What Waiver Services Mean to Me: Clayton Carroll

This spring, the Department for Medicaid Services (DMS) is debuting a new feature called What Waiver Services Mean to Me. We hope you enjoy learning more about each edition’s featured waiver participant and the impact waiver services have on their life.

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.

“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 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.

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.

“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.”

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.

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.

To hear Clayton’s song Dear Dad
https://www.youtube.com/watch?v=mmPvEauUw_E

Learn more about Williams Syndrome
https://williams-syndrome.org/

ACM Lifting Lives Camp
https://www.acmliftinglives.org/lifting-lives-music-camp

Help Available to Kentuckians In Need of Internet Access
Cost is a barrier many Kentuckians, including some participants in Medicaid’s 1915(c) Home and Community Based Services (HCBS) waiver programs, face when trying to get internet access. The Department for Medicaid Services wants to share information on a new federal program designed to help eligible Kentuckians get connected. Congress established the Emergency Broadband Benefit Program in response to the COVID-19 pandemic. The program offers a discount on both broadband service and the purchase of a computer, laptop, or tablet. Eligible households can receive:

- Up to $50 a month toward broadband internet service.
- Discounts up to $100 toward a one-time purchase of a computer, laptop, or tablet if the household contributes more than $10 but less than $50 toward its purchase from a participating broadband provider.

Households are considered eligible if one member of the family meets at least one of the following eligibility criteria:

- Has an income at or below 135% of the Federal Poverty Guidelines or participates in certain assistance programs, such as Medicaid.
- Is approved to receive benefits under the free or reduced school lunch or breakfast program (including through the USDA Community Eligibility Provision in the 2019-2020 or 2020-2021 school year.
- Received a federal Pell Grant during the current award year.
- Experienced a substantial reduction in income through job loss or furlough since February 29, 2020, and the household's total income in 2020 was at or below $99,000 (for single filers) or $198,000 (for joint filers).
- Meets the criteria for a participating provider's existing low-income or COVID-19 program.

If you are interested in applying or want more information, you can:
- Call (833) 511-0311 between 9 a.m. and 9 p.m. Eastern any day of the week.
- Email EBBHelp@usac.org
- Visit getemergencybroadband.org

It is important to note this is a temporary program. The discount will be available until all funding is used or six months after the Department of Health and Human Services declares an end to the COVID-19 pandemic.
Electronic visit verification system improvements continue

Required use of electronic visit verification (EVV) in Kentucky remains paused while the Department for Medicaid Services and the Office of Application and Technology Services works with Netsmart (formerly Tellus) to improve the Tellus EVV system. DMS and OATS announced the pause in mid-March ahead of the previously scheduled April 1, 2021, deadline to begin using the EVV system. States are required to implement EVV for certain services provided through 1915(c) Home and Community Based Services as part of the 21st Century Cures Act.


Temporary Waiver Updates Due to COVID-19 Extended

In March 2021, the Centers for Medicare and Medicaid Services (CMS) approved a renewal of the temporary updates DMS made to the 1915(c) HCBS waiver programs in March 2020 due to COVID-19. These updates, which are outlined in Appendix K of the 1915(c) HCBS waiver application, are designed to help providers and participants adapt to changing services needs due to the pandemic. DMS continued most of the temporary updates initially approved in 2020 and added a few additional updates. They include:

- Expanding the provider type for participant-directed case management in the HCB waiver to include Community Mental Health Centers.
- Allowing a participant to receive waiver services when in acute hospital settings where they hospital cannot meet the participant’s non-medical, disability-related needs.
- Adding an extra unit of case management to allow case managers/support brokers/service advisors to assist participants in obtaining the COVID-19 vaccine if they choose to get one.


All COVID-19 waiver updates will remain in effect until six months after the federal public health emergency declaration ends. This will allow for a transition period for returning to normal waiver operations.

Interested in getting a COVID-19 vaccine but not sure where to start? Help is available!

Talk to your case manager, take a look at our Guide to Getting a COVID-19 Vaccine at https://bit.ly/kycovidvaccineguide, visit the state of Kentucky’s vaccine website at vaccine.ky.gov or call (855) 598-2246.