

Let's Advocate for the Kids

By Pamela Walley

We have all the luck.

I pause to write this, between Callie's respiratory treatment and another position change. Still mindful of last night's seizure, I wonder whether to call the neurologist or just pray that we're back to our "normal" type of seizure today.

I'm still watching for signs, performing all the other ongoing assessments, no matter what else I'm doing. In the back of my mind are the next medications, the equipment repairs and supply orders that are way past due. The fact that no matter how overwhelmed I feel, at least I can use words to express my frustration. Callie is still patiently waiting for the right communication device that will allow her to fully translate 20 years of thought into sounds the rest of the world can hear...

So how is it we are the lucky ones?

In just a few minutes, Callie's nurse will arrive and she will head off to her second week of summer camp. She will be greeted by friends, some she's known for the last 10 years. She'll also meet new people, some at the campsite and some when she goes out to explore Athens, GA. Callie's afternoon may include an hour in a karaoke bar or a leisurely walk through the Botanical Gardens or whatever "20-somethings" in this college town are doing. All the while, Callie's medical needs are being met by her qualified nurse who has been trained to monitor and intervene for Callie (the patient) when needed. Equally important, this nurse has been trained to blend into the background and afford Callie (the young woman) the maximum amount of independence possible in her ever-widening world.

Unfortunately, there are those who aren't so "lucky," though just as medically-needy. They aren't getting necessary nursing support.

These individuals are at high risk for the acute complications of chronic conditions and slow deterioration that results when families aren't able to meet all their child's needs.

Even the most dedicated families find themselves facing a terrible choice: do I keep my child at home where I know I can't meet his medical needs or do I access medical care in an institutional setting?

This is a choice no family should ever have to make, and the fact that we've not faced it is another reason we count ourselves lucky.

We are able to advocate not only for Callie, but for everyone who needs medical support. Because we know that community-based services work, we are passionate about advancing the mission of the Children's Freedom Initiative, which recently observed a 10-year anniversary. The Georgia Advocacy Office, Georgia Council on Developmental Disabilities and other partners have invited us to help pave a path in Medicaid Early and Periodic Screening, Diagnostic and Treatment reform and to work with policymakers to improve services over the years.

We consider this our responsibility. Our job isn't done until all Georgians with disabilities have the opportunity to live in real homes, not in a facility.

So as one of the lucky ones, Callie will continue to live her life as an example of what's possible when adequate community supports are in place and continue to pave a path for community access.

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PERSPECTIVES



PAMELA WALLEY is a parent mentor in Madison County with the Georgia Parent Mentor Partnership. The partnership is established in 90 school districts around Georgia to improve outcomes for children and youth with disabilities and their families. She is pictured above with her daughter Callie.



To learn more about the **Children's Freedom Initiative**, visit www.georgiacfi.org