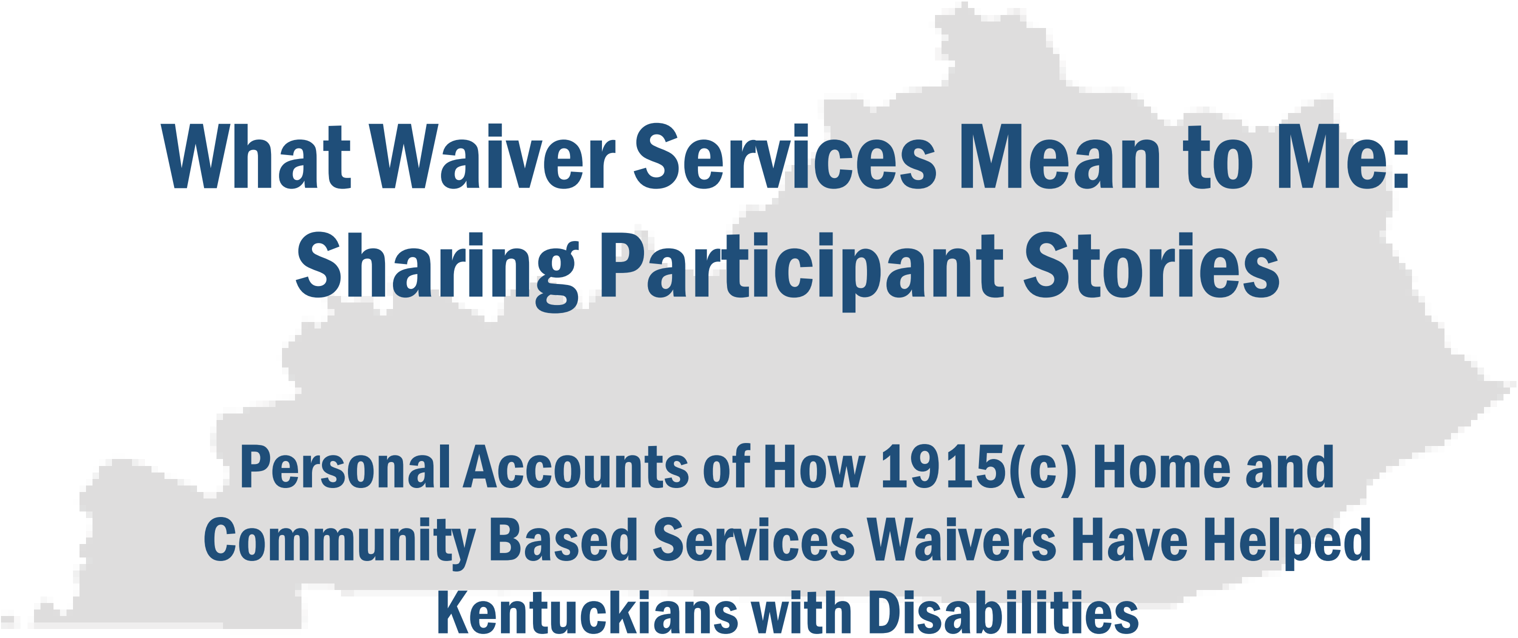
CABINET FOR HEALTH
AND FAMILY SERVICES
Medicaid Services



What Waiver Services Mean to Me: Sharing Participant Stories

Personal Accounts of How 1915(c) Home and Community Based Services Waivers Have Helped Kentuckians with Disabilities

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Introduction

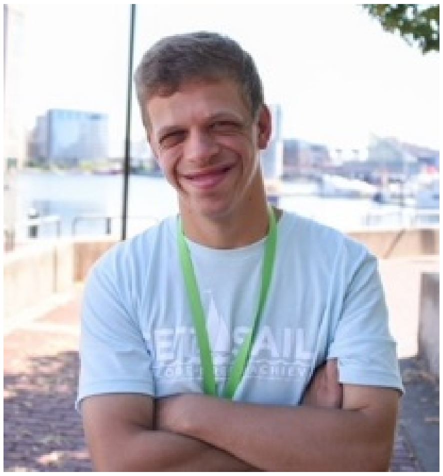
In 1987, Kentucky created its first two 1915(c) Medicaid waiver and began offering Home and Community Based Services (HCBS) to individuals who are aged, have a physical disability, or are ventilator dependent. Since then, HCBS in Kentucky has expanded to six waivers serving a range of populations including those with brain injuries and those who have an intellectual or developmental disability. Over the years, Kentucky's HCBS programs have helped thousands of individuals live life in their chosen communities.

In spring 2021, the Department for Medicaid Services (DMS) began to share HCBS waiver participant stories in the DMS Division of Community Alternatives quarterly newsletter, the Medicaid Waiver Review. The goal is to show the services HCBS waivers offer and how individuals can tailor them to their needs and goals. We are thankful to participants who have taken the time to speak with us and share their stories. If you would like to share your story or know a waiver participant who would like to share, please contact DMS by emailing MedicaidPublicComment@ky.gov or call (844) 784-5614.

Waiver Participant Stories

Clayton Carroll, Michelle P. Waiver

Not everyone can say they've performed on stage at the Grand Ole Opry with some of country music's biggest stars, but Clayton Carroll can.



Clayton Carroll, 25, receives Michelle P. Waiver services.

"Luke Bryan, let me see, Big and Rich, Rascal Flatts, Chris Jansen, he's good," says Clayton.

It's all part of the Academy of Country Music (ACM) Lifting Lives Music Camp. Clayton typically travels from his home in Dunnville, Kentucky to Nashville each spring to attend, however, the camp was held virtually this year and last due to the COVID-19 pandemic. The camp is designed for musically talented individuals who have a developmental disability.

"I love it, it's a great camp," says Clayton.

Clayton performing on stage at the Grand Ole Opry during the ACM Lifting Lives Music Camp.

The 25-year-old has Williams Syndrome, which affects about 1 in 10,000 people. While it can cause heart problems, developmental delays, and learning challenges, individuals are often musically talented, have great verbal abilities, and are highly social as well.

Clayton received his diagnosis at nine months old. His mother, Stella Beard, says Clayton failed several hearing tests and didn't meet some milestones, leading her to suspect something more serious might be going on. Eventually, a week-long hospital stay due to pneumonia led to the discovery that Clayton had Williams Syndrome. Once the pneumonia cleared, doctors detected a possible heart problem. Stella took Clayton to see Dr. Jacqueline Noonan, a well-known pediatric cardiologist at the University of Kentucky. The late Dr. Noonan is renowned for having identified a heart condition now known as Noonan Syndrome, which mirrors Williams Syndrome. She quickly identified it as the cause of what Clayton had been experiencing.

Clayton with his siblings and mom, Stella (right).

"My world at that moment was like turned upside down," says Stella.

Genetic testing confirmed the diagnosis and the family began their journey with Williams Syndrome, which included addressing Clayton's medical concerns and receiving early interventions through First Steps. Stella learned as much as she could about Williams Syndrome and found she didn't just want to help Clayton, she wanted to help other families too. This mission led her to a job as a Family Resource Coordinator with Fayette County Public Schools (FCPS). She now works for the Kentucky Special Needs Information Network, but it was during her time with FCPS that she learned about Kentucky's Medicaid waiver programs and how Clayton could benefit. Clayton began receiving Michelle P. Waiver services in 2009. The family uses the participant-directed services (PDS) delivery model. Clayton calls his PDS employees his mentors. While they started by hiring family and friends, Stella says she quickly realized that wasn't the best for Clayton.

"I fired them all because that didn't work," says Stella.

Stella and Clayton focus on hiring a variety of PDS employees to meet Clayton's different needs. Expanding their circle of PDS employees beyond family and friends has enhanced the quality of waiver services and their impact on Clayton's life. Stella credits one former PDS employee, a young man named Zach, for recognizing and growing Clayton's musical gifts.

"Zach saw things in Clayton that I had not seen. He saw his ability to sing even more than what I thought he could sing. He got things out of him that I could never get out of him," said Stella.

When Clayton's father died in 2011, Zach used Clayton's love of music to help him grieve. Together they wrote and recorded a song as a tribute.

"He just took Clayton's words and put them to music," says Stella. "It was a perfect way for Clayton to be able to express his feelings."

Watch Clayton sing his song "Dear Dad" on YouTube at
https://youtu.be/mmPvEAuUw_E

Stella recognizes hiring new people as PDS employees can create anxiety for waiver participants and their families. To make it easier, she suggests conducting thorough interviews of potential employees and having signed agreements in place before employment begins that detail the expectations of the job, the services being provided, and how the individual should be treated.

“Sometimes we have to take that chance because you know there may be that perfect one out there that’s going to make the difference,” says Stella.

Regardless of the service delivery model used, Stella encourages families to really get to know the waiver programs and the services offered. This can help waiver participants and their families find ways to tailor services to the participant’s needs.

“Think outside the box, be really creative, and use the services to the best you can,” she says.


CLAYTON WITH FRIEND AND PDS EMPLOYEE, ISAIAH

These days Isaiah, a UK student, is one of Clayton’s PDS employees. The pair went to high school together and Clayton now goes to Lexington every few weeks to spend a couple of days with Isaiah. While the pair works together to help Clayton improve on his life skills, they’re also friends who do what many young men in their mid-twenties do – got out and have fun. They recently celebrated Cinco de Mayo and are planning a trip to see the Cincinnati Reds play soon.

“If I need help with anything, he can help me,” says Clayton. “I’m just glad to have Isaiah as my mentor. He is a great guy.”

“He’s with a peer doing things that 24 and 25-year-olds do,” says Stella. “I love that that opportunity is available and that’s all because of waiver services.”

Clayton is also a public speaker and travels regularly to Florida to visit his girlfriend of four years, Isabel. He and Isabel, who also has Williams Syndrome, met at the Lifting Lives Music Camp. He continues to receive MPW services and is on the waiting list for Supports for Community Living. Regardless of what happens with waiver services, Clayton has plans for the future and he and his family are working toward making them happen.

“I want to have my own house one day on the farm and then I would like to marry my girlfriend one day,” says Clayton.


CLAYTON AND HIS GIRLFRIEND, ISABEL

Will Bentley, Michelle P. Waiver

WILL BENTLEY, 17, FIRST RECEIVED SERVICES THROUGH THE HOME AND COMMUNITY BASED WAIVER. HE IS NOW A PARTICIPANT IN MICHELLE P. WAIVER

At 17, Will Bentley is like any teenager. He's finishing high school, trying to become independent, and making plans for the future

"I'm learning about farming because I want to be a farmer," says Will.

Will works toward this goal each day by taking care of the animals on his family's farm in Mount Sterling, which include a horse, donkey, mules, and cats. His mom, Katie, says it's a fitting career choice.

"Our horse really loves him, I mean, really loves him," says Katie. "Will has a gift with animals. It's definitely something that we noticed when he was very young that animals would run to him. Animals that wouldn't let anyone else touch them, loved him."

WILL'S CAREER GOAL IS TO HAVE A FARM THAT THE PUBLIC CAN VISIT.

The people of Mount Sterling feel the same way about him. Will is well known in the community and friendly with everyone from the Sheriff to his state senator and representative.

"People are just naturally drawn to Will. People just like him. We get compliments on him all the time, what a nice young man he is," says Katie. "He would go to breakfast with Papaw and come back and he knows all kinds of farmers here and I don't even know these people and we're at Court Days (a yearly festival in Mount Sterling) and they're like 'Hey Will'."

Will is using his love of connecting with people to form a new community group called The Mavericks, which is named after his horse.

"It's for local people with and without disabilities," says Will.

WILL PRACTICES DRIVING ON HIS FAMILY'S FARM IN MOUNT STERLING.

Will has worked hard to get to this place in his life. As a toddler, he began having seizures. Doctors diagnosed him with a seizure disorder, an intellectual disability, Ehlers-Danlo Syndrome, and other health conditions.

The seizure disorder proved to be the most challenging. The seizures affected Will's development. Often, he would make progress only to have a seizure strike and erase what he had worked so hard to gain.

"He couldn't hardly function at all… He couldn't talk half the time, he'd learn words and lose them," Katie says.

He required around-the-clock supervision since his seizures were most common when he slept and would cause him to stop breathing. Katie had to quit her job due to Will's care needs and frequent appointments. Her husband worked as much as possible to support the family and pay for Will's expensive seizure medication. They were in what Katie describes as "survival mode."

"I was exhausted and my husband worked every minute of overtime that he could and he was trying to be my relief," says Katie. "It was really hard."

Will received services through First Steps and attended a half-day program for children with developmental delays in northern Kentucky, where the family lived at the time. It was through the half-day program that the family learned about 1915(c) Home and Community Based Services (HCBS) waivers. Will began receiving services through the Home and Community Based (HCB) waiver at age four, which included much-needed respite and therapies. The Medicaid state plan also covered Will's seizure medication. It was a turning point for him and his entire family.

"The waiver just changed his whole life," says Katie. "There was a lot of stress lifted off our family when Will was able to get what he needed… I know that he's where he is because of the support. We could not have done this by ourselves."

Will began receiving Michelle P. Waiver (MPW) services at age six, at the suggestion of his HCB case manager. While both waivers met Will's basic support needs, meeting other waiver participants showed Katie the same programs could also help him thrive and live the life he chose for himself.

"Waiver services kind of gave us some hope," Katie says. "It made me think I could dream a little… and I felt like for a long time I couldn't… now me and Will are dreamers."

WILL POSING IN ONE OF HIS FAVORITE PLACES - THE FARM.

Will worked hard over the years to gain all the skills doctors said he'd never learn. He's been seizure-free for five years. Now, he's focused on learning to be independent. Katie works with him as his Community Living Supports provider.

"You can't be a part of the world if you're never in it… so Will has always gotten Community Living (Supports)."

He's making great progress. Will is learning how to drive, cook, and manage money.

"It (the waiver) helped me be safe in the community, encouraged me to keep learning," says Will.

The family gets creative to help Will reach his goals. Technology helped them find a way for him to stay home alone and discontinue the use of respite.

"We started using the iPad and I would just check in with him and that worked out great and he felt confident and he learned how to be safe at home," says Katie.

Katie will be the first to tell you, this is all Will. He runs his own person-centered service team meetings and sets his own goals.

"I can pick stuff all day but if it's not important to him, he's not going to do it," says Katie. "We had to be his voice from a long time… now he is his own voice."

Both Will and Katie are advocates for all individuals with disabilities. Will traveled to Washington, D.C. at age seven to tell his story and Katie eventually returned to work in roles with Kentucky's First Steps program and the Commonwealth Council on Developmental Disabilities. Currently, she is working with other families to create a statewide disability network.

"The reason that I help families today is because of Will," says Katie.

They encourage families to plan for the future early on and to make sure services are person-centered and tailored to not just what their loved one needs, but what they want to achieve.

"Families need to start thinking about where our children, whether they're young or they're adults, where are they going to be when we're not here. To me, that's building that best plan for the person," says Katie.

Will knows exactly where he's going to be.

In addition to learning to drive, Will is also working on his cooking and money management skills.

"Own a farm, be a farmer, and have a family," says Will. "I want to be a Dad someday."

Although, much to Mom's delight, he doesn't plan to go too far.

"I would like to be neighbors with my parents," says Will.

"This was his idea. It's very sweet," says Katie.