The month of March is designated to bring awareness to two groups served by Kentucky’s 1915(c) HCBS waivers: individuals with brain injuries and individuals with developmental disabilities. Please enjoy a special edition of The Medicaid Waiver Review in honor of Brain Injury Awareness and Developmental Disabilities Awareness.

What Waiver Services Mean to Me: Todd Gregory

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

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 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).

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...
Having a Brain Injury
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.
Brain Injury Resources in Kentucky

Acquired Brain Injury Waiver Information
https://chfs.ky.gov/agencies/dma/dca/Pages/abi.aspx

Traumatic Brain Injury Trust Fund
https://chfs.ky.gov/agencies/dail/Pages/tbitrust.aspx

Brain Injury Alliance of Kentucky
https://biak.us/
**DEVELOPMENTAL DISABILITIES AWARENESS**

**FACTS AND STATISTICS ON DEVELOPMENTAL DISABILITIES**

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**

Per a Centers for Disease Control (CDC) study, developmental disabilities increased between 2009 and 2017.

<table>
<thead>
<tr>
<th>Year</th>
<th>Percentage</th>
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<tbody>
<tr>
<td>2009-2011</td>
<td>16.2%</td>
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<tr>
<td>2015-2017</td>
<td>17.8%</td>
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</tbody>
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The increases were specifically seen in ADHD, autism spectrum disorder, and intellectual disabilities.

**Why the increase?** The CDC did not examine the reasons in its study but says previous research indicates improved awareness, screening, diagnosis, and service accessibility may all play a role.

**Developmental Disability Resources in Kentucky**

- Department for Behavioral Health, Developmental and Intellectual Disabilities
  [https://dbhdid.ky.gov/ddid/default.aspx](https://dbhdid.ky.gov/ddid/default.aspx)
- Michelle P. Waiver Information
  [https://chfs.ky.gov/agencies/dms/dca/Pages/mpw.aspx](https://chfs.ky.gov/agencies/dms/dca/Pages/mpw.aspx)
- Supports for Community Living Information
  [https://chfs.ky.gov/agencies/dms/dca/Pages/scl-waiver.aspx](https://chfs.ky.gov/agencies/dms/dca/Pages/scl-waiver.aspx)
- Commonwealth Council on Developmental Disabilities
  [https://ccdd.ky.gov](https://ccdd.ky.gov)
- Kentucky Department of Education
  [https://education.ky.gov/specialed/Pages/default.aspx](https://education.ky.gov/specialed/Pages/default.aspx)
- Kentucky First Steps
  [https://chfs.ky.gov/agencies/dph/dmch/ecdb/Pages/firststeps.aspx](https://chfs.ky.gov/agencies/dph/dmch/ecdb/Pages/firststeps.aspx)
- Kentucky Special Needs Information Network
  [https://www.kyspin.com/](https://www.kyspin.com/)
- The Arc of Kentucky
  [https://arcofky.org/](https://arcofky.org/)
- University of Kentucky Human Development Institute
  [https://hdi.uky.edu/](https://hdi.uky.edu/)

**Source:** CDC Developmental Disabilities Homepage
[https://www.cdc.gov/nccddd/developmentaldisabilities/facts.html](https://www.cdc.gov/nccddd/developmentaldisabilities/facts.html)
On March 4, 2022, Governor Andy Beshear declared March Developmental Disabilities Awareness Month in Kentucky by signing a proclamation in the State Capitol Rotunda in Frankfort. Thanks to our friends at the Commonwealth Council on Developmental Disabilities (CCDD) for capturing the event and sharing their pictures with us!

Top Left: CCDD staff with Governor Beshear at the proclamation signing.
Top Right: CCDD members and staff watch as Governor Beshear signs a proclamation designating March as Developmental Disabilities Awareness Month in Kentucky.
Bottom Left: A copy of the proclamation signed by Governor Beshear.
Bottom Middle: A member of CCDD speaks at the proclamation signing.
Bottom Right: Governor Beshear’s dog Winnie attended the event too!
This newsletter is produced by the Kentucky Department for Medicaid Services, Division of Community Alternatives

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