trust](#) for the benefit of their child, thereby allowing the child to continue receiving important means-tested benefits, such as Medicaid.

Personal advocacy with elected officials by parents and other family members can effectuate enormous change. The disability community may not have tremendous financial resources, but persistence and passion can transform the law at the local, state and national levels.

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