



## **Desperately Needed: More NOW/Comp Waivers**

*Developmental disabilities are lifelong disabilities that begin at birth or during childhood, and significantly impact a person's daily life in areas like self-care, mobility or communication.*

**If you are a Georgian with significant developmental disabilities, you have 3 choices.**

- 1. Spend your life in a facility**, like a private intermediate care facility or a nursing home.
- 2. Get a NOW or Comp waiver.** These waivers are for people whose disabilities are significant enough to qualify for ongoing care in a facility, and provide services and supports that allow people with developmental disabilities to live in real homes in their own communities.

Virtually everyone would choose a waiver rather than be stuck in a facility. But just because you qualify for a waiver doesn't mean you get one. **And that's the third choice:**

- 3. Hang on as best you can, wait, hope and pray for a waiver.**

**Over 8,000 Georgians and their families are desperately hanging on as they wait for a waiver.**

Tradetta Lane is a strong, lovely woman with a beautiful spirit. She has always adored children and was working towards her goal of becoming a teacher when she was in a serious car accident at 18 years old, a few months after graduation.

**After weeks in the hospital, Tradetta's insurance was exhausted, and hospital staff told her family that their only choice was to put their 18 year old daughter in a nursing facility.** Her mother still refused, but on one of her rare trips away from the hospital, Tradetta's father was convinced to sign the papers.

**That was seven years ago, and 25 year old Tradetta has lived in a nursing facility ever since.** She has made progress since her accident, and is able to move and recognize voices and make sounds to communicate. Her mother is convinced that Tradetta's progress would be even greater if she could get support for her daughter to live in the community. **At the nursing facility, "I always have to get onto them about little things, making sure she's bathed, she's clean. I feel like she can get better care if she's not in there.** With her in there, I'm so limited in the people, the therapists, that can come to her."

The family applied for a Comp waiver, "years ago – but we're just so far down the list. **It would be so nice if somebody would just care about Tradetta and get her out of there."**





Nine year old Ivey Sirmans is described by her dad as a “bundle of joy”, who laughs and plays and is amazing at sign language. Ivey lives with her mom Gwen, her dad Matt, and her two big brothers in Rome.

Ivey was born without eyes and she has multiple disabilities. Ivey is deaf-blind, is not yet walking, has seizures and eats via G-tube.

**Despite Ivey’s level of need, getting and keeping any support from the state is a bureaucratic nightmare for her family.** Matt has come to expect that he will have to drive to a state office each year to defend Ivey’s annual reapplication for the Katie Beckett waiver. He recalls, “I’ve been told, ‘We didn’t receive your packet’ and I pointed it out, it was right there on the person’s desk.” The constant rotation of new night

nurses sent under Katie Beckett was so stressful for Ivey that her parents finally stopped the nurses from coming, meaning, as Matt says, **“It all falls on me and Gwen.”** Gwen puts it simply: **“High level of care 24/7. We are exhausted.”**

And despite Ivey’s years under Katie Beckett, it was only this winter that her parents learned they could apply for a NOW or Comp waiver to help with their daughter’s extensive daily support. (Katie Beckett only covers strict medical expenses.) While the Sirmans family is just beginning their journey into NOW/Comp territory, **their story is typical of thousands of families in Georgia: a family bound by love yet ragged from the constant demands of caretaking, and deeply frustrated by how difficult to impossible it is to receive any help from the state.**

The state of Georgia offers several different waivers for people with needs significant enough to qualify for facility care. **The NOW/Comp waiting list is by far the longest.**

Waiver Name	People Served	Active as of 9/30/15	Wait List as of 9/30/15
<b>Community Care Services Program</b>	Elderly & individuals with disabilities	8,866	2,462
<b>SOURCE</b>	Elderly & individuals with disabilities	15,311	0
<b>Independent Care Waiver Program</b>	Individuals with significant physical disabilities	1,375	107
<b>New Options Waiver/ Comprehensive Supports Waiver</b>	Individuals with developmental disabilities	11,917	<b>8,090</b>
<b>Community Based Alternatives for Youth</b>	Youth with severe emotional disorders	76	No Waiting List

The state of Georgia spends over \$23 million a year that is NOT matched by Medicaid on services for people with developmental disabilities. A large number of people receiving these state-funded services are eligible for Medicaid waivers.

If Georgia converts 20%, or \$4.75 million, of unmatched state funds to Medicaid waivers, that will bring down an additional \$10 million in federal funding and cover up to 1,000 new waivers.

**FY2017 ask: Support the 100 new NOW waivers in Governor Deal’s budget AND Convert unmatched state dollars to Medicaid waivers to get people off the NOW/Comp waiting list and into needed services.**