

‘What happens when we die?’ NC parents seek housing for adult children with disabilities

BY TRENT BROWN. DECEMBER 27, 2019 09:53 AM, UPDATED DECEMBER 30, 2019 03:15 PM

CHAPEL HILL

Dylan Hoyle paces back and forth through his kitchen and living room. He does that sometimes when his environment changes abruptly. This time it’s because two new guests just walked in.

Noticing his pacing, Dotty Foley asks her son, “What is it you want me to do that will make you feel good right now?”

“Dr. Pepper?” he asks. She’s busy, but a member of his support staff is there to walk with him down the street to Harris Teeter.

Dylan, 29, has autism and lives by himself with the help of supported living staff.

This house, just off East Franklin Street in Chapel Hill, has been good for him over the past two years. It’s the latest in a series of living situations he’s had over the past decade, since he moved out of his parents’ house.

But his family has been told that he’s soon going to lose the services that let him stay.

DYLAN: A ‘SUPPORTED LIVING PIONEER’

Later that evening, Dylan calms his anxiety with an episode of Pokémon on his iPad.

Then, he asks for one more trip out before dinner, a short car ride with his support staff person.

The rides just go around the block when it's dark out, and he sits in the back seat. He doesn't talk much, but he likes to sing country songs sometimes in the car. Other times, he starts giggling at random things and can't stop for 10 minutes.

"A day at home for Dylan looks pretty similar to all of our days at home," Foley said. "Which is what's really cool about supported living."

He creates his own day with the help of the paid workers who are with him 24/7. Together they might do chores around the house, navigate Chapel's Hill bus system, or attend different volunteer opportunities throughout the week.

He also has a shredding business, [Shredding To Go](#), that he runs out of his spare bedroom. Foley got him an industrial shredder, had a website made for the business and helped Dylan find customers.

"I want him connected to a community," she said. "That's why we intentionally moved him to Chapel Hill to a community that I feel is really open and diverse. That's really important."

The job gives Dylan dignity and pride, something he hadn't gotten from past living situations.

"When I'd take him back to Murdoch after a day out, he'd just immediately get back in bed," explained Foley, a former special education teacher. "Now it's like he woke up."

Murdoch Developmental Center in Butner, N.C. , is one of three state-operated developmental centers that offer round-the-clock residential clinical services.

North Carolina has worked for half a century to move people with intellectual or developmental disabilities out of institutions like Murdoch and the state's psychiatric hospitals.

From 1964 to 1981 alone the state's psychiatric hospital population fell from around 10,000 to 2,700. It's now down to around 900, while there are more than 12,000 people served by North Carolina's Innovations Waiver, a Medicaid program that was enacted statewide in 2013 to help people like Dylan.

STATE FUNDING CUTS

From 2015 to 2017, North Carolina's seven managed care organizations — the regional agencies that handle waiver funding, among other programs — received an average of \$2.6 billion in state and federal money annually to serve Medicaid recipients in their counties.

But as audits showed how much of that money the organizations were saving instead of spending, lawmakers cut funding by \$458 million from 2015-18. By then a [2018 state audit found the companies had amassed a total of \\$439 million](#) from 2014-2017. It blamed the excess savings on an explicit goal never being set for how much they should save.

“They are sitting on the savings,” State Auditor Beth Wood said [in an interview in March](#). “They have spent down very little of the money.”

Some state legislators said the organizations had enough savings to offset the cuts.

But the managed care organizations say they were being fiscally responsible and that the cuts have made it harder to provide all of the services some of their clients need.

They also are saving less. In 2015, the seven organizations saved 11.3 percent, or \$291.2 million, of their revenue. By 2017, the savings were down to 3.2 percent, \$82.6 million.

Unlike a previous program, which served half as many people and was fully funded by Medicaid, the Innovations Waiver program requires additional state dollars. Cardinal Innovations, the managed care organization for a large portion of North Carolina, reported a \$68.2 million total net operating loss in 2018 and 2019.

State Rep. Verla Insko said the cuts are hurting people.

“I just don't think Republicans understand how care organizations operate,” the Orange County Democrat said. “They're billion dollar organizations, and they require a certain amount of savings.”

Trey Suttan, the CEO of Cardinal Innovations, said he's “worried that families are going to get disrupted or hurt by the chaos” of the ongoing fight between care organizations and the legislature.

Still, the organizations say they are working to fund the services people like Dylan need to live as independently as possible.

“You’re not going to achieve your goals in life without housing,” said Rob Robinson, CEO of Alliance Health, the managed care organization for Durham, Wake, Cumberland and Johnston counties.



Dylan Hoyt, 29, hangs up his bath towel after a shower in Hoyle’s own home which he has lived in despite a diagnosis of severe autism since 2017, with 24-hour one-to-one staff support like Lamar funded by a Medicaid waiver, on Thursday, Nov. 11, 2019, in Chapel Hill, NC. Casey Toth
CTOTH@NEWSOBSERVER.COM

MOVING OUT

A year after getting the waiver, Dylan, then 21, moved out of his mom’s house into in a six-person group home.

Because of his anxiety, he didn’t react well, and Foley got a week’s notice to move him out. So, he moved to Murdoch for a three-month evaluation period that turned into a two-year stay.

His last stop was at a group home in Albemarle, N.C., for almost five years. But more problems plagued his stay.

Around the same time, the state approved a program called Supported Living funded by the waiver to provide support staff in people's homes.

So, Foley bought an apartment home for Dylan in Chapel Hill, using his Supplemental Security Income (SSI) to make payments on it. She knew there would be challenges, especially since Dylan was one of the first to use the program at support Level 3 — requiring supervision day and night.

It's still a service that is rarely used at that level. In 2018, only 24 of the 120 North Carolinians using Supported Living were Level 3, and only 10 were diagnosed with Autism Spectrum Disorder.

Now in its second full year, there are 209 people who use the service.

“The first year was a really tough transition year. ... It was like we were building the plane as we're flying it,” Foley said. “(Supported Living) was so new. And Dylan living on his own with staff was so new.”

One of the earliest issues was finding and keeping staff for Dylan.

Dylan requires 168 hours of one-to-one staffing a week, and sometimes, a support staff member might have to work from 8 a.m. to 10 p.m. At \$10 to \$11 an hour, “people are pretty transient,” Foley said. “They kind of come and go.”

But a much bigger issue for Dylan and Foley has been finding, and keeping, a provider who will offer supported living to Dylan.

Because he's Level 3, it costs much more to serve him than someone who doesn't require continuous assistance. Many providers told Foley they couldn't do it.

Originally, their provider was The Arc of North Carolina, but it discharged Dylan last year because of financial issues. Foley found Monarch Healthcare soon after. But about a month ago, Monarch told Foley it too would be ending Dylan's services in about a year.

Care organizations are required to adhere to the \$135,000 per year cap from the Innovations Waiver, and it's not enough to cover the costs of Dylan's care.

“In some cases where funding is inadequate, we have extended services beyond what will be paid to us to allow the families to identify other residential options,” Monarch President and CEO Peggy Terhune said in a statement “Our ultimate hope is that elected officials identify a long-term funding resolution soon, so that people in our community can receive the services they need without funding cap restrictions.”

BRIAN: WAITING FOR THE WAIVER

Orah Raia, her husband, Joseph, and their son Brian moved to North Carolina nine years ago.

Brian was diagnosed with Fragile X Syndrome at a young age, a genetic disorder that is one of the leading causes of autism — which he was later diagnosed with. As soon as they moved, they applied for the N.C. Innovations Waiver for Brian, who was 23 at the time.

He's 32 now, and they're still waiting. The Raia family is one of more than 12,000 families that are on the waiting list in the state.

There are 1,000 new Waiver spots — 500 to be available in 2020 and 500 more in 2021 — in the most recent state budget that was vetoed and delayed until January 2020. But Insko doesn't think all of the spots will make it into the final spending plan. “We'd be lucky to get 200 or 300,” she said.

Because the Raias are still waiting, Brian has to live at home. While the family could pay for an apartment that he could live in on his own, they don't have the money to pay for the support that he would need. Without the waiver, an individual doesn't have access to many services. Brian currently only gets about eight to 10 hours per week.

Brian spends most of his time either working shifts at [HandMeUps Thrift Store](#) in Raleigh — created to employ people with intellectual or developmental disabilities — or Target, volunteering, bowling or

learning photography from his dad. He understand language, but is non-verbal. His mother describes him as empathetic and humorous.



Brian Raia pictured at a photo reception at the Cary Arts Center in May, for his picture of Cary's downtown park fountain. Brian was diagnosed with Autism at a young age and has been waiting almost a decade for the NC Innovations Waiver to receive services. ORAH RAIA

Working has been good for him but it has also been a challenge.

For instance, he doesn't really understand money, so he can get confused by customers at work and has relied on coworkers' good will. Raia said that in the past, when people who helped her son left, he's gotten fired soon after.

And she worries that Brian's quality of life isn't what it should be. She says that when he's at home, he spends most of his time alone in his room.

“He can’t say he doesn’t want to be there,” she said. “But his behavior displays it.”

According to the [Autism Housing Network](#), of the 87% of people with autism who live with their parents, only 22% want to live there.

Raia is a friend of Foley, and stories like Dylan’s have made her wary of being too optimistic about the Innovations Waiver. While Brian would be considered Level 2 under the Waiver, he still needs the funding to get the care he needs to live on his own.

Raia hopes they’ll get the waiver in the next couple of years. For now, she and Joseph, 64 and 69 respectively, have the same worry that many similar families in North Carolina are starting to have.

“We don’t have many years left to figure it out,” she said.

BEN: STAFFING A NEW HOME

Ben and Chris Holland live at home in Johnston County for now with their parents, Jeff and Tonya.

Ben, 18, has autism and will graduate from high school in December. Chris, 20, has Down Syndrome and recently graduated in May. Both have Innovations Waivers.



Chris Holland is 20 and is diagnosed with Down Syndrome. He goes to Able to Serve for a day program and his parents hope to find individual housing for him in the next five years. JEFF HOLLAND

Jeff Holland met Foley when she was setting up Dylan's house, and this seemed like a real option for his children. While Chris currently goes to a day program in Garner at Able to Service, they've been working to get Ben into a home this year.

Jeff Holland met Foley when she was setting up Dylan's house, and this seemed like a real option for his children. While Chris currently goes to a day program in Garner at Able to Service, they've been working to get Ben into a home this year.

Recently they bought a house, which they plan to pay for using Ben's SSI funds. They're looking for a roommate in a similar situation, hoping it would make the financial situation easier on both of them.

They aren't sure that Ben fully understands the house is just for him; he knows it's "Ben's house," and he's seems happy to call it that.

The most difficult part, has been figuring out his support staff. Ben is Level 3 and sometimes has behaviorial issues, so he requires continuous care.

And unlike most supported living situations, the Hollands are staffing the home on their own, using the money allotted through the waiver — a bit over \$200 a day. They're acting as the provider company for their son, which means they not only have to find workers, but they have to go through training and certification sessions.

This type of family-directed care without a provider is new, added to the waiver in July.



Ben Holland attaches a light to the back of his dad Jeff's bicycle in late summer, 2019. Ben is diagnosed with Autism, and will be moving into his own house soon. JEFF HOLLAND

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But that still hasn't made it easy to keep support staff.

"I can't even begin to count the number of people that have been in our home," Jeff Holland said.

After a struggle with getting furnishings and other items for the house approved by Alliance, they moved Ben in just days before Christmas, two weeks later than expected.

AN INTENTIONAL COMMUNITY

Along with figuring out his own son's future, Jeff Holland is trying to help other families in Johnston County.

He remembers hearing from Foley about a group she, Orah Raia and others had started in Chapel Hill called [Housing Options for People with Exceptionalities](#) (HOPE).

Working with another group, PACID, or [Parent Advocates for Adult Children](#) with Intellectual and/or Developmental Disabilities, HOPE meets monthly with about 200 families to talk about creating housing options for their children.

"I saw that and thought, 'We need to do something like that over here,'" Holland said.

So he created a Facebook page and named it PACT (Parents of Adult Children in Transition) for families in Johnston County.

HOPE and PACT are working toward the same goal: an intentional community for their children. To Dotty Foley, that means getting past the "illusion of inclusion" and allowing people like Dylan to truly be part of a real community.

For Foley and the others in HOPE, an intentional community would include at least 15% of residents with disabilities, alongside others who make a conscious choice to live in the same neighborhood.

PACT would like to make a community where all residents have intellectual or developmental disabilities.

Both groups have met with developers. HOPE has been working with Chapel Hill to possibly acquire a 14-acre plot of town-owned land on Homestead Road that has been designated for affordable housing.

At a HOPE meeting in October, around 100 people showed up. Urgency framed conversations about how to get affordable housing for their children, quickly.

“What happens when we die?” Foley said. If they can’t figure it out, she worries Dylan may end back up in the last place she wants him to be: an institution.