

## Parent Advocacy Tips

- 1. Document everything in writing.** The first rule of advocacy is that if it isn't written down, it didn't happen! Follow-up on every conversation with therapists, staff, administration, and others, with a note or letter saying, "These are the points made during our conversation as I recall. If you disagree with the contents as I have stated them please respond in writing as soon as possible." If this is a very serious matter such as health or safety issues, or if you just want proof of receipt, send the letter certified mail with a return receipt. It may seem like a lot of extra work, but if there is an ongoing problem this will help resolve it much quicker. Also, when you put something in writing results are often obtained quicker, as you are taken more seriously.
- 2. Write a general narrative about your child.** It should be concise and no longer than two pages. Include your child's age, diagnosis, likes, dislikes, abilities, schooling received, therapies, current placement, etc. Also write what you would envision for your child as their possible outcome. For example, if you see your child in a community integrated living situation working and socializing within the community then write that down. It doesn't matter where they currently are, or what funding constraints you've been told of, this is your vision for your child. Save this document on a computer so you can make adjustments as needed, or add an updated page when appropriate. This letter can be used in many ways. Give it to new personnel working with your child, attach it to letters advocating services for your child, etc.
- 3. Write to your local, state, and national representatives and senators introducing yourself as a constituent family and attach your letter describing your child.** Don't complain or ask for anything, just say, "Hi, how are you, here we are..." Then when you do write for assistance or to voice an opinion, they are familiar with you. They know you are a proactive person who knows what they are talking about.
- 4. Know your candidates for all offices.** Every year is an election year of some sorts. Be informed. Contact every candidate regardless of political party or level of government and ask what their platform on disability issues are. Be specific. Ask what about funding for community placement? What about home services? Ask about issues that you face. Again, during the campaign send your letter and compliment the candidate on knowing the issues or ask why they are not aware of these issues and offer to educate them. Give them resources to contact to find out more. Then tell them you expect a follow up letter, once they have researched the issue, telling you their position.
- 5. Utilize natural supports.** Yes, many services are required to be provided to individuals with disabilities. However, families must also look for creative ways to solve problems. For example, a family needed some additional therapy and socialization for their child with autism. Funding was unavailable as were opportunities. This parent approached high school honor groups to "adopt" her son as a project. These young people carried out therapy activities and took him on social outings regularly. He gained a great amount of independence and skill, the kids who worked with him have a greater awareness of what having a disability is like for both the individual and their family; and it didn't cost anyone anything! Groups often provide transportation, supplies, and assistance in many forms as a volunteer community service. Utilize these agencies and organizations. Contact PRN for suggestions on where to look for the assistance you need.

*This fact sheet was developed by Mother's From Hell 2, a national group of parents, relatives, and friends fighting for the appropriate education, community acceptance, desperately needed services, rights of and entitlements for individuals with disabilities.*

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