

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.

"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 CARROLL, 25, RECEIVES MICHELLE P. WAIVER SERVICES.



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.”

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.

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

“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

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



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 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.



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



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.

Grace Anna Rodgers, Michelle P. Waiver

Singer. Entertainer. Author.

Advocate. At 11-years-old, Grace Anna Rodgers has an impressive resume. It started young with a performance of the Star-Spangled Banner that went viral online and led to an appearance on the Katie Couric Show at age three. Grace Anna credits God for her singing talent and her mom, Angela, with helping her develop it before she was even born.



GRACE ANNA RODGERS, 11, PARTICIPATES IN THE MICHELLE P. WAIVER PROGRAM.

“...Really it was from God. I’ve been singing since I can remember. My mom sang to me since birth. She says she even sang to me when I was in her belly. It just makes me happy to sing. I’ve always loved to do it... If you don’t like to sing, you are missing out.”



GRACE ANNA SNAPS A PICTURE WITH HER MOM, ANGELA RODGERS, AND COUNTRY MUSICIAN TYLER STEPHENS. GRACE ANNA AND STEPHENS RECORDED AND RELEASED A DUET IN FALL 2021. CLICK THE PICTURE TO HEAR THEM SING!

Grace Anna now has millions of followers between her YouTube and Facebook pages. While she’s known for her singing and piano playing, Grace Anna is multi-talented: she hosts a cooking series and has started creating movies. She recently teamed up with country musician Tyler Stephens to record a duet version of This Little Light of Mine, which the pair released in fall 2021.

Grace Anna also uses her platform to show her progress in overcoming the challenges of Conradi-Hunermann Syndrome or CHS. Grace Anna’s family received the diagnosis about six weeks after her birth. Angela says the news came with some relief, as doctors initially thought Grace Anna had a different condition with a poor prognosis.

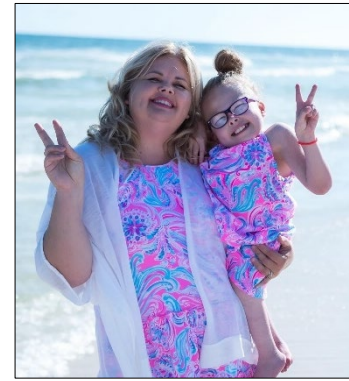
“I was shouting Hallelujah,” said Angela. “They told us (with CHS) she would have medical issues, but she could live a long life.”

CHS is a rare form of dwarfism. According to Kaiser Permanente, in addition to short stature, it can cause skeletal malformations, skin abnormalities, and cataracts. Grace Anna has had 13 surgeries in her young life, countless doctor’s appointments, tests, and procedures, and

regularly attends both physical and occupational therapy. She first began receiving support through Kentucky’s First Steps program. Angela enrolled Grace Anna in 1915(c) Home and Community Based Services at age four, after learning about the programs from their First Steps therapist. Grace Anna currently receives services through the Michelle P. Waiver program.

“It has been a lifesaver for our family,” says Angela.

“I get to do my therapy which helps me learn to walk,” says Grace Anna.



GRACE ANNA AND ANGELA

In addition to meeting her physical needs, waiver services have allowed Grace Anna to become independent, to be part of her community, and to share her singing talent in-person with people around the country.

“I take piano lessons and travel to sing. Knowing I have someone to help me and keep me healthy makes me less nervous about getting out,” says Grace Anna.

The family initially hired outside caregivers to help with Grace Anna’s needs.

“We had a special lady, Linda, that helped for a long time, then she had to leave and take care of her own family,” says Angela.



GRACE ANNA ON THE COURT, CHEERING ON CASEY COUNTY IN BASKETBALL.

Grace Anna and Angela live on a farm in Casey County, along with dad Jeff and older brother Isaiah. While they love the farm, living in the country often means a smaller pool of caregivers to hire from.

“Many times, in rural areas, you cannot find people with the medical abilities to care for someone as diverse as Grace Anna,” says Angela.

Angela, a former teacher, now provides Grace Anna’s waiver services through the participant-directed services (PDS) delivery model.

“One wrong decision with her care can affect the rest of her life,” says Angela. “I am so thankful I have the opportunity to care for her.”

“The waiver helps me feel safe in my life... I trust Mom to take care of me and help me,” says Grace Anna. “I get to keep my privacy and live my life the way I want to live it.”

Grace Anna and her family aren't just focused on her well-being. They are also advocates for all individuals with disabilities. Angela serves on Kentucky's Hart-Supported Living Grant Council. The Hart-Supported Living Grant provides funds to individuals with disabilities to allow them to continue living at home and in the community. Isaiah works as a sibling advocate and serves as a mentor to another waiver participant.

In 2017, Grace Anna's story and her family's advocacy efforts found a wider audience when Angela's book, *Grace Anna Sings*, was published. It all started with an email from a literary agency that had heard about Grace Anna and wanted to share her journey.

"It was one of those things God brought together," says Angela. "I prayed about it and agreed to do it."

Within just two months, three publishing companies made offers to publish a book about Grace Anna. Angela chose a company that also agreed to publish children's books. Angela set to work putting Grace Anna's story in writing, a process she says she found both difficult and joyful.

"It was gut-wrenching... I spent many days in tears recalling things Grace Anna had gone through. I also was able to revisit all those moments God has blessed us and brought us through some incredibly tough times," says Angela.

With Angela's book complete, Grace Anna received the opportunity to become an author. An encounter during a trip to the doctor led to the idea she and her mother used for their children's book.

"...This couple kept looking at me. I don't know if they thought I was cute, or they were trying to figure out what was 'wrong' with me. It's hard sometimes feeling different and not knowing what people think about me. So, I asked Mom what she thought when people looked at me. She told me most people probably saw a beautiful warrior or a sassy little girl. I told her I wanted to tell people who I really am. She then said, 'Grace Anna, I think that would make a great children's book'."

The pair wrote *What Do You See When You Look at Me?* which was released in 2019.

"Every kid needs to read it. It shows you who I am. I am a real person like everyone else. Just because I use a wheelchair doesn't mean I can't live life like everyone else," says Grace Anna.

And just like everyone else, Grace Anna has many hopes and dreams for the future. Some focus on gaining greater independence...

“I hope one day to be able to live in my own house,” says Grace Anna. “I would one day be able to walk without a walker, but I don’t know if it will happen.... It hurts my heart to think I won’t, but I may not. I do think I can be happy though whether walk without a walker or not.”

...while others include making a life in the spotlight.

“I want to have my own TV show where I sing, cook, dance, and act,” says Grace Anna.

Both Grace Anna and Angela want people to know waiver services can make a big difference in helping people with disabilities reach their goals, whatever those may be.

“Life can be very tough for people with disabilities and those with severe medical conditions. The waiver program keeps it possible for people with these issues to live life abundantly... It helps them be a part of the community and have meaningful, happy lives. It helps the people in our society who need help the most. It is one of the most important programs in our world. And for a little girl from rural Kentucky who was given little hope from the beginning of her life, chase her dream and make a difference in this world,” they say.



GRACE ANNA LOVES TO ENTERTAIN PEOPLE VIA HER FACEBOOK AND YOUTUBE PAGES. SHE HOPES TO ONE DAY HAVE HER OWN TV SHOW.

For More on Grace Anna’s Journey

Online: [graceannasings.org](https://www.graceannasings.org)

YouTube: <https://www.youtube.com/user/gracie2bug>

Facebook: <https://www.facebook.com/graceannasings>

To hear Grace Anna’s Duet with Tyler Stephens:

<https://distrokid.com/hyperfollow/graceanna/this-little-light-of-mine-feat-tyler-stephens>

Todd Gregory, Acquired Brain Injury Long Term Care

For Todd Gregory, helping others is what life is all about. Whether it's taking out the trash for a neighbor who struggles with stairs, driving someone to an appointment who can't drive themselves, or coming up with a plan to deter package thefts in his apartment building, Todd is happy to help.

"My goal in life, believe it or not, is to make a difference in someone else's life," says Todd.

Todd lives independently in an apartment in Georgetown with a tight-knit group of neighbors around him.

"Everybody knows everybody... real friendly.... We sit outside and shoot the bull and goof off when it's nice."

He is an active member of his community, in part, because of the services he receives through Kentucky Medicaid's Acquired Brain Injury Long Term Care (ABI LTC) waiver.

A series of brain tumors led to Todd's brain injury. The first tumor appeared at age six. The surgery to remove the tumor destroyed his pituitary gland. As a result, he stopped growing and needed special medication not available in the U.S. at the time. He developed a second brain tumor around age 11 and had surgery again. Afterward, Todd says he changed.

"...My total attitude, disposition, personality wasn't the same. I joked all the time, cried very easily, attention-seeking, very impulsive and, at times, very inappropriate," says Todd.

The sudden personality change caused years of struggles and left him, and his family puzzled. It wasn't until he neared adulthood when his mother went to hear a doctor speak about



TODD GREGORY RECEIVES SERVICES THROUGH THE ACQUIRED BRAIN INJURY – LONG TERM CARE WAIVER.

traumatic brain injuries, that they identified what he was dealing with. The injury is the result of the second brain tumor and the surgery to remove it.

“Not knowing that I had brain damage for all those years, I was different in my life. I didn’t have any real friends, I wasn’t invited to the parties or get-togethers over the weekends with my classmates...” says Todd.

To cope with his brain injury, Todd receives Counseling, Behavior Supports, and Occupational and Speech Therapy services through ABI LTC. He also has a Companion who helps him out twice a week.

“I take it day by day. It could be a lot worse. I know brain injury survivors that are a lot worse off than I am,” Todd says.

Todd later experienced a third brain tumor. It was inoperable but, thanks to an experimental radiation treatment, it was gone after six weeks. He’s now tumor-free but suffers from painful headaches caused by nerve damage from his previous surgeries. He’s now an advocate for brain injury survivors and brain injury prevention.

“It’s life-altering. It’s not like a broken bone or a cut... You’re never gonna be the same,” says Todd, “You need to protect your brain at any cost.”

He formed a brain injury support group in Louisville known as Headliners and is actively involved with the Brain Injury Alliance of Kentucky (BIAK).

Extra, extra! Read about Todd’s efforts to raise brain injury awareness featured in the Georgetown News-Graphic.

[Brain Injury Survivor Gives Back with Helmet Giveaways](#)

[Police Offering Ice Cream for Bikers Caught with Helmets](#)

Every two years, Todd raises money to buy helmets for children. He works with BIAK to get the helmets and distribute them to kids in Georgetown. He’s also participated in a “ride-along” with Georgetown Police where they stop and “ticket” kids who are wearing helmets. The tickets are coupons for free ice cream at Dairy Queen.

When he’s not working to better his community, Todd pursues a range of other interests. He completed the Citizens Police Academy in Georgetown. He’s a talented artist whose mediums include masking tape art, glass etching, stippling (artwork created by using small circles or dots), and 3-D printing. He designs small-scale boats on his computer and builds them with scrap wood. He

also enjoys assembling intricate, wooden 3-D puzzles. One of his builds is a car with 728 pieces of wood and working parts such as windshield wipers, pistons, and doors and windows that

open and close. He's currently working on a wooden puzzle robot with a friend. Once they get it completed, they plan to donate it to Norton Children's Hospital in Louisville. Todd is also an author. He's written more than 70 poems and says it's something he loves.



A GLASS ETCHING TODD CREATED. GLASS ETCHING IS ONE OF HIS MANY ARTISTIC TALENTS.

"I don't know if I was like that before my brain injury or not because it was such a young age... who knows?"

Others recognize his talent too. He's sold some of his glass etchings and wooden boats and several of his poems have been published.

In the future, Todd is planning to get a car and to keep enjoying life in his community, with his 13-year-old chihuahua by his side. He took the dog in after its owner passed away. He says waiver services will continue to play a role in helping him along the way.

"The waiver program is great for all of us who have suffered brain injuries because it helps you get a life. It helps you with the appropriate therapies... so we can live the best quality of life... and live as independent as we can," Todd says.



A SELECTION OF TODD'S ARTWORK. WE ARE GRATEFUL TO TODD FOR SHARING HIS TALENTS WITH US!

Having a Brain Injury

Poem Written by Todd Gregory

Having a brain injury isn't what I had in store. Through the years I've come to realize I'm not alone anymore. Life has been tough, in fact, it's been hard to face, in fact it feels like I'm running an ongoing race. You want to try to get ahead even though you're far behind. Sometimes the road is straight and narrow but then it starts to wind. You have to keep a positive attitude and keep your head held high and ask what can I do to better my life and not dwell on how come or why. Just take it as it comes to you and come what may. As far as trying to improve your life, you'll find you're improving every day.

Cayden Winstead Acquired Brain Injury – Acute

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 WINSTEAD, 23, RECEIVES SERVICES THROUGH THE ABI WAIVER FOLLOWING AN ANOXIC BRAIN INJURY HE SUFFERED IN 2022.

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 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.



CAYDEN WITH HIS PARENTS, CHRIS AND LESLEE WINSTEAD.



CAYDEN SPENT 19 DAYS IN A COMA DUE TO AN ANOXIC BRAIN INJURY.

“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.



CAYDEN SPENT THREE MONTHS IN VARIOUS HOSPITALS BEFORE GOING HOME.



CAYDEN CAN STAND WITH ASSISTANCE AND IS WORKING TOWARD WALKING AGAIN.

“So much improvement,” says Cayden.

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.



CAYDEN AND HIS PARENTS WITH THE SIRAGUSA FAMILY AFTER LEARNING HE WAS GOING TO SUPER BOWL LVII.

“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.



CAYDEN ON THE JET HEADED TO GLENDALE, AZ FOR SUPER BOWL LVII.

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.

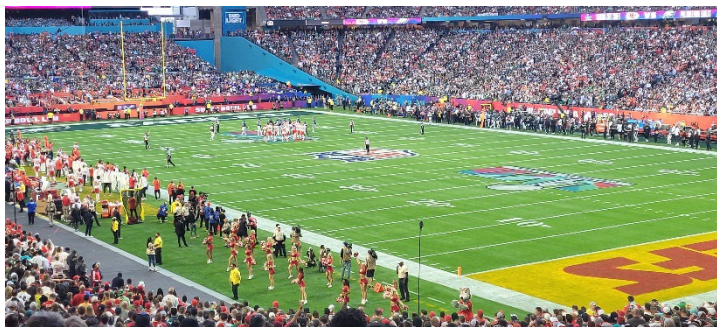
“It was like ‘Leslee, what is wrong with you? What are you hiding? I’m like nothing.’ The only person I could tell was my mother-in-law because... she knew somebody in there and had heard the rumor,” says Leslie.

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.



CAYDEN’S VIEW FOR SUPER BOWL LVII IN GLENDALE, AZ.

... 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 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](#)