What Waiver Services Mean to Me: Grace Anna Rodgers

In spring 2021, the Department for Medicaid Services (DMS) debuted a newsletter feature called What Waiver Services Mean to Me. We hope you enjoy learning more about each newsletter’s featured waiver participant and the impact waiver services have on their life.

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.

“...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 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 F. 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.

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 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.

### For More on Grace Anna’s Journey

- **Online**: [graceannasings.org](http://graceannasings.org)
- **YouTube**: [https://www.youtube.com/user/gracie2bug](https://www.youtube.com/user/gracie2bug)
- **Facebook**: [https://www.facebook.com/graceannasings](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](https://distrokid.com/hyperfollow/graceanna/this-little-light-of-mine-feat-tyler-stephens)

### Waiver Participants: Share your story with us!

DMS wants to hear how Medicaid waiver services have positively impacted your life. If you are interested in being featured, email MedicaidPublicComment@ky.gov.
There is additional assistance available to 1915(c) HCBS waiver providers and participants affected by the December 10-11, 2021, tornado outbreak in western Kentucky. On January 7, 2022, the Centers for Medicare and Medicaid Services (CMS) approved an Appendix K amendment to the 1915(c) HCBS waiver programs related to the natural disaster. Appendix K is an extra appendix of the 1915(c) HCBS waiver application that allows states to make short-term changes to their waivers due to an emergency. Appendix K – Natural Disaster gives providers and participants the flexibility to meet needs caused by the tornado outbreak. Copies of Appendix K and a summary of updates are available at the links below.

Appendix K – Natural Disaster Summary: https://bit.ly/kyNDsummary

Please note that Appendix K – Natural Disaster only applies to providers and participants in the following 23 counties: Breckenridge, Boyle, Bullitt, Caldwell, Christian, Edmonson, Fulton, Graves, Green, Hart, Hickman, Hopkins, Logan, Lyon, Marion, Marshall, Monroe, Muhlenberg, Ohio, Shelby, Spencer, Taylor, and Warren.

Other resources available to providers and participants affected by the natural disaster can be found in the Storm Recovery Resources for 1915(c) HCBS Waiver Participants and Providers and on the Governor's Tornado Resources website.

If you have questions or have a waiver-related need due to the natural disaster, you can also contact the 1915(c) Waiver Help Desk at (844) 784-5614, option 7 or 1915cWaiverHelpDesk@ky.gov.

Want to get your COVID-19 vaccine and haven’t yet? Now is the time!

Getting a COVID-19 vaccine is easier than ever. Here are a few helpful resources:

Waiver Participant Guide to Getting a COVID-19 Vaccine

Kentucky COVID-19 Vaccine Information
vaccine.ky.gov

For Help Scheduling an Appointment
Call (865) 598-2248

Facts about the COVID-19 Vaccine
ACQUIRED BRAIN INJURY (ABI) WAIVER RENEWAL UPDATE

ABI Public Comment

DMS is in the process of renewing the ABI waiver application with CMS. To continue offering waiver services, Kentucky must renew each waiver application every five years. DMS released the renewal application for public review and comment from December 6, 2021, to January 9, 2022.

DMS thanks the stakeholders who took the time to review the proposed ABI waiver application and submitted comments during the formal public comment period. Stakeholder input is key to helping DMS evaluate potential updates to Kentucky’s 1915(c) HCBS waiver programs.

DMS thoroughly reviewed the comments received and issued a response on February 17, 2022. DMS received a significant number of comments regarding the Occupational and Speech Therapy services offered through the ABI waiver (see ABI Public Comment by the Numbers, right). Due to the volume of comments related to those services, DMS issued two response documents. The first document addresses all non-Occupational and Speech Therapy comments. The second only addresses comments about Occupational and Speech Therapy.

ABI Public Comment Response

ABI Public Comment Response – Occupational and Speech Therapy

DMS is now in the process of making the updates to the waiver application as noted in the public comment response and will submit the ABI waiver application to CMS for approval soon.

DMS is dedicated to recognizing and considering stakeholder input at any time. It is important to note that DMS is continuously accepting comments about the waiver programs. Comments submitted before December 6, 2021, and after January 9, 2022, are addressed through DMS staff interaction. Comments can be submitted to MedicaidPublicComment@ky.gov.

ABI Public Comment by the Numbers

March is Brain Injury Awareness Month!

To mark this important month, members of the ABI staff will attend the annual Brain Injury Alliance of Kentucky conference virtually to learn more about the latest approaches to improving outcomes for individuals with an ABI. Additionally, ABI staff will mark this month by sharing facts with and educating fellow DMS staff about brain injuries.
Electronic Visit Verification (EVV) Updates

- Effective February 1, 2022, Netsmart’s EVV live training has changed. Training modules for the Mobile Caregiver+ app, provider portal, and claims portal will be held bi-weekly. You can view specific training dates and times by visiting 4tellus.com/training and clicking “Register Now” next to your chosen module. Recorded modules are also available.
- Netsmart continues to offer weekly, live question and answer (Q&A) sessions. The sessions are an opportunity to ask questions about the Mobile Caregiver+ system and view live demonstrations. You can view specific dates and times for Q&A sessions by visiting 4tellus.com/training and clicking “Register Now.”
- Netsmart has added a new topic under the Video Tutorials area of the Training section in the Mobile Caregiver+ provider portal. The Updates and Enhancements topic features training videos about Mobile Caregiver+ system updates.
- New and updated user guides have been added to the Training section in the Mobile Caregiver+ provider portal.
- If your direct service provider or financial management agency has experienced staff changes, DMS kindly asks you to update your agency’s contact information for EVV-related communications using the following form: https://forms.gle/uEt1w9N7PP4cryd0. DMS wants to ensure all EVV-affected providers receive updates.
- A full list of EVV support resources, including where to find user guides and quick reference guides is available in the EVV QRG: Who to Call. The Who to Call includes a list of common EVV issues and who to contact for help.
- If you have policy questions about 1915(c) HCBS waivers and EVV, please email 1915cWaiverHelpDesk@ky.gov or call (844) 784-5614.
- If you have technical issues with Mobile Caregiver+, submit a ticket using the Netsmart Customer Support Portal or call Netsmart at (833) 483-5587. You can also use the Netsmart Customer Support Portal to check the status of your ticket, track known issues with Mobile Caregiver+, and search an online knowledge base for answers to common questions.

Enhanced FMAP Plan Receives Conditional Approval

As part of the American Rescue Plan Act, Kentucky is receiving extra money to improve 1915(c) HCBS services. This is known as enhanced FMAP funds. To use the money, Kentucky had to submit a spending plan to CMS and on February 14, 2022, CMS gave Kentucky’s plan conditional approval. This means Kentucky can begin spending the money if it continues to meet CMS requirements.

Work is starting on major spending plan initiatives such as reviewing the service menu for all 1915(c) HCBS waivers along with reimbursement rates, growing and maintaining a robust network of 1915(c) HCBS caregivers, removing barriers, and making access to 1915(c) HCBS easier, implementing crisis services, and transforming and potentially expanding current waiver offerings. The following resources are available to help stakeholders understand Kentucky’s plan for the funds:

Enhanced FMAP Spending Plan

Enhanced FMAP Spending Plan Webinars:

Updates on our progress and additional opportunities to get involved will be released soon. To make sure you don’t miss any updates, subscribe to email updates using the How to Subscribe guide at https://bit.ly/subscribeupdates or email MedicaidPublicComment@ky.gov.

Mom’s Meals Now Available to Home Delivered Meals Recipients

In October 2021, Mom’s Meals became a Home Delivered Meals provider in Kentucky. 1915(c) HCBS waiver participants can now receive nutritious, ready-to-heat meals delivered to their doorstep. The meals can be refrigerated for up to 14 days.

The addition of Mom’s Meals makes the Home Delivered Meals service available in hard-to-reach areas of the state and expands options for those with specific nutritional needs. You can learn more about Mom’s Meals at Momsmeals.com or by watching the video in the box to the right.

Home Delivered Meals service is only offered through the Home and Community Based (HCB) waiver, however, due to the COVID-19 pandemic, it is also available to participants in the Acquired Brain Injury, Acquired Brain Injury Long Term Care, Michelle P. and Supports for Community Living waivers.

Waiver participants interested in receiving Mom’s Meals should talk to their Case Manager, Support Broker, or Service Advisor. Directions for adding Mom’s Meals to the person-centered service plan are available in the Mom’s Meals announcement DMS sent in October 2021. If you have questions about Home Delivered Meals policy, contact the Department for Aging and Independent Living at (800) 564-6930 or DailHCB@ky.gov.
This newsletter is produced by the Kentucky Department for Medicaid Services, Division of Community Alternatives

**Contact Us**

**Online**

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