

THE MEDICAID WAIVER REVIEW

NEWS FROM KENTUCKY’S 1915(C) HOME AND COMMUNITY BASED SERVICES WAIVER PROGRAMS

SPRING 2023

What Waiver Services Mean to Me: Cayden Winstead

Thank you to Cayden Winstead for sharing his story with us. To read other participant stories, visit <https://bit.ly/kywaiverstories>. If you’d like to share your story, email MedicaidPublicComment@ky.gov.

On February 12, 2023, Cayden Winstead, 23, found himself among the tens of thousands of fans packed into State Farm Stadium in Glendale, Arizona watching Super Bowl LVII. It’s a remarkable experience for anyone, but for Cayden, it was one-part miracle and one-part odds-defying hard work. Exactly one year earlier, he suffered an anoxic brain injury and doctors did not expect him to survive.

“It was the anniversary, the one-year anniversary,” said Cayden’s mom, Leslee Winstead. “From turn the machines off to...you’re going to the Super Bowl.”

Cayden’s brain injury occurred on February 12, 2022, while Cayden was hanging out with friends. His mother, Leslee, says he fell, hit his head, and at some point, became unconscious. His friends thought he was asleep, so it took at least eight hours for anyone to realize Cayden needed help and call 911. Paramedics intubated him at the scene and rushed him to a Louisville hospital. When his parents arrived, doctors told them Cayden had little to no brain activity and recommended palliative care and the removal of life support.

“We both said absolutely not... God’s got plans for him and there’s not a reason in the world we’re giving up on him,” said Leslee. “It was the most scary, shocking thing that a parent can ever witness to see your child laying like that with tubes. He was in a coma.”



Cayden spent 19 days in a coma due to an anoxic brain injury.

Cayden proved his parents right. While still in a coma, he was moved from the hospital where he initially received treatment to Kindred Hospital in Louisville. Kindred is a long-term, acute-care hospital designed specifically for patients with serious medical conditions who need ongoing care. 19 days after his injury, Cayden woke up. “A nurse was in the room, and he said ‘Mom’... that was the first word he said, and she said, ‘did you just hear that?’ remembers Leslee. “It’s like hearing it when your baby says it for the first time, you know. So that was incredible.”

Cayden suffered a heart attack shortly after his brain injury and developed COVID pneumonia during his time in the hospital, which complicated his recovery. Still, Cayden fought, and with the help of Kindred staff weaned off his sedation medication and ventilator within weeks of waking up, which allowed him to talk and even sing – a favorite activity of his before his brain injury.

“Kindred Hospital was absolutely, without a doubt, amazing, and I wish that more people knew that that facility was here,” said Leslee.

He eventually began a physical, speech, and occupational therapy regimen to regain what he lost due to his brain injury.

“They mostly just started with stretching and things like that,” says Leslee.

Cayden eventually moved to Jewish hospital in Louisville before heading home where he received OT, PT, and ST from the Visiting Nurses Association until a spot opened at Frazier Rehabilitation Institute’s outpatient clinic. Cayden now goes to Frazier three hours a day, three times a week. There have been some setbacks along the way. About three months after going home, Cayden fought two rounds of pneumonia, leading to another hospitalization. On his way home from the hospital, he became sick and had to go right back to have surgery to treat seven ulcers in his stomach. Cayden didn’t let it derail his recovery. He got right back into the groove with PT, OT, and ST once he was feeling better.

“He pushes himself 110%, no joke, every day,” says Leslee.

His drive is obvious when you see how far he’s come. While Cayden is using a wheelchair to get around, he can stand with assistance. He deals with weakness, spasticity, and tone problems on his left side, but is getting stronger. He is also starting to regain some movement in his legs, which will help him toward his ultimate physical goal.

“Walking,” says Cayden.

“Walking is his biggest goal. And that’s going to happen no matter what because I’ve already seen so much happen,” says Leslee.

“So much improvement,” says Cayden.



Cayden Winstead, 23, receives services through the ABI waiver following an anoxic brain injury he suffered in 2022.



Cayden with his parents, Chris and Leslee Winstead.



Cayden spent three months in various hospitals before going home.

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Cayden can stand with assistance and is working toward walking again.

Cayden also lost his vision due to the brain injury. Doctors initially told his family it wouldn't come back but, once again, his recovery is defying the odds. His vision is about 60% back. His body is making up for the vision loss in other ways too.

"My hearing... ever since my accident... I can hear like Spiderman," says Cayden.

Cayden receives much-needed services at home through the Acquired Brain Injury (ABI) waiver program. Leslee learned about ABI through a hospital social worker. Cayden and Leslee work with ABI Case Management in Louisville and case manager, Laura Frick, to manage his services.

"She follows up with us constantly. She has a really good rapport with Cayden. They have similar tastes in music. She's really part of our lives. She's not just somebody... that checks a box," says Leslee.

The waiver provides critical supplies. Cayden also receives traditional services through Senior Helpers. A direct service worker comes to help get Cayden ready for his therapy appointments.

"They have a really good relationship, and she is very kind," says Leslee.

After Cayden's injury, Leslee quit her job and has been providing around-the-clock care. Laura encouraged her and Cayden to build a service plan that gives her a break as well.

"Laura helped me to realize, Leslee you need a little, even if it's a couple of hours a week, go to your room, fold laundry or, watch a movie," says Leslee. "I was very hesitant about it at first because I had been with him this whole time."

Having a caregiver is a complete 180 for Cayden. Before suffering his brain injury, he worked for Home Instead as a direct service worker for a man with physical disabilities.

"It's like a flip, you know?" says Leslee.

"From being a caregiver to doing this," says Cayden.

"So, he kind of has a clue what I do every day," says Leslee.

"Yes, I do," says Cayden.

Music played a big role in Cayden's life before his brain injury. He was an avid guitar player and is working to get his skills back.

"He was an amazing guitarist... really, really, really good... like could have been a band but with him being so shy he never wanted to pursue anything like that," says Leslee.

Right now, he can strum his guitar. He hopes to one day combine his experience with brain injury and his musical talent to help others.

"Bring my guitar to places and play for kids," says Cayden.

"He wants to take his guitar and play for patients who are in similar situations with brain injuries that might be in a coma... he remembers hearing music.... So, he wants to be able to play for other people so that they can maybe hear that music as well," says Leslee.

While he's no longer an in-patient, Kindred Hospital continues to play a big role in his post-injury life. Cayden connected with a fellow patient, another young adult who is recovering from a serious medical condition, whom he goes back to visit. Kindred also did a video on Cayden's story, which led to his trip to the Super Bowl. The trip was sponsored by Goose Flights, which is named for Tony "Goose" Siragusa. Goose spent 12 seasons in the NFL, winning a Super Bowl as a Baltimore Ravens player. Following his NFL career, he co-founded and ran a private aviation company. He planned to create an organization to offer free private charter flights for individuals and families dealing with serious illness but passed away last year before bringing his vision to reality. In his memory, his wife and three children picked up where he left off and created Goose Flights. Cayden's trip was the organization's inaugural flight.

"They saw his video and thought that he had kind of encompassed the same types of things their dad was about: big dreams, and goals and working hard to achieve what you want," says Leslee.

Leslie learned Cayden had been selected weeks before Goose Flights surprised him with the news. She had to keep it secret from both Cayden and Cayden's dad, Chris, until the official announcement.

"It was like 'Leslee, what is wrong with you? What are you hiding? I'm like nothing.' The only person I could tell was my mother-in-law because... she knew somebody in there and had heard the rumor," says Leslie. Cayden and Chris were shocked when they learned about the trip at a press conference on January 18, 2023. Several Louisville television stations and the Courier-Journal were on hand for the announcement, making Cayden a bit of a celebrity around town.

"When we go to therapy... there's not a day that goes by that somebody's like 'I saw you on television,' says Leslee. "He's the kindest, sweetest, gentlest person that you'll ever want to meet. He doesn't speak ill of anybody; he's got a very kind heart... so for him it's really hard to take those accolades and things."

Just before the Super Bowl, Cayden and his parents boarded a private charter flight and jetted off to Arizona. It was a bumpy ride to get there...

"The plane ride was pretty rough because I'm tall...I kind of slid around a lot," says Cayden.

... But the trip itself was as smooth as possible. Goose Flights took care of every detail from getting Cayden on and off the plane comfortably and safely, to hiring a driver with an accessible vehicle to transport the family around Glendale and booking an accessible Airbnb for them to stay in. The house provided Cayden



Cayden on the jet headed to Glendale, AZ for Super Bowl LVII.



Cayden and his parents with the Siragusa family after learning he was going to Super Bowl LVII.

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Cayden's view for Super Bowl LVII in Glendale, AZ.

the opportunity to experience something most of us take for granted: a shower. The family's Louisville home doesn't have an accessible bathroom and Cayden has been getting sponge baths since his injury. "I saw this shower. I'm like 'oh my gosh, they have a shower Cayden'. He's like 'I want to take one right now'," says Leslee. Highlights of the trip included a tour of State Farm Stadium, a behind-the-scenes tour of the Fox Sports production set and meeting the crew, and holding Chris Stapleton's guitar. On the night of the big game, the family had a small section of the stadium to themselves with an accessible restroom nearby. They also took steps to keep Cayden comfortable, such as extra blankets to keep him warm due to his circulation issues and earbuds and

noise-canceling headphones to help manage his heightened sense of hearing.

"It was really loud, but he did so great. We had an amazing time. It was so different. When you watch it on television, it's not even in your spectrum of imagination to what you see in real life," says Leslee.

"Not even close," agrees Cayden.

Ultimately, it wasn't the star treatment that made the trip special but rather the chance to remember what life was like before Cayden's injury.

"It was just such a much-needed mind break from all of this... let you step out of the caregiver and the patient role for a while and allowed us to just... be for once," says Leslee.

With the trip behind them, Cayden is now back to therapy and working hard on reaching his goals. He's determined to see the journey through, no matter how long it takes.

"It's a marathon, it's not a race, so just take your time, be positive, keep your eyes forward and up, and don't give up ever," says Leslee.

If you or someone you know is recovering from a brain injury, Cayden and Leslee recommend learning as much as possible by reading, researching, and asking both medical professionals and fellow survivors questions.

"It takes time, but you'll come back from it," says Cayden.

They hope Cayden's story encourages and inspires other brain injury survivors.

"Cayden's not even supposed to be here and look what we got," says Leslie. "God has a plan for him and if he didn't, he wouldn't be here... count your blessings every day, every single day, count your blessings," says Leslee.

"And I do," says Cayden.

More on Cayden's Journey

[Cayden's Story from Kindred Hospitals](#)

[Announcement of Cayden's Super Bowl Trip](#)

[Goose Flights](#)

Local Coverage of Cayden's Super Bowl Trip Surprise

[WAVE](#) | [WLKY](#) | [WHAS11](#) | [WDRB](#) | [Courier-Journal](#)



Calling All Waiver Participants!

We want to hear from YOU! If you are interested in sharing your story and how waiver services have helped you, we'd love to feature you in the newsletter. You can email MedicaidPublicComment@ky.gov for details on how to participate and share your story. We want to hear from as many participants as possible!

Brain Injury Awareness



Every 9 seconds someone in the U.S. sustains a brain injury.

More than 3.6 million people sustain an acquired brain injury (ABI) each year. **At least 2.8 million** sustain a traumatic brain injury (TBI) each year.

An ABI is a brain injury that is not hereditary, congenital, degenerative, or induced by birth trauma. A TBI is caused by trauma to the brain from an external force.



Causes of ABI include electric shock, infections, lightning strikes, oxygen deprivation, toxic exposure, vehicle accidents, seizures, trauma, substance use, and stroke.

The **leading cause of TBI** is falls, which account for nearly half of all TBIs. Other causes include assaults, vehicle accidents, and being struck by something.

Information from Brain Injury Association of America: <https://www.biausa.org>



Brain Injury Resources in Kentucky

[Acquired Brain Injury Waiver](#)

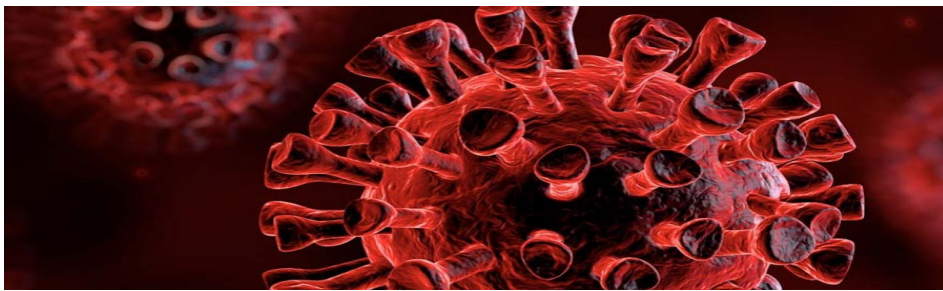
[Traumatic Brain Injury Trust Fund](#)

Brain Injury Alliance of Kentucky
<https://biak.us/>

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COVID-19 FEDERAL PUBLIC HEALTH EMERGENCY ENDING THIS SPRING

EXPIRATION SET FOR MAY 11, 2023



procedures related to the transition back to pre-PHE operations. We anticipate releasing information, guidance, and answers to frequently asked questions soon. To ensure you receive updates, you can email MedicaidPublicComment@ky.gov to be added to our stakeholder email list.

In January, the federal government announced [it will allow the COVID-19 federal public health emergency \(PHE\) to expire](#) at the end of the day on May 11, 2023. It is important to note, the shift away from the emergency phase will not result in changes to Kentucky's 1915(c) Home and Community Based Services (HCBS) waivers at this time. **Kentucky's Appendix K amendment will remain in effect for up to six months after May 11, 2023.** The Department for Medicaid Services (DMS) is working on policies and

Children's Waiver Feasibility Study Begins

The Cabinet for Health and Family Services (CHFS) has kicked off a [Children's Waiver Feasibility Study](#) to explore the possibility of adding a 1915(c) HCBS waiver targeting individuals from birth to age 21 with:



- Severe emotional disability (SED);
- Intellectual disability and/or related conditions (ID/RC); or
- Autism spectrum disorder (ASD).

The study will look at whether a waiver can improve access to care for children by using innovative ideas and integrating services and supports that currently exist. Relevant information is being gathered through stakeholder input, research on similar programs in other states, analyzing data on the needs of children with SED, ID/RC, and/or ASD, and a survey of the provider network to determine if it can serve an additional HCBS population. The study will also look at the projected cost of adding a new 1915(c) HCBS waiver. Guidehouse is assisting with the study.

Stakeholder Input

CHFS created a Children's Waiver Feasibility Study Stakeholder Advisory workgroup, which includes caregivers, advocates, providers, and government representatives, to provide input on the study. Additionally, CHFS is holding focus groups in spring 2023 to allow HCBS participants, individuals on HCBS waitlists, caregivers, providers, advocates, and others to provide input. Details on the focus groups and how to participate are available at <https://bit.ly/ApplyForKYCWFFocusGroup>.

How to Stay Up to Date

To ensure you receive updates about the study, send your email address to MedicaidPublicComment@ky.gov.

For questions about the study, email CHFS.HCBSWorkGroup@ky.gov.

Developmental Disabilities Awareness



Governor Andy Beshear signs a proclamation for Developmental Disabilities Month on March 2, 2023. Photo Credit: Governor Andy Beshear's Office

What are Developmental Disabilities? Developmental disabilities include physical, learning, language, or behavior conditions diagnosed in childhood and expected to last throughout a person's life. Examples of developmental disabilities include attention deficit hyperactivity disorder (ADHD), autism spectrum disorder, cerebral palsy, hearing loss, intellectual disability, learning disability, or vision impairment.*

As many as 17% of children aged 3-17 years old have a developmental disability. That's about **one in six** kids.

Developmental Disabilities are more likely to affect:

Boys compared to girls

Non-Hispanic white children and non-Hispanic black children

Children living in rural areas

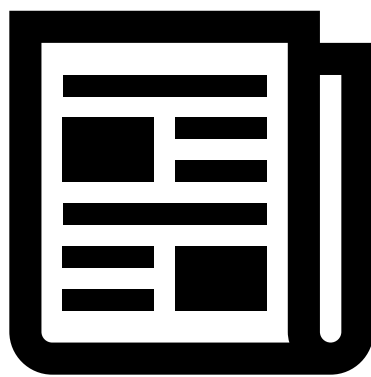
Resources for Kentuckians with Developmental Disabilities

<https://ccdd.ky.gov/Pages/resources.aspx>

*Source: CDC Developmental Disabilities Homepage
<https://www.cdc.gov/ncbddd/developmentaldisabilities/index.html>

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OTHER NEWS AND NOTES



Waiver Service Spotlight: Respite

Providing 24/7 care for an adult or child with disabilities is a demanding job. Too often, caregivers don't take much-needed time for themselves. The good news is five of Kentucky's 1915(c) HCBS programs offer a service meant to give primary caregivers relief. Respite services provide short-term care to a waiver participant so their primary caregiver can temporarily step out of the role. A participant and their caregiver may benefit from respite services if the caregiver:



- Is responsible for 24-hour care of the participant.
- Is experiencing signs of burnout such as lack of self-care, and increased conflict between the caregiver and the participant.
- Needs to take care of personal matters and/or needs to take part in activities that relax, re-energize, and refresh them.

Respite can be provided by a traditional agency or through participant-directed services. While the caregiver is away, the participant will continue to have their needs met and work toward goals as outlined in their person-centered service plan. An added benefit of respite is that it allows the participant to get to know and become comfortable with other caregivers. If you or a waiver participant you know could benefit from respite, talk to the participant's case manager or contact DMS at (844) 784-5614 or 1915cWaiverHelpDesk@ky.gov

Study Looks at Air Travel for Wheelchair Users

The [University of Kentucky Human Development Institute](#) wants to know what challenges individuals who use wheelchairs encounter when they fly. Researchers are



interviewing Kentuckians to document their experiences and their thoughts on needed changes to make flying more accessible. They've also researched federal legislation related to air travel and passengers with disabilities. You can read more about their work at

<https://uknow.uky.edu/research/uk-hdi-researchers-study-air-travel-accessibility-people-who-use-wheelchairs>.

Community Resource Spotlight: STABLE Kentucky



Did you know there is a way for individuals with disabilities to save and grow their money while they continue receiving benefits such as SSI, Medicaid, and SNAP?

In December 2014, Congress passed the Stephen Beck Jr. Achieve a Better Life Experience (ABLE) Act, which allows states to create tax-advantaged savings programs for individuals with qualifying disabilities. State Treasurer Allison Ball's office launched STABLE Kentucky in 2016 to allow Kentuckians to take advantage of this financial opportunity. Kentucky partners with Ohio to operate the program.

STABLE Kentucky requires individuals to make an initial deposit of \$25 and there are limits on how much an individual can contribute each year. STABLE Kentucky also offers multiple investment plan options to choose from.

To learn more about STABLE Kentucky, who is eligible, and how it works, go to stablekentucky.com or call (800) 439-1653 from 9 a.m. to 8 p.m. Eastern.

Students Find Success in New UK Program

In the last issue of the Medicaid Waiver Review, we told you about the University of Kentucky's new



[College and Career Studies program](#). Five students were enrolled in the program during the fall 2022 semester at UK. For many of them, it was their first semester in the program. Read more about their experience and how they benefitted from the program at <https://uknow.uky.edu/campus-news/i-m-fulfilling-my-dream-uk-college-and-career-studies-program-finishes-1st-semester>.



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This newsletter is produced by the Kentucky Department for Medicaid Services, Division of Long-Term Services and Supports

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Phone

(844) 784-5614

Email

1915cWaiverHelpDesk@ky.gov

To Receive Email Updates or Make a Comment

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Mail

Department for Medicaid Services,
Division of Long-Term Services and Supports
275 E. Main Street, 6W-B
Frankfort, KY 40621