

If You're Not Representing Your Family Member With Disabilities, Who Do You Think Will?

We have just watched another legislative session come and go, and medically necessary dental benefits are no longer available for Tier 4 Medwaiver consumers. The waiting list continues to grow, and there seems to be no sense of shame that this is the best we can do for people with Developmental Disabilities in the State of Florida.

But have we done what we can to change this negative spiral? Or are we waiting for other interests to scoop up the budget dollars while we remain on the sidelines?

We can assist legislators in prioritizing the needs of our family member. We must make this effort whether we're coping with being on call 24-7 for our child or have the luxury of hours a month to invest. It can be done, and after looking into your child's eyes and considering their future, you know it must.

Remember that our Florida government is only in session for the months of March and April each year. For the rest of the year our Senators and Representatives go back to their jobs as attorneys, doctors, businesspeople, farmers, realtors and every other occupation imaginable. Each legislator, just like us, is a member of a family, and one that may have a special needs person close to their heart. But if not, it is our responsibility to make the face of our loved one a touchstone when they are doing their work in Tallahassee.

First a family should identify both their Senator and Representative in the Florida legislature, along with the Health and Human Services committee members. This information can be found for our area at the end of this article.

The time to approach your government representatives is during the summer, while they are in their home communities. This saves you the long trip to Tallahassee during session while their focus will be working on bills they gathered information about during the previous summer. Its true that all politics start locally, so take advantage of their presence in your county while they have time to hear your story.

Start by writing your legislators with an outline of concerns you have regarding your child's needs. Follow up a week or two later with a call to their legislative aide, asking for a calendar appointment with the legislator to introduce yourself, and perhaps your child so that you can state your concerns in person. Be sure that you are well prepared to state your case in a timely manner, and leave written material with the office to support and document your visit. It is not necessary to bring proposed legislation to this meeting, but make a request for assistance on how to resolve the concerns.

After this meeting the relationship has only begun. You and your family member are now tangible to your legislator, and if they are not well-versed in disability issues, as many are not, this is the time to continue the relationship. Offer information, and even a dialogue if time permits to focus on specific disabilities. Ask their perspective on changes in statute or policy could improve the lives of people with disabilities and specifically the life of your family member.. Quick, respectful notes to the aide that you have worked with getting your original appointment, should keep your family's issues on their mind.

The Legislative aides are also responsible for arranging the local delegation meeting, and it is wise to schedule with them for a short presentation, if time permits during this meeting. This is an opportunity to bring your issue to multiple legislators that represent you locally, but by this point, all of them should already know you from prior one-one-one meetings. It's a chance to reinforce your concerns, and other advocates will see that you're just as dedicated to your child's cause as they are to different issues.

A thoughtfully forged relationship, that acknowledges your family's expertise through experience, should prove vital to your legislator. When they have questions, make sure you are a valuable resource to them for information on disability issues.

You must get out of your comfort zone and invest the time to represent your family member. Do not allow them to continue to be a number on the waitlist or have services reduced. This is important for the physical safety and health of individuals with disabilities, a claim very few other budget categories can demonstrate. Families getting appropriation excuses, not services must require the State of Florida to hear, respect, acknowledge and meet their child's needs. Your partner in the legislature can help make this happen.

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