



## The Oguagha's Story: A Few Dollars Too Much...

With limited means, Pamela Oguagha has been resourceful enough to create a life full of enriching, therapeutic activities for her daughter Taylor, along with educationally and medically needed services. But she finds the process overwhelming. "Because my daughter is high-functioning, less is available."

"About 90% of the time, Taylor is a typical teenager who happens to have autism," says Pamela Oguagha of her 15-year-old daughter. "She knows her way to school, the store, she has her own key. She uses the bus herself."

But Taylor isn't quite typical. In addition to autism, she lives with ADHD, beta thalassaemia sickle cell disorder, learning disabilities and behavioral challenges. At an age when other girls might start babysitting, Taylor has a constant need for supervised, structured activities.

Divorced from Taylor's father and with an older daughter away at college, Pamela works full-time and has arranged for before and after school care for Taylor. "She has a scholarship through Girl Scouts for sleep away camp, and the choir lets her participate without paying. We pay a portion when we can."

The Oguaghas live in Maryland, which provides the family with up to \$3,000 per year in flexible funding known as Rolling Access. "Rolling Access funding is my saving grace," says Pamela, who uses the funds for Taylor's eyeglasses, camp, family support services, and co-payments.



Her diagnosis of Autism does not hold Taylor Oguagha back from enjoying the Girl Scouts' sweetheart dance

Pamela spends a tremendous amount of time coordinating her daughter's care. "I'm on the phone with someone all the time, or texting or e-mailing." Her employer is understanding, but it's difficult when she has to arrive to work late or leave early, like when she must take time off to pick up Taylor's prescription—considered a controlled substance—in person at the doctor's office. Last year, in order to make sure Taylor's special education program was meeting her needs, Pamela had to hire advocates to attend Taylor's IEP meetings. She still spends a lot of early mornings at Taylor's school, from which getting to work on time requires a more costly commute.

"I have had to quit work, take a lower-paying job and change my work hours to provide support and parenting for Taylor," Pamela says.

Currently, Taylor is struggling with two recent blows: the death of her grandmother, who provided a significant amount of caregiving and support, and Pamela's own active treatment for breast cancer. Grieving and anxious, this semi-independent young woman has lately needed assistance with even basic tasks. A behavior specialist comes every day to help her get ready for school. Pamela initially paid for that out of pocket, but successfully advocated to get it covered as emergency respite care.

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Even with these resources, however, Taylor's need for mental health services continues to be inadequately addressed. Pamela is looking for a suitable provider, but few are trained to treat mental health issues in adolescents with autism. When she does find someone she will have to pay part of the cost, which may be up to \$240 per session. In the meantime, Taylor attends a grief support group for teens, for which Pamela negotiated a \$10 co-payment instead of the regular \$20.

"I make about \$5 too much to qualify for SSI for Taylor," Pamela says. "It is so small, it's killing me. The impact has been phenomenal, because if I could get SSI, Taylor could get medical assistance. And whatever that medical assistance didn't cover, my insurance would kick in. So I'm strapped both financially and medically. But that would change our lives."

## Pathways to Financial Hardship for Families of Children and Youth with Special Health Care Needs (CYSHCN)

1. **Higher health care costs:** Because there are a limited number of mental health providers with specialized skills to work with young people with autism, Pamela may have to use a provider who is not in her insurer's network, and may have to pay up to \$240 per session for her daughter to receive appropriate care.
2. **Higher routine expenses:** Fifteen-year-old Taylor requires supervision and structured activities year-round while her mother is working: summer camp is the biggest expense, followed by before and after school care and recreational programs. Pamela has also had to hire legal and educational advocates to secure services for Taylor, and she incurs higher cell phone and commuting costs to coordinate her daughter's care.
3. **Loss of employment income:** Over the course of her career Pamela has left jobs, decided not to apply for positions for which she was qualified, taken positions with lower pay and less-skilled work, and reduced or changed her work hours to provide support for Taylor. She is willing to sacrifice higher pay for better benefits.

## Breaking the Link to Financial Hardship for Families of CYSHCN

1. Maryland's Rolling Access provides **flexible funding** to families and is working well to help the Oguaghas pay for needed services for Taylor and some family support services.
2. A [Medicaid buy-in program](#) like the one that is part of the federal [Family Opportunity Act](#) would not only allow Pamela to accept higher-paid employment, but also to purchase Medicaid benefits for Taylor specifically designed to supplement her own insurance.
3. [Care coordination services](#) could help Pamela minimize her absences from work and improve the efficient organization of Taylor's services and benefits, as well as help Taylor and her mother plan for her [transition](#) into adult services.

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## About the Catalyst Center

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