

## Faces of Medicaid

### The Brandt family – Springfield, VA (VA-11)



Bailey is a ten year old little girl who lives with her two parents and two younger siblings. She was diagnosed at birth with intractable (uncontrolled) seizure disorder, cerebral palsy, aspiration and significant global delays. She needs total assistance and support with all daily living and recreational activities. She's had hemispherectomy (removal of part of her brain) for brain abnormality and seizure control. She has a shunt, G-tube, and uses a communication device. Bailey still has many seizures. She's had orthopedic issues, including a hip displacement and leg length discrepancy.

Bailey relies on Medicaid for medical care and daily support needs including respite, in-home supports, assistive tech and environmental modification. Medicaid is secondary insurance and has paid for her seizure medications - she's had over 20. Medicaid has helped cover her durable medical equipment needs (like her wheelchair). It has helped cover her hospital bills from surgeries such as the hemispherectomy and hip surgery, and the inpatient rehab services (3 months for the brain surgery). When she gets older she will need Medicaid for long-term support needs, such as residential and day support.

If the services were lost, one of the family members would have to stop working completely (probably Mom) and one would have to work significantly less (probably Dad). This would jeopardize the stability of his small business and would have a mental health impact on siblings and Mom. It would impact Bailey's ability to participate in her community and would be detrimental to her (and her family's) quality of life. If either of the parents were unable to provide care, she would be institutionalized. This would be devastating not only to Bailey, but her family. She would regress and potentially lose her independence, social, and communication skills.

\*\*

## Farris Family - Missouri City, TX (TX-09)



Jody and Ryan Farris are parents of a ten-year-old son, Nolan, who is partially blind, non-verbal, and has autism. Nolan was born three months prematurely, weighing one pound, and required a tracheotomy to breathe and a feeding tube to eat. Within months of Nolan's birth, the Farris' exhausted their private insurance and their savings caring for their son. The waiting list for Medicaid was very long in Texas, and the family moved to Colorado after three months so Nolan could receive Medicaid benefits immediately. After spending the first year of his life in hospitals Nolan was able to go home where he learned to sit, stand, walk, play and become more independent, thanks to Medicaid Early Childhood Intervention and home health care services. Nolan received in home therapies 5-6 days a week. At age 3, the boy who wasn't supposed to walk, was walking.

At the age of 4 Nolan had managed to get his tracheotomy tube removed and breathe on his own, but Colorado's altitude was still not the ideal environment for his continued health. The Farris family took a job in Texas, relocating the family to sea-level. What the Farris family didn't anticipate was losing Medicaid and the vital support it provided to continue Nolan's progress. Nolan was put on an 8-year waiting list for Medicaid, so the family again purchased private health insurance through a high risk pool for Nolan. But after depleting their savings within 18 months his parents had to temporarily put Nolan into a nursing home to get Medicaid coverage. Through Medicaid, Nolan was able to get his specialized medical food and resume therapy where he quickly learned how to swim, could go to school by himself, and learn how to play music on a variety of instruments.

Presently, through a home-based therapy program called **Community Living Assistance and Support Services**, Nolan is able to live with and be cared for by his family. Jody fears that proposed cuts to such programs would make it impossible for Nolan to live at home, limiting his future and requiring additional costs such as paid care to look after him. "Children need to be at home, need to be with their families. I can't imagine telling his sister he has to live in an institution because we can't afford him," she said. Cuts to such programs also could ultimately cost taxpayers more money.

\*\*

## Young-Chavez Family - Chesterfield, VA (VA-07)



Shareen Young-Chavez is the mother of a beautiful son, Stefon, 18, who has multiple disabilities, including Angelman syndrome (a genetic deficiency of the 15<sup>th</sup> chromosome), cerebral palsy, an intellectual disability, epilepsy, asthma, language impairment, and neuromuscular scoliosis. Stefon uses assistive devices for ambulation and requires support 100% of the time.

For many years, Shareen was unable to work and unable to afford the type of services her son required from outside providers. She and her son lived in distressed neighborhoods in public housing and relied on food stamps to survive. Stefon's assistive technology, environmental and therapeutic needs, although acknowledged, were not being met. They lived in survival mode, simply trying to overcome medical obstacles, one emergent event after the next. Their lives were dominated by doctor appointments, surgeries, and training for Shareen to provide Stefon with the care he needed in order to stay at home.

In 2000, the family received a Medicaid waiver for critical services, and finally Stefon began to thrive. Medicaid made it possible for the family to train someone to provide supports for Stefon. He was able to get into a day program where he could continue to receive socialization and integration within the community, when his health permitted. His mother was able to work outside of the home with peace of mind knowing that Stefon's needs were being met while still playing an integral part in all key decisions.

Stefon is now able to live at home, and his mother has been able to thrive in her professional life and have a personal life. Her employment has eased the family's long-standing financial burden. Stefon is now much happier. He has graduated from high school, attended his senior prom, and even won national recognition for athletic achievement.

He still has health battles and major surgeries ahead. But without Medicaid, Stefon would lose his vital services and his mom probably would have to quit her job and get back on public assistance to take care of him. His quality of life would be dramatically reduced.

\*\*

## Bender Family - St. Paul, MN (MN-04)



Jean and Paul Bender's 24-year-old son David has multiple disabilities, including Down syndrome, autism, and epilepsy. David is one of three children, but he needs significantly more support and resources than do his siblings. Jean decided to quit her job to better support David's transition to adult life, requiring his siblings to find their own resources for college and transitions to adulthood.

The family sought programs to provide day training, vocational, and rehabilitation services, but found none that would allow David to explore his interests, build his skills, and maintain his physical fitness while participating in local community activities. David receives these services through a Consumer Directed Community Support plan, which costs Medicaid about \$20,000 per year less than receiving similar, but less personalized, support services through conventional programs. David is limited in his vocational options, and his options for living somewhere other than his parents' home are even fewer. So, despite the fact that Jean recently quit her job, the Benders took a new, 30-year mortgage on a duplex to ensure that David can move to his own home while his parents are able to support his transition.

Even though the Benders have had to make some sacrifices and difficult choices, David is one of the lucky ones. He has a Medicaid waiver to receive personal assistance, therapeutic and community activities, and coverage for extra cost of medically prescribed diets, and other health care. Almost 4,000 individuals in Minnesota are still waiting for such services, and the numbers are expected to grow. If David were to lose his Medicaid-provided services, he would not be able to stay in his duplex and would likely end up in an institution. Using Medicaid dollars to support individuals like David in living at home, with his family providing the majority of care and support during his lifetime, saves tax dollars. As Jean says, "You can cut the programs, but it doesn't make the needs go away."

\*\*

**Wang Family - New York, NY (NY-14)**



Jessica Wang, in her mid 40s, has Asperger syndrome, an autism spectrum disorder characterized by difficulties in language processing and social interaction. After years of education and vocational training, she remained frustrated with limited and inappropriate employment choices: many years of doing food service, in spite of a sharp intellect. Her parents, Yung and Ming, have helped Jessica all her life with education, employment and health issues, but they have reached the age (and have their own health issues) where they must rely more and more on social workers and others to provide services and supports for their daughter.

Jessica recently discovered art, design and working with animals as excellent fits for her personality and aptitude. She is currently working part time at a doggie daycare and seeking more training in art. Jessica is determined to earn her GED in order to be able to take college level art classes, and she is very focused when she is doing homework to reach this goal. She has passed 4 of the 5 GED tests, with math being the only one remaining.

Jessica's improved life and prospects for a fulfilling career depend greatly on service coordination, life skills training, supported employment services, speech therapy, and health care services she receives through Medicaid. Her mom says that cuts in Medicaid will be disastrous to her chance for a meaningful life.

\*\*

## Meredith family - Littleton, CO (CO-06)



Alex Meredith, 27, has autism, which is severe to moderate, depending upon the day, hour, or minute. His needs are unpredictable, and he sometimes displays behaviors that could put him or someone else at risk. In May 2002, he turned 18 and became eligible for Medicaid because he had a significant disability and had no income or assets. After careful consideration, his family decided to risk using only Medicaid to pay for Alex's healthcare. That same year, Alex also became eligible for Home and Community Based Medicaid waiver programs, qualifying for 3 hours of help a day with cooking, cleaning, laundry, planning meals and other household activities, and helping him to stay safe.

When Alex turned 21, he was no longer eligible for public school. His father, John, started working fewer hours, and worked with Alex's mother, Carol, to tag-team his care. The situation was exhausting and not sustainable; Alex required nearly constant support. During this time, Alex's behaviors became extremely violent, resulting in injury to his parents and himself and damage to his home. The family requested and received emergency Supported Living Services, a waiver to support people with developmental disabilities. It kept him safe, but his quality of life was poor.

Then, in 2008, the Colorado legislature allocated some extra funds to the Residential/Comprehensive Medicaid waiver, and he qualified for an emergency resource. Luckily, Carol had put him on a waiting list for Section 8 housing, and a miracle occurred—he got off both waiting lists within a matter of weeks. A woman who had supported Alex, part-time, over the years came to live with him and help him transition into independent living. As long as Alex's parents are healthy and willing to provide a lot of volunteer time, they can make current arrangements work, but if Medicaid is cut significantly, everything the family has worked for years to put in place will fail.

\*\*

**Keaton family – Milton, WV (WV-03)**



Amanda and Greg Keaton are parents to 18 month old Graysen, who has DiGeorge Syndrome. He was born with two severe congenital heart defects, and has been on ventilator assistance since birth. Graysen has suffered two strokes and three open heart surgeries. Amanda is a cardiac intensive care nurse and Greg is a driver for a heavy equipment company.

Graysen spent his first six and a half months in the hospital, and his one year anniversary of being home will be June 21, 2011. Born on December 9, 2009, Graysen hit the million dollar cap on Amanda's insurance by end of April 2010. SSI helped with coverage while he was still in the hospital, but ended when he was home, and now Greg's insurance is the primary coverage for Graysen's needs. The Keatons still don't have final bill from hospital.

This little boy's medical costs were so high that with two incomes, they were going to lose their home and everything else they worked hard for until receiving Medicaid through this CDCSP. Graysen's nursing care and tube feeding are covered by Medicaid through the Children with Disabilities Community Services Program (CDCSP). Drastic cuts in Medicaid could lead to Amanda quitting her job to help take care of him, as they couldn't afford the nursing care without Medicaid.

\*\*

**The Rodriguez family - Tomball, Texas (TX-10)**



TJ (31 years old) was born with significant intellectual and developmental disabilities. TJ needs assistance with everyday activities - bathing, brushing his teeth, getting dressed in the morning, communicating effectively, walking, eating, etc. As he has gotten older, TJ's physical challenges have greatly increased along with his medical needs.

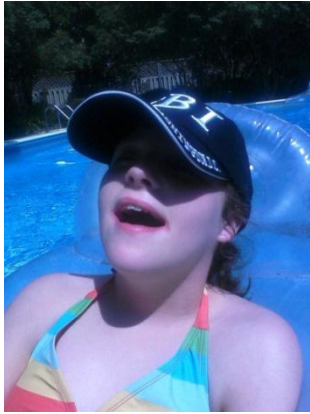
Despite these challenges, TJ is very happy as he lives in the community and is living as independently and productively as possible because of Medicaid health care and Home and Community Based Services. Medicaid covers TJ's neurologist, endocrinologist, physical therapist, occasional home care, speech therapist, orthopedic specialist, and primary care, and his prescriptions. In addition, through TJ's Medicaid Home and Community Services slot (which took 9 years to receive), his parents received funds to make home modifications to better suit TJ's emerging mobility issues including funding for renovating the bathrooms so that TJ and his wheelchair can navigate the entrance and shower area, building ramps throughout the house so that TJ can be mobile without assistance, adding hand rails throughout the residence, lowering sinks, and raising toilets.

Without these modifications it would be virtually impossible for TJ to live in his home, possibly forcing his parents to move. Moreover, if TJ were to lose the Medicaid services, his parents could not afford the specialized medical supports he requires, thus forcing them to deplete their savings in an attempt to keep TJ healthy in the community and ultimately leaving them no other option than to place him in archaic institutional type care, an unimaginable nightmare for them.

\*\*



## The O'Brien family - Wayside, Georgia (GA-01)



Deirdre O'Brien has two children, including her beautiful 13 year old daughter, Clare, who has significant intellectual disabilities. Because of her needs and the needs of other Georgians, Deirdre accepted the position of Executive Director of The Arc of Georgia. This job is based in Atlanta whereas she lives in southeast Georgia. So Deirdre lives away from her family approximately four days a week.

Clare also has a medical problem- abdominal migraine. These are similar to traditional migraines but the pain is in the stomach. She would vomit continuously for days. Two years ago, her migraines became very severe occurring nearly every two weeks. Her hemoglobin dropped severely, she missed a significant amount of school and Deirdre's husband stayed home to take care of Clare.

The O'Brien family saw no alternative but for Deirdre to quit her job at The Arc and stay at home in case her daughter became ill. The state stepped in and awarded Clare a small home and community based waiver. She had been on the waiting list but her illness allowed it to be granted immediately. This waiver has allowed Deirdre to hire staff to care for her daughter. Staff is well trained to deal with any medical issue that arises. Clare's waiver has allowed Deirdre to continue to work and their family does not revolve around illness, but health and happiness.

\*\*