Good Afternoon….

We're Steve and Debbie Streng and we have a disabled adult son whose name is Danny. Dan was born with a rare genetic disorder that has left him with severe developmental disabilities that has required him to need a great deal of care and oversight on a daily basis. His diagnosis at birth was one rarely seen at Children's Hospital, and 44 years ago he was the first child to have survived this genetic anomaly. We are thankful he continues to thrive, and bring joy and inspiration to everyone who takes the time to get to know him.

After the shock of realizing that our child would never be "normal", we started to try and get our brains around how we were ever going to provide lifelong care for him, while trying to also maintain a normal family life not only for Danny, but also ourselves and our other son. We knew from the beginning that life for all of us would never be normal, but somehow with God's grace and support of family and friends that we would make this situation into the best possible family scenario.

Initially of course, our most immediate priority was Danny's survival. The first many years were worrisome and there was always uncertainty about what tomorrow would bring, but eventually we got to the point where the realization starts to set in that getting Danny to adulthood was not a certainty, and planning for his future years was going to be a real challenge.

We'll fast forward through most of the really challenging years and we will simply say life has never been take for granted in our home. The years have passed quickly, but sometime during our planning, we did have the foresight to establish a personal needs trust for Danny, and started to develop a team of experts to assist us in developing a plan for Danny that would not only provide the best possible life for him, but also a plan that would be sustainable and reasonably affordable. It's a discussion for another day but the creation of Dan's personal needs trust has benefited Danny very little as his Medicare / Medicaid benefits would be jeopardized if his money is used to pay for anything that Medicare might cover. We continue to live and learn.

When Danny was in his mid to late 30's, we were becoming more hopeful that Danny was probably going to outlive both of us. That's what most parents hope for with their children but for ageing parents who has a special needs child, it is also a worry.

At this point in our lives we confronted the reality that continuing to care for Dan in our home, although the easiest option, was not really in Dan's best interest. Imagine how cruel and shocking it would be for our son if we continued living life as if life was forever, then one day we are gone, and not only is Danny left without parents and caregivers, we have essentially left him totally in the care of the County Board of DD. They would be forced to handle his housing, doctors visits, food preparation... everything you do for yourselves would have to be done and handled as an emergency by the county board. Not a good option.

So, with that backdrop, we purchased a home 2 doors away from our residence when it went up for sale, then spent the better part of a year refurbishing it, making it ADA compliant, etc. We set up the interior to resemble our own home as closely as possible to reduce the shock of his move. Coinciding with the house preparation, we were partnering with the Union County Board of DD to arranged for Danny to receive a waiver that would assist in paying for Danny's future caregivers...DSP's.

Finally... after many months of planning meetings and interviewing and hiring staff to be Dan's caregivers, invitations were sent out to all of Dan's family and friends. Many members of Dan's church family came and along with the Pastor Blessed Dan's house and his future caregivers, a food truck came and served about 200 meals to the group. The invitations sent to everyone said we were celebrating "Danny's Independence Day"

Everything was exceeding our expectations for several years. Dan was thriving with his new found independence, the caregivers were awesome and truly became part of the family, and for the first time in 15 years we took a vacation away from Dan. Nothing big, 2 day trip to visit Nashville, but it was, we thought, a gateway to maybe more senior type trips.

Then reality sets in. What we didn't and couldn't have planned for is the events of the last several years that basically changed everything in Dan's home. Caregivers were leaving the house, we assume because of money. Service Providers were giving us notice that they were ceasing offering services to Dan's house because of a lack of DSP's. The cliff note version of this disaster is that despite all of our planning, time and money we put into Dan's plan, its all falling apart because no one was wanting to do caregiving type work anymore. We were told that there were too many higher paying options for these individuals, and that maybe even not working and drawing unemployment benefits would be more profitable for them than working. We are not informed enough to speak to the why this was occurring. We can only see the impact this lack of DSP's was having on our family. We were once again almost full time caregivers.

The most concerning thing about all of this change and instability is not the impact it has on us, but this change has not been good for Dan. People come and receive their training only to leave after a week or less for what they perceive as a better job. He is constantly being forced to having a stranger in his home. Imagine if you needed assistance bathing, and needed help with your toileting, with food preparation, dressing... everything, and you never would know who would be helping you do these things. We can all imagine how uncomfortable that would be for any of us.

With a nighttime care giver available at Dan's, our daily routine starts at 6:30 by administering his first seizure medicine. We return at 8:40 to take him to his employment at UCO. He has assistance there doing his job of unwrapping folios for Honda. We pick him up at 2:30 and have kept him with us until 10:00 until just recently. We have hired a 2nd agency who has provided a caregiver and we remain prayerful that the relationship continues. But with this newfound relationship, we still return at around 10:00pm for his last seizure meds and night prayers. On weekends we have Dan with us from 8:30-7:00 both Saturday and Sunday.

Despite all of the many issues we have briefly presented, we view Danny's situation as being better than many if not most of our disabled population because Danny still has us. So many of our disabled have no one other than government or county employees to oversee their care. Imagine how traumatic it must be in those homes when a caregiver doesn't show up for work.

This is truly a dark time for family's attempting to find care for disabled loved ones. You can understand as caring, ageing parents ,why dieing in peace is not an option right now. Sadly… we realize that we, despite our best planning, are only a heartbeat away from our son's care being put into the same uncertain limbo that most other disabled people in this state find themselves in. However, we are confident that better days are ahead, and are hopeful that once this DSP issue is resolved, we might be able to see another show in Nashville… but we'll see. Thank you for your time…

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Home » News » Caregiver shortage puts strain on area families

NEWS

Caregiver shortage puts strain on area families

By Michael Williamson — November 23, 2022 No Comments 12 Mins Read

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Steve and Debbie Streng always knew they wouldn't have a typical retirement.

A close-knit family living in Marysville, the Strengs did hope to spend their later years doing some of the typical activities retirees might enjoy: socializing, traveling and celebrating things like their 50th wedding anniversary, which passed in August.

But even with anticipating an atypical retirement, those hopes haven't exactly been fulfilled, not to the degree they'd like.

Steve and Debbie have an adult son, Danny, who suffers from severe developmental disabilities and requires a great deal of care on a daily basis. Their son was born with a genetic condition that the couple said most infants die from, and that Danny was the first at Children's Hospital to survive it.

The Strengs have cared for their son since he was born, 44 years ago, and typical people with his condition don't live that long, they said.

Given all his needs, the Strengs realized very early on that giving Danny the kind of lifelong care he needed would require some precise planning. For much of that time, they could also count on the system in the form of medical professionals and the Union County Board of Developmental Disabilities, of which Steve is a member.

What they didn't count on was a major shift in the caregiving profession, an already taxed system even before the acceleration by the COVID-19 pandemic, where a lack of available caregivers has forced Danny back into the care of his septuagenarian parents.

The Strengs' situation is becoming more common in Union County, the state and around the country and as home health care numbers diminish, those who need care are finding themselves looking to family for help.

Planning for the future

Steve and Debbie took on the responsibility of caring for Danny in a variety of ways, including setting up a fund for their son early on that could go to future care and medical related costs.

They also looked into options for how to provide housing for Danny that would both allow him some independence as well as accommodate his continued need for care.

"We, like a lot of other parents, are getting older and one day we won't be here," Steve said. "So trying to head off that sudden shock for Danny and the emergency situation it creates for the county in finding him a residence, we elected to do this on our own."

Eight years ago, the couple purchased a home just a few doors down from their current house which was then renovated and made ADA (Americans with Disabilities Act) compliant.

Danny has a job through UCO Industries, a not-for-profit corporation in Marysville that specializes in light assembly, re-packing, and warehousing which provides work for people with developmental disabilities.

He is able to attend work in the first portion of the day, but once he returns home, he has caregivers that come to the house to help.

"He is a total care kind of guy. We wish that Danny had more skillsets that we could build on, but he's not able to pour himself a glass of milk," Steve said. "Everything is done for Danny and it's not an indictment of who he is, he's a great guy and we love being around him, but when you are around him and you're in charge, it's total care."

"A real crossroads"

Recently, care has gotten a little more complicated to work out, Steve said, adding the pandemic may have changed it most of all.

"Within the last couple of years, we've reached a real crossroads where we can't find people to work in the house," he said. "What was a smooth running machine – we've now reached this bottleneck where we are providing much of the care for Danny once again."

He said the couple is, of course, OK with it, but it has them worried about what the future holds for their son.

Danny experiences seizures, Steve said, which he takes medication multiple times of day to help alleviate – something caregivers typically administer, but has been the responsibility of his parents more recently. The family does have two caregivers but their shifts cover the more difficult times to fill: nights and weekends.

"The two caregivers that we do have do a great job, but they can't work all the time," Steve said.

A typical day for the Strengs includes administering their son's first seizure meds at 6:30 a.m., then taking Danny to work at 8:40, where he stays until 2:30 p.m. In the past, Danny received total, 24-hour care between work and caregivers in the home. Lately, the Strengs will pick Danny up from work and go out to find activities to do unless there is a caregiver available, in which case, they take him home and the caregiver takes over until about 7 p.m. That's when the Strengs drive back over and stay with Danny until 9 p.m., when the second caregiver arrives.

Steve and Debbie return at 10 p.m. to administer CBD oil medication which Debbie said helps her son with seizures.

“He was having 30 seizures a day and we’re pretty well maxed out on meds and so our doctor suggested to do that,” she said.

Danny is assisted through Medicaid but because of that, there are restrictions in place preventing caregivers from administering the CBD oil. The cost for a small bottle is $280 but the Strengs said it’s worth the cost given that it reduced Danny’s seizures from 30 to two or three a day. That reduces the amount of times the couple has to go to Danny in the middle of the night.

The CBD oil is one of at least 18 medications, not including occasional antibiotics, that Danny takes regularly.

When the overnight caregiver arrives, Steve will leave and Debbie will stay and debrief the incoming help which generally gets them through until 6:30 the next morning, barring no middle of the night seizures or other issues.

The Strengs bring their son to their home on weekends and stay with him nearly all day each day.

“We’re not complaining about this because, like we said, we like spending time with Dan, he’s our son. He’s our responsibility, we’re not trying to push him off on society. It’s our issue,” Steve said. “We do know that life could be better for him and for us if we can get this caregiver thing solved.”

“In a perfect world…”

UCBDD Superintendent Kara Brown said the Strengs’ story is increasingly common, both around the state and in Union County. The lack of caregivers has forced many individuals back in the care of sometimes aging parents and both Brown and the Strengs say they are one of the fortunate families.

“Debbie and Steve are in pretty good shape. Not all the parents who have 44-year-old sons aren’t always able to provide the kind of care that they’re able to provide,” Brown said. “They’re not the only family we’re trying to help through this and we also serve several adults who don’t have anybody else, they’re ours to try to figure out how to help and serve.”

She added that even though the Strengs are fortunate, things shouldn’t work this way.

"In a perfect world, that's not the way it would work," Brown said. "Providers would call the next morning and say, 'Danny got sick last night, he had a seizure.' In a perfect world, you wouldn't have to go over in the middle of the night."

The Strengs currently have two caregivers for Danny, one for the overnight shift and one for weekends. Both are out of county and drive every day from Columbus, which the Strengs said is difficult for them with low wages. They provide meals and gas cards as often as they can for the two caregivers.

Brown said a family in their situation should have at least five.

"There would be an afternoon, an all-night, then he goes to work and it starts all over," she said. "Weekends would be three eight-hour shifts."

She said the situation facing many families is dire and that the board is beyond any and all contingency plans. She said it's not even that there are no certified caregivers to help, there are no people even under-qualified to help.

"There are just no bodies to hire," Brown said. "There are just no people."

Debbie said even when the family can find help, often people with very little experience, those caregivers don't stay for long.

"People will come in and get trained and you think, 'OK, this isn't perfect, but this is going to work,'" she said. "And a week after they're there, they say, 'I just don't like this' or 'I'm not getting paid enough' and they're out of there. And then you start all over again."

She said it's also hard on Danny because he has to get used to a new stranger in his home periodically and can sometimes act out.

"If you needed total care and you needed assistance in the restroom and you needed assistance with bathing and you needed assistance with all your food and you never knew who was walking in the door, it would be a really uncomfortable situation," said Brown. "And it's the same for Dan."

She said families could live with a lack of experience and a lack of quality of care if there were enough people to fill those roles, but she said they "can't even get that."

The county doesn't provide the care, rather provider agencies are contacted through the State of Ohio as Medicaid-certified providers, she said.

What can be done

Brown said there are several reasons for this shortage, starting before the pandemic, and not all of it is financial.

"It's not just 'throw more money at it.' It's not just 'call one more place.' We've gone through Plan X, Y and Z," Brown said. "We're at the end and there's no place left to call."

One of the things that needs to happen, she said, is that Medicaid rates have to "come into the 21st century."

"We haven't seen rate increases since 2006 in terms of provider agencies," she said. "Up until two years ago, they were making $10 an hour. The statewide average right now is up to $13. With some promise from county boards and, quite frankly, we were pretty aggressive as a county board in saying we would give as much as we could give."

She added there is a 6.5% "longevity bonus" out there that could bring providers up to about $15 an hour. She said increased wages could help but wouldn't help enough to bring numbers up to where they need to be. The more than 15-year delay on updating the law has now put even more pressure on the system to add an even larger amount of money, which Brown said is hard for officials to agree to.

"Our county was willing to put up an additional 16%. We were one of only three counties willing to go that high in the state. And of course we all have to live within our levy means and have budgets we have to live within, so I'm not knocking the other counties, I just think if we don't get this rate where it needs to be, we don't stand a chance," Brown said. "Whether we have to pass a levy to do it or not, if we can't provide care, then why do we exist?"

Sorting out the money issue would only get families so far, she said. There are other issues such as the Medicaid restrictions on things like medication and certifications to handle specific needs. Medicaid law states that rates are set and can't be supplemented, which ties the board's hands.

The Strengs said even the trust they set up for Danny all those years ago can't be used for as much as they thought it could, given the restrictions.

"Now that we've reached this point, we found out there are only very few things he can pay for with that personal needs trust without jeopardizing his eligibility for some of these other services," Steve said. "Having a personal needs trust doesn't fix any of this."

Even groceries can't be bought with that money since Medicaid contributes to those needs. Clothes and some household items can be bought, but there are limitations.

"Every nickel" spent on something for Danny is reported to their attorney and Debbie said when Danny dies, anything left over will go to the state, including the trust.

Brown said meetings are happening at the state level but it takes a lot of effort and money to get the situation resolved.

"This is not a money problem, this is a math problem. There's simply not enough people," she said. "If you look at nationwide data, there are a lot of people retiring and a lot of people left the workforce during the pandemic, which rushed it, but we knew we were getting to this point anyway."

She said she personally has had staffing issues conversations for the last 10 years and those conversations continue today. She said this "didn't come out of nowhere."

The Strengs said they are optimistic that this issue will get resolved one day but can't help but to live with concern for their community and their son.

"If we can ever get to the end of this dark tunnel, where there's no one to be had to care for him. If we can get to that point, we can die in peace," Steve said. "Right now, that's not an option. We're a heartbeat away from Danny being in the same boat that most of our other people in this county are in."

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