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MOTHERHOOD

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Mother fears being forced to choose between her daughter and homelessness

Carly Anastasion shares her story in the fourth installment of In Her Words

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“If they pay me, I could stay with my child, I could provide the things she needs, get off social services and food stamps and feel like I don’t have to rely on the state. I could be self-sufficient. Under this new program, I felt like I could get there, and now I don’t.” — Carly Anastasion

This is the fourth installment of our occasional series profiling mothers raising disabled children. The narrative was crafted from an interview with the mother and told in her words. You can read the previous installments here, here and here.

Carly and Meadow

I grew up in the Midwest, in Michigan.

My childhood was… not good, so I don't know what else to say. Then I moved to the south, to South Carolina. I went to the University of South Carolina, got a Bachelor's degree in Biology. I got married while I was still in college, very young. I even went to post-bac work at Columbia College in South Carolina and got my teaching certificate.

I became a certified high school biology teacher and I did that for four years. But I was injured on the job, chaperoning a field trip. It was one of those team-building trips where we took the kids up to a camp. I tripped on the hike and dislocated my jaw. I already had really bad issues with my joints and had to have TMJ surgery before that. I had to fight with the school district for three years to get surgery (after the accident). I had to start taking really strong pain killers. I tried to teach, but I was in so much pain and so stressed out, I basically had a nervous breakdown. I couldn't do it anymore.

This was way before the opioid epidemic was a thing, 1994. I was on 'em for a long time, but I took them as directed. The point was that they messed with my head so much that I couldn't teach. I couldn't think straight. I was hospitalized at that point, being on the pain meds that I was on really contributed to my depression. I think a lot of it was exacerbated by the pain meds. I resigned in 2003, divorced my husband in 2009. I didn't work that whole time, I tried to get (social security) disability, couldn't get it. In 2007 or 2006, I finally received a settlement (from the district).

That was the money I used to leave my husband. I moved out to California. Didn't do much there but spend all my money; I was just not myself.

So I moved back home with my mom. Started seeing this guy and got pregnant in 2011. This is my first pregnancy, first child. Her father and I were not married and I had no intention of marrying him because he was not a good person.

It was a horrible pregnancy. Because of my age (38), I had to have ultrasounds every four weeks. They said there was a 12 percent chance she could have genetic defects. There was no question: I was not going to terminate the pregnancy because of that.

Meadow was born and it was very apparent right away that something was wrong. To start with, there was some facial dysmorphism. She just – I mean, she's beautiful, but there were just some traits – wide eyes, body hair.

She was in the NICU with breathing trouble and vomiting. After a few days of vomiting, she stopped suckling all together. So they gave her an NG tube (a nasogastric tube through the nose to the stomach). At 2 ½ weeks, she got a g-tube placed (a surgically implanted port for long-term feeding directly to the stomach). I had no idea what those were at the time.

After one month in the NICU, she came home. She didn't reach her milestones. She did finally start sucking on the bottle once the vomiting stopped, but GI (gastrointestinal) issues plagued her first years. This whole time, we had no diagnosis. At age 4, they finally gave her the diagnosis of cerebral palsy. During all these years, she's being tested for all these various genetic disorders. Nothing ever came up. Finally at age—I think 6, no 7—she just turned 7, they finally did a whole exome sequence. It's an ASXL3 mutation and the syndrome is called Bainbridge-Ropers syndrome. We got that diagnosis in the summer of 2018.

Really the only thing that changed for us was that it gave me a support group. And that gave me knowledge that had been gained by other parents. The syndrome was only discovered in 2013. The first patient — Della — her parents started a research foundation. It's an ultra-rare syndrome. None of her doctors had ever even heard of it. The genetics place had never even heard of it. All across the world, there's only very few of us—very few of *them*. I joined a group and that was huge for me. We tried to join some CP (cerebral palsy) groups and I just didn't feel like I belonged. We're a pretty tight-knit group. It's just really nice to have that.

After many years of being very ill, and in and out of the hospital, since we moved to Oregon, she's been thriving. She's been absolutely thriving.

I came out here because of my partner. He was moving to Portland for his job. We weren't married, just dating, but I vetted Portland and I vetted the health care system here. Quite frankly, her health care back in Columbia (South Carolina) was atrocious. When I read about OHSU Doernbecher (Children's Hospital), I was really impressed. I had to vet the social programs as well. I just decided that for the sake of my daughter's health, being in Portland was better than being in South Carolina. So I moved here for her, basically. And it worked. The doctors at OHSU are so much more on top of things.

We moved out in August 2019—she was on oxygen at the time. I flew with her by myself. It was very difficult. We had to set up everything ahead of time—getting through security.

She loved it though.

In early December 2019, her sats (oxygen saturation levels in the blood) started dropping and she was admitted to Doernbecher. My boyfriend was having serious mental health issues at the time, too. He had a six-figure income, but not really good credit so when we got here we had corporate housing for 30 days and after that we had nowhere to go. We couldn't get a lease.

I was a stay-at-home-mom and these places wanted me to fill out an application, too, but I had no income. So we stayed at AirBNBs and that was eating up all of our money. We had to move every two weeks. It was a nightmare. Then we were in hotel rooms here and there.

He became suicidal. Tried to jump off the Morrison bridge. I had to get some help. OHSU Doernbecher social workers, they encouraged me to reach out to CPS (Child Protective Services) and do a self-call. That's literally what I had to do. I had to do that for my daughter. So I did that.

Basically, we were considered homeless. And here he is making six figures. It's just really ridiculous. It's absurd. While he was in the hospital, CPS said: 'It's not a crime to be homeless here, we'll get you into shelter.' And what they also did was they placed Meadow into the (Providence) Child Center (a long-term care facility). And because it was a CPS placement, she was able to stay longer. She was only supposed to stay for a couple months, so we could get housing and we could get him stabilized on meds. We got out of the shelter really quick, but then I couldn't go visit her because of COVID.

I got to see her one time in like six months. It was just awful. But the decision was made to keep her there once COVID hit. We felt it was safe. When I say "we," I mean myself and the people at Providence and CPS.

We spent six months in the motel. I'm doing all this stuff, cuz he's working. We managed to find a place for rent by owner that wasn't so strict on the rental application.

I was very grateful for that. Meadow came home in January 2021. There were some problems while she was in there with things they were neglecting. I don't want to get into that. I don't want it to be part of the story but what I'm trying to get at is institutional care is not good. It can be good but it's not like home.

Four months after she came home my partner assaulted me. He strangled me. So he had to go. He got arrested, went to jail. So he left, just left. Went back to South Carolina.

I found out after he left that he wasn't paying the rent for six months. I didn't think he would lie to me like that. Because I would ask every month: "Did you pay the rent?" "Yeah." "Did you pay the rent?" "Yeah." We got rental assistance from DD (developmental disabilities) services, from the OERAP (Oregon Emergency Rental Assistance Program). The landlady was trying to work with me. If not for her, I don't know where I would be right now.

I found out with the unpaid rent in June that there was a temporary program where parents could be paid as caregivers. (It started in February 2021.) Probably a lot of parents don't know that cuz they don't tell us anything. My case worker couldn't tell me much. I didn't do it at first because I didn't know if it would mess with my Medicaid or food stamps. If I lose my medical insurance, I'm screwed because I have multiple chronic illnesses. I sent a lot of emails to OHA (the Oregon Health Authority) to try to figure this out. A lot of them didn't even know. I finally got the answer I needed from them. That because of the pandemic, no matter what you start earning, you will still qualify for Medicaid. So then I finally signed up to do it.

That money—just like all the parents have been saying—it pulled us out of poverty. I've been able to buy things that I never, in my child's whole life, have been able to buy her.

We'd had a storage unit — he stopped paying that as well. After he left, I found a letter that he had stashed under the rug. It said: "due to nonpayment your items have been auctioned off."

We lost a lot of stuff. I was able to replace furniture, buy a bed for myself, buy her toys. I was able to give her a Christmas tree this year with ornaments. I was able to give her a good Christmas because she LOVES Christmas lights. I could buy extra syringes for her gtube feedings. It's just the little things too. It's not even big things. We bought an A/C for the house so we can be cool in the summer. Clothes, when she needed them. Her whole life, I chose to stay poor and in poverty to stay home because I didn't want anyone else taking care of her.

Once this ends and there's no caregiver pay, I have no caregiver. I can stay with my child, lose my apartment and go into a shelter with her. Or, put her in foster care. What they call foster care here: group homes.

I'm pretty devastated that that's what's going to have to happen. There's nowhere to go. Her father lives with his mom in South Carolina. He's absolutely toxic. He doesn't care about Meadow at all. My mother is extremely verbally abusive towards me. She doesn't believe I should have a child; blames me for her disability. It's so toxic to me that it affects my mental health. I can't stay with her.

Meadow is 10 years old now and not so sick. Before, she was in and out and in and out. I couldn't even tell you how many times she's been in the hospital. So now it's time to stand on my own and not have to rely on anybody. Like family, or a man. If they pay me, I could stay with my child, I could provide the things she needs, get off social services and food stamps and feel like I don't have to rely on the state. I could be self-sufficient. Under this new program, I felt like I could get there, and now I don't.

Meadow's not even in school. I kept her out because she can't wear a mask. The surge didn't die down, not until late February, and then the school said 'OK, we're ready now.' But it took 10 days to even set up the bus route. Then it was four weeks to get a bus. She's been to school a sum total of three days and she got sick already. I can't even send her to school and rely on school to go to work. She's not the type of child who can even go to school full time. She relies on me every day, 24-seven, 365 days a year.

Meadow needs full assistance. Diapers, dressing, tube feedings, tooth brushing, transfers. I have to do all that for her.

Obviously, she's not going to be in foster care forever. But see: there's the problem with that. If she's in foster care, she gets pulled off K-plan (the in-home caregiver program), so I can't even look for a caregiver while she's gone and say: "OK, it's set up, you can come home now."

I know I'm in this situation as a result of my poor life choices. However, I'm trying to right the ship now and this (parent caregiver program) would have been really nice to help me out. I called the caregiver agency yesterday—they still don't have anybody to do this job. My question is: What are these agencies doing to try to attract caregivers to the field and to the business? It just seems like with so many families in need, there could be more of an effort to recruit. It's a field that pays. Although, you get all sorts. I had a lady slap my daughter's hands right in front of me. I said: If you're going to do that right in front of me, what will you do if I'm not here? I let her go.

It feels almost like a hopeless situation. Because I know this has been going on for years. It's been at least 10 years that I've been dealing with it and it's been way longer than that. It just feels like the government doesn't care about our families. People always say to me: "I don't know how you do it." And what I say to them is, "I love my child, just like you love your child. I don't love her any less." And I think caregiving is also one of the hardest jobs on Earth. I feel absolutely trapped. Without this, I can't pay my student loans. The government thinks I'm not disabled "enough" for benefits. I'm disabled. I have chronic pain from fibromyalgia. It's extra hard for me. I have anxiety and depression. I'll tell you, there's been a couple times where I've almost had another nervous breakdown. I haven't though. Those couple times before when I called CPS was when I felt like I just couldn't go anymore, do anymore, taking people's crap, fighting.

I had to call the crisis line a few weeks ago. My therapist has been out of town for a few months. And then I see the letter saying that paid parent caregiving is going to end soon. I had a meltdown when I saw that letter. I about lost my mind. The next morning at 6 a.m., I called the crisis line. The guy I spoke with, he had worked for the county in wrap-around services so he got Meadow into wrap-around services. Someone to help with finding housing, someone for food, someone for utilities.

I said: You guys are going to have all these people doing all these things. If you would just keep paying me, I wouldn't need any of those people. None. I would be totally self-sufficient.

It just baffles me. It blows my mind.

Medical Motherhood's news round up

Snippets of news and opinion from outlets around the world. Click the links for the full story.

- From Concord Monitor: "Parental push for special education watchdog opposed by child advocate, disability rights group"

> Parents of children with disabilities have raised concerns about New Hampshire's special education system – and the difficulty in navigating the appeals system – for years. This year, the New Hampshire House is considering a bill to create a special watchdog position for special education services to investigate practices and advocate for individual families.
>
> […]"There is no doubt that this is a severe problem, and ABLE NH believes that schools need to transform themselves to places where all students belong in classrooms learning side by side, having inclusive general education classrooms where there's co-teaching and students have para support and there's universal design in the curriculum."
>
> But the creation of a state advocate represents a false solution that would fall short of what is needed statewide, Beaudoin argued.
>
> "It really ends up being a panacea because the bill is not constructed to deal with the systemic issues that our public schools are facing," she said. "And while it might be able to resolve issues for a few families a year, it's not actually going to establish a mechanism to change what's broken."
>
> Still, Senate Bill 381 appears to have strong support from parents – and lawmakers. Sixty-five people signed in to the House committee in support of the bill, with five people opposing it. The bill passed the Senate by unanimous voice vote in March.

> “Instead of lawyering up, schools should be asking why so many people are asking for help,” Metzner said. “Parents do not understand the process and they don’t feel heard.”
>
> The House Education Committee will vote on its recommendation for the bill Wednesday. It will receive a vote in the full House in the coming weeks.

• From Illinois Public Media: ““The forgotten piece of the whole picture”: supporting the siblings of children with disabilities”

> Siblings of special needs children often get less attention, face more parental expectations, and may struggle with their mental health. Being a caregiver or growing up alongside a disabled child often comes with many concerns for the child and their well-being, but also, concerns with managing one’s own social and emotional health.
>
> […] symptoms range widely in children with special needs and can affect everything from physical and motor skills, like cerebral palsy, to learning and processing — such as dyslexia and ADHD, and they can also relate to speech and behavior.
>
> The 21st [a show on Illinois Public Radio] was joined by three guests who have navigated these dynamics to talk about the different aspects of these unique relationships.

• From Insider: “2.7 million disabled Ukrainians, including children, are 'trapped and abandoned' in desperate circumstances as war rages on, warns UN”

> The UN Committee on the Rights of Persons with Disabilities statement said people with disabilities "have limited or no access to emergency information, shelters and safe havens, and many have been separated from their support networks."
>
> It added that "there are ongoing reports that many people with disabilities, including children, are trapped or abandoned in their homes, residential care institutions and orphanages, with no access to life-sustaining medications, oxygen supplies, food, water, sanitation, support for daily living and other basic facilities."

Medical Motherhood is a weekly newsletter giving those raising disabled children the news and information they need to navigate complex systems. Get it delivered to your inbox each Sunday morning or give a gift subscription. Subscriptions are free, with optional tiers of support. Thank you to our paid subscribers!

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Do you have a question about raising disabled kids that no one seems to be able to answer? Ask me and it may become a future issue.
