Geoff Bennett: More than half-a-million Americans are on waiting lists to receive long term care in their homes, instead of at institutions. Most people on these lists have intellectual and developmental disabilities, and sometimes need help with daily activities, like cooking, maintaining a job or getting around town. Last year, Oklahoma passed a law to end its 13-year-long disability services wait-list that had grown to more than 5,000 people. But, as Judy Woodruff reports, in the first of several stories on the challenges facing those with disabilities, many families are still waiting for the help they need. It's part of our new series called Disability Reframed.

Judy Woodruff: Fourteen-year-old Milena (ph) Castillo loves hanging out in the kitchen with her mother, Maria. This week is special, because grandma is in town from Mexico.

Milena Castillo, 14 Years old: I made these with my grandma.

Judy Woodruff: Most of the time, however, it's just the two of them. Milena has several diagnoses, including autism and ADHD, and Maria worries about her future.

Maria Baca Carrasco, Mother: She depends 100 percent on me. So I don't know. I don't know if she's going to be able to be on her own.

Judy Woodruff: You have a full-time job, and you are making sure that, when she's not in school that everything is all right. And how is that working? What do you need that you're not getting right now?

Maria Baca Carrasco: I think sometimes just a little break, maybe to have one or two hours a week for myself. That's also really, really hard.

Judy Woodruff: Hundreds of thousands of Americans, like Maria's daughter, are waiting for services that could help them live independently. Oklahoma is just one of 37 states that have wait-lists for waivers entitling them to Medicaid home and community-based services, benefits that help people with disabilities live and work outside of institutions. These waivers cover the costs of things like behavioral therapy, job training, and caregivers who teach life skills. Medicaid is funded jointly by states and the federal government, which doesn't guarantee that home and community-based care will be paid for. So, states like Oklahoma can limit the number of people receiving those services. And once states meet their own limit, the wait-list begins. Most days, Maria can't let Milena out of her sight. She says that getting off the wait-list would make it possible for her to get an in-home caregiver.

Maria Baca Carrasco: It's going to be like that period of time where I can focus on many other things that I can't focus when I am taking care of her, because, sometimes, I just feel like I can't do it no more.

Woman: The governor signed a bill into law which includes millions in funding.

Judy Woodruff: Maria saw that glimmer of light in 2022, when state lawmakers committed funds to start chipping away at the disability services wait-list. But even with the Oklahoma legislature approving $32.5 million last year to help meet the needs of individuals with developmental and intellectual disabilities, there are still questions about whether every family in this state will find trained providers to help care for their loved ones. As part of the new funding, caregivers in Oklahoma received a 25 percent pay raise, up to an average of $12.50 an hour.

David Goldfarb, The Arc of the United States: You may have seen reports of salaries going up in places like McDonald's and Walmart and Target. The problem is that the Medicaid payments have not kept pace with that. And so it's adding even more of a challenge to find these workers.

Judy Woodruff: David Goldfarb is with The Arc of the United States, a disability rights organization. He says the problems with long-term care are systemic.

David Goldfarb: These services are provided through Medicaid. And so Medicaid as a whole has often been underfunded. With COVID-19, we've seen a major exiting of the work force across all long-term care and health settings, and that does not appear to be coming back.

Beth Scrutchins, Oklahoma Developmental Disabilities Services: This is the front door to our service system.

Judy Woodruff: Faced with a shortage of providers, the state of Oklahoma is giving parents the option to use waivers to hire family and community members with less formal training as caregivers.

Beth Scrutchins: We found that actually friends and neighbors as staff worked well in some situations.

Judy Woodruff: Beth Scrutchins heads Oklahoma's Developmental Disabilities Services, a division under Oklahoma's Human Services Agency.

Beth Scrutchins: We're continuing forward with some of those flexibilities. But we know that the answer to the work force crisis has to be a multipronged approach.

Judy Woodruff: Still, advocates say some parents feel pressure to quit their jobs while waiting to get the help they need.

State Rep. Ellyn Hefner (D-OK): When I started that process, the person the other line asked me if I would quit my job to take care of William. If that is their answer to the caregiving hole that we have, to have me quit my job, that was not our option.

Judy Woodruff: Oklahoma Democratic State Representative Ellyn Hefner has an 18-year-old son, William, with a developmental disability.

William Hefner, 18 Years old: I got two grilled cheese.

Judy Woodruff: William works part-time at a coffee shop that employs people with disabilities. After waiting for more than a decade, he was approved for an emergency waiver in January after he started to have life-threatening seizures. As a single mom, Ellyn says she was grateful and relieved when William's co-worker, Jared Cooling (ph), stepped in to care for him.

State Rep. Ellyn Hefner: If we wouldn't have known Jared, I don't know what I would have done. And I know of a couple of families that are still calling agencies: Do you have someone available? And so they still do not have relief. So, instead of feeling that caregiving hole, we're putting the weight again on the families to solve it.

Judy Woodruff: Jared's presence has already proved to be literally lifesaving. William, tell me about Jared.

William Hefner: Jared is a good man. We were at Planet Fitness. I was on a treadmill. And I — I fell and had a seizure. And he saved my life.

Judy Woodruff: After William's seizure, Ellyn checked in with Jared.

State Rep. Ellyn Hefner: I told him. I said: "I'm giving you an out. I know that's hard. So if you don't think that you can do this job, I'll understand." And he said: "I think I want to do this job more." He said: "I can do it." And he said: "I really enjoy spending time with William." I want to pay him more. I want to give him benefits. I don't want him to leave now. There's such a great feeling when that you know you can trust someone else to take care of your son.

Judy Woodruff: Jared helps William take his medicine, drives him to work and the gym, and helps him find missing puzzle pieces.

Jared Cooling, Caregiver: Is it this one right here?

Judy Woodruff: He also teaches him life skills, like cooking and lends an ear when he practices for his school musicals. Back at the state capitol building, William's mother is working to pass a bill that would require Oklahoma Human Services to track the help families receive after they get off the wait-list.

State Rep. Ellyn Hefner: The agency should tell us, how's it going, who's being helped? Why are people remaining on the list? That's a really big question. So I'm still waiting for those answers.

Judy Woodruff: Scrutchins says it does take time to connect families to exactly what they need. It takes, I understand, six to nine months to process an individual or an application. Why does it take so long?

Beth Scrutchins: It depends on where they are in the process. It depends on what kinds of services and supports the families need. But they do have a wait-list specialist who is helping through every step of the process.

Judy Woodruff: In 2021, Americans with intellectual and developmental disabilities waited longer for these Medicaid services than any other group, including senior citizens, an average of 5.5 years. In the meantime, families have to step in.What would it mean if you could have some help for a few hours a day?

Maria Baca Carrasco: It would be very good for my mental health, because I know that's something that I need to take care of it too. And if I am OK, she's going to be OK.

Judy Woodruff: What is your wish for your daughter? What do you want for her?

Maria Baca Carrasco: I want her to be a good human being. I want her to be a good person. I want her to have a good quality of life.

Judy Woodruff: For now, Maria and Milena hold on another day, waiting for the care they have been promised.

Maria Baca Carrasco: Wow. Look at you.

Judy Woodruff: For the "PBS NewsHour," I'm Judy Woodruff in Oklahoma City.