

## Advocacy for Parents of Children with Disabilities

To say that parents of children with disabilities have learned to multitask is an understatement. Providing for the many personal and care needs of your child on a daily basis requires you do this. There may be a way of caring for your child that you have not participated in up to this time. By advocating for your child and other children with disabilities, you are caring for your loved one as well.

This guide highlights several tips and ideas for being an effective advocate with elected local, state or national representatives. I have done this several times with the New York State Early Intervention and Care at Home programs on behalf of my son. Most recently I successfully lobbied my local congressman and state senator to sponsor a Bill to support Spinal Muscular Atrophy.

A major part of being an advocate involves talking with officials and staff of agencies and organizations, as well as government representatives, who really can make a difference in the lives of your loved ones. You want to be prepared for this task in order for your efforts to bring positive results for those persons whose cause you support.

### Tips for Effective Advocates

1. **Make your contact personal.** Your contact will be remembered long after your call or visit if you explain how a legislative proposal, request for services or equipment will impact your family. The person whom you are addressing will not have first hand knowledge of what your family is going through. Whenever possible make your case more personal and less abstract. Remember that your knowledge, interest and passion will be remembered long after your visit.
2. **Be Prepared.** State the issue in a clear and concise manner. Know the language in your insurance policy or the rules of the government program you may be dealing with. If you are lobbying the legislature know the bill number, where the bill is in the legislative process, who is in favor and who is against the bill. Have your talking points ready for who might be opposed to your position. Do your research and always be truthful.
3. **Be passionate, not demanding.** Remember the old saying “you get more with honey, than vinegar”. Advocates who present an impassioned plea will be heard. But those who are belligerent will likely turn off the listener. Always be polite to whom you are speaking, particularly staff. That may be the difference between getting to a decision maker. Be mindful of what you teach your own children “please and thank you” really do go a long way.
4. **Follow up.** By sending a handwritten note or letter, your correspondence will stand out. The people you are contacting are dealing with hundreds of emails and letters each day. A personal letter is a great way of sharing your story and educating the person you are addressing. Be persistent. You do not need to accept “no”. If at first you do not succeed try and try again. Ask to speak to a supervisor, then a manager, and then ask if there are other avenues of appeal.

Sometimes caring for family involves more than the daily activities of providing food and shelter. Sometimes we have to go outside of our comfort zones to do the right thing for our family and others. When you are passionate about helping your loved one and others, these tips can help you expand your reach outside your home or community. Maybe you could be the one to make a real difference statewide or nationally, for your loved one and others by your efforts at advocacy.