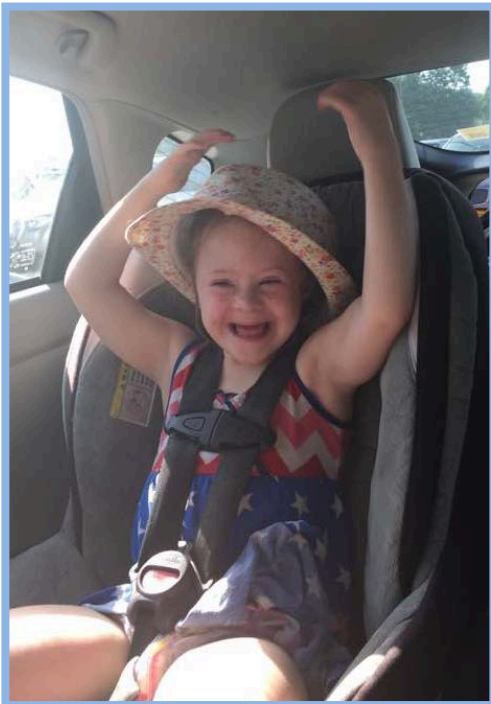




Medicaid is Integral to Children with Complex Health Care Needs



I experienced myriad emotions when my little girl was born: joy, relief, and fear. Julia has Down Syndrome and, at that time, I had no idea what challenges or costs it would entail. Thankfully, I learned quickly about the support system of other parents who have children with disabilities--there are more than 200 families in the lowcountry who have kids with Down Syndrome. They told me about a South Carolina Medicaid benefit, called TEFRA (Tax Equity and Fiscal Responsibility Act). TEFRA provides Medicaid to children who would otherwise not qualify, but whose medical and social needs can be prohibitively expensive.

When I was growing up, I heard stereotypes about people on Medicaid being “lazy” and “scamming the system.” I was taught that, if you worked hard enough, you wouldn’t have to “rely” on the government. Yet Medicaid, in the form of TEFRA, has enabled us to take Julia to three therapies a week (speech, occupational, and physical therapies) and pay for numerous doctor visits due to her ear infections, constant strep throat, Celiac disease, and generally low immune system. “Lots of kids get sick,” you might think, but the difference here is that our kids, kids with disabilities, will have limited resources when they are older. If we didn’t have TEFRA, we might still do all of these therapies, but there is no way we could save for Julia’s future; paradoxically, the fewer procedures and therapies she gets, the more beholden she will be to the state and federal governments later in life.

I’m really thankful to South Carolina for providing this benefit and allowing us to keep working, saving, and making Julia’s future as bright as it can be. With the permission of my friends, I wanted to share some of their stories, too.

This is Jude. According to his mother, Gini Nichols, Jude receives therapy 4 times weekly. As is the case with most policies, including mine, insurance covers 30 visits a year, meaning they would exhaust this in about 3 months. According to Gini, “TEFRA also covered open heart surgery, multiple hospital stays, and continued specialist visits.”

This is the case for most of our kids, including Mae. Her mother, Jaime Thomas Nettles, adds that “Research shows that children with Down Syndrome thrive in the community by early intervention [our children also receive this benefit until they turn three]...She deserves to be a working thriving member of society just like everyone else.”

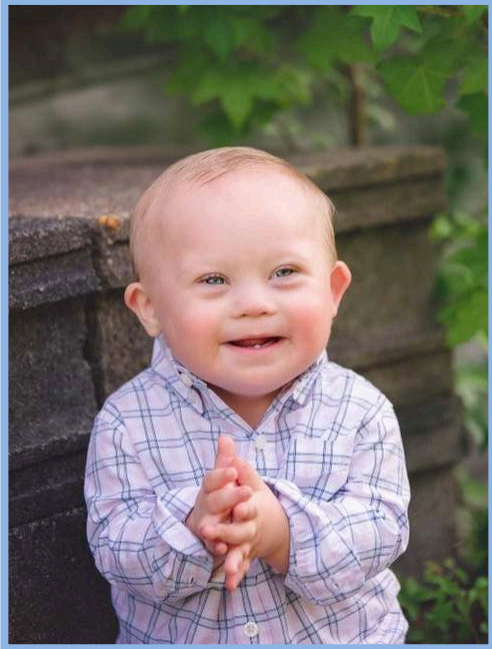


According to Jill Griffith, mother of Parker, this would also cost our state families with valuable skills (I teach at the College of Charleston, and my husband is an IT director at MUSC). She writes that, “after multiple surgeries, 4 therapies a week, and possibly an upcoming eye surgery, a significant portion of our household income would be tied to Parker's medical expenses without TEFRA.”

Denise Brewer Brown has not one, but two children with special needs. According to Denise, “Jack receives PT twice a week, OT, EI [early intervention] and Speech. “He has a helmet and special shoes to help walking. Evan receives PT, OT and EI. “That's not including specialist appointments.”

Callie, the daughter of Kerry Litten, also receives four therapies a week, along with the many services already mentioned.

One of the stories I've been following closely is that of Daisy, daughter of Holly Nye. Like many children with Down Syndrome, Daisy also deals with heart conditions. According to Holly, she “spent the first 9 weeks of her life in various units of MUSC, has many appointments with multiple specialists, PT, OT, and SLT [speech language therapy] weekly, EI biweekly, has had 5 surgeries so far including open heart surgery, among multiple hospital stays.” Like almost all of us, Holly and her husband work full time but would be in debt if it were not for TEFRA.



We all come from different places, have different experiences, different faiths, and different political beliefs, but our stories are unbelievably similar. We all work hard, we adore our kids, and we want them to be productive members of society. We all believe that providing them with the services they need (without bankrupting us) will allow for that to happen in future.

Many of the pictures I was sent were of the babies in our group, like Davis Dawson who has also had a number of medical issues and seemingly lives at MUSC. But I don't want to forget that our kids will grow up and have different, no less important, needs.

They need to integrate into school, like Lily Waddle and services like occupational therapy are essential to that. Sheyenne Morris graduated from high school due in part

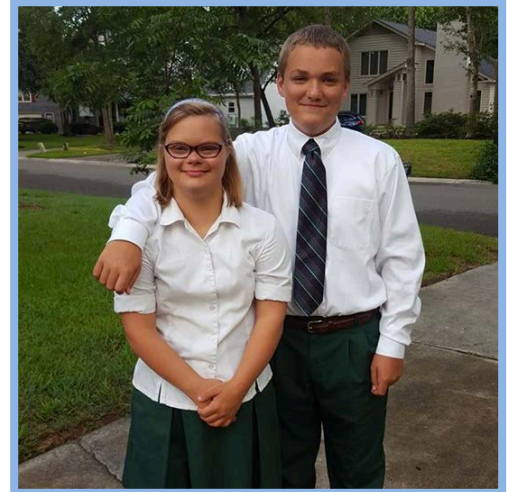
to the services she received from the state. Sheyenne, 21, received services in elementary and high school. According to her mom, Julie Morris, she would not have made it as far as she has" if the family had not received assistance. "She is a very strong-minded young lady," Julie writes, and she is "so proud of all [Sheyenne] has accomplished."

And, as Gene Carpenter, mother of Elizabeth, says, Medicaid not only helps individuals and their parents but is also essential to the well-being of siblings, like Elizabeth's brother Edwin, pictured here.

As Gene writes, Elizabeth "is the success story of Medicaid... Today she is a rising junior at Bishop England High School in completely inclusive classes and goes to school with her "baby" brother, Edwin. "Elizabeth," writes Gene, "is going to make it – she will live independently, she will hold a job. Edwin is the lucky one – his life is rich from his experiences with Elizabeth but his future will not be burdened with the responsibility of full time caregiving because Elizabeth received all the services she needed from Medicaid."



These are just *some* of our stories, and this is just the Down Syndrome community. I also have friends whose children are on the autism spectrum, or have cerebral palsy, or suffer seizures that require constant supervision. Look at these faces: these children are anything but lazy, and their parents are not only not exploiting Medicaid but are using its benefits to create better lives for both their children and their siblings.



Many of my friends do not live in South Carolina and do not receive Medicaid. Kaetlyn Spivey’s mother, Kelly, writes that they moved from Seattle, where they did not receive Medicaid benefits. When Kelly’s employer asked them to return, Kelly rejected the offer because “this is better for Kaetlyn. The other side is very very expensive.”

I want to be clear that we are so very grateful for the assistance you, the taxpayers of South Carolina, have given to us. Please know that, as you and your legislators prepare to make choices regarding health care reform, these children continue to count on you.

- *Kathleen Béres Rogers*



Top Row: Sheyenne, Parker, Mae, Lily, Kaetlyn, Julia
Middle Row: Jude, Jakob, Freddie, Jack & Evan, Elizabeth & Evan, Davis
Bottom Row: Asher, Callie, Daisy, Behr, Danny, Becka

Kathleen Béres Rogers is a South Carolina teacher and mother. Rogers decided to share her story and the stories of numerous other families in similar situations to highlight the importance of Medicaid.