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Subject:
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EY

Young

Story:

Medicaid is important to myself and my family. I am a personal service care provider to my adult disabled daughter. My job for Acsentria is funded through a Medicaid waiver called the CFI waiver or choices for independence. That is the New Hampshire Medicaid waiver for the elderly and disabled. Disability can happen to anyone at any time in my life and my daughter's life took a turn we didn't expect when at age 11 she developed complex regional pain syndrome. At that time, she was also diagnosed with a genetic connective tissue disorder called Ehlers-Danlos. She also has postural orthostatic tachycardia syndrome, as well as cyclic vomiting, migraines, mass cell activation disorder, and other medical conditions that affect her every day. At age 11, she sprained her ankle and has become permanently disabled in her left leg due to this injury as she has developed CRPS. This is a Neuro inflammatory condition which affects her entire nervous system. She's in constant pain. It's considered the highest pain level of any condition known to medicine. There are times when she's unable to move. She can't tolerate sound or vibration or touch and can only lie in bed in extreme pain and suffering. Her leg swells is modeled and discolored and ice. She becomes unable to move or walk at all or weight bear on her leg at all. It is Cold to touch. It also causes extreme nausea and she is unable to eat when her pain is that bad. When she is bedridden, she can't even move and needs assistance with everything. Complex regional pain syndrome causes extreme nerve pain and sensitivity at all times. At 22 without my care, she would be in a nursing home as she can't do the things she needs to daily to care for herself for her apartment. Home care providers, such as myself or personal service care providers or direct service professionals provide home care for clients such as my daughter. I am unable to work a full-time job outside of the home as her care needs are too high and we travel every two months out of state to treat her rare medical condition. She has weekly doctors, physical therapy, and Even a home nurse with infusions weekly infusion called intravenous immunoglobulin or IVIG. All of these treatments and her medical conditions combined mean that she needs assistance. I'm not independently financially wealthy. I am divorced a single mom and I care for her every day. I work two jobs because I can't make enough as a caregiver to pay for our rent my car payment for a car that can hold her wheelchair, food, all of our bills, etc. So in addition to caretaking, I still have to work a second job. If I could make enough as her caretaker, to not work a second job, her quality of life would be better and I wouldn't have to leave her or give up some for medical treatment so that I could go to work at my second job. However, working as her caretaker does allow me to be home more. I can arrange my hours as we need, I can take her to her doctors and her treatments and get her the care she needs. Medicaid pays for all of this. I didn't expect for her to be disabled. You have hopes and aspirations for your child as she did for her own life. We did not ask for this. However, she is severely ill with progressive and debilitating, chronic pain condition as well as a genetic disorder, which is multi systemic. She needs help for cooking cleaning, grocery shopping, many other daily tasks that a disabled person needs help with. Without Medicaid, none of this would be possible and she would just be suffering alone in bed inhumanely. Before we got the CFI waiver, I had to leave her to work full-time and her quality of life suffered. She was alone in pain without meals until I returned and no care. When she qualified for the CFI waiver, it was life-changing and affected her quality of life. I am able to provide her basic daily care and also pay rent for a very small low income apartment, which is nothing spectacular, but it is safe and our home. It is not even handicap accessible, and as she requires a wheelchair, we can't even afford an apartment that is accessible for her, but we do have a place to live because of my job Although it is hard and we barely get by financially we do and this is all because of the CFI waiver and my job as her caretaker. Even if something happened to me, and my daughter was left alone she would still need a caretaker. So the CFI waiver would provide for a different caretaker to come over to her shopping cook for her clean take out her trash help her with her medication's. They provide everything she needs to live in a clean and safe environment and has the medication's on hand and the doses she needs at all times. Without help from a caretaker, she literally could not survive on her own. A 22 year-old should not be in a nursing home and with the loss of Medicaid those will be closing as well anyway. A disabled 22-year-old person should live at home have a quality of life that they have a right to and a home caregiver to see that their needs are met. Medicaid pays for her medication's, her wheelchair, her personal care assistant. I don't know what she would do without Medicaid. Due to no fault of her own and a genetic condition and a progressive debilitating our own inflammatory condition called Crps. She is unable to work. She cannot pay for insurance. She cannot get herself to the doctors or the treatments that she needs. Home care providers, such as myself, or if I was not here someone else provide a humane and quality existence for disabled adults, living alone. Not everybody has family that can take them in and provide their 24 seven care needs. She needs the help from a personal care assistant or a 22 years old, she would be placed in a nursing home which without Medicaid as I stated, wouldn't even exist anyway so she would be left alone homeless without access to medical care or a caregiver. Medicaid is her lifeline she wishes she didn't have to rely on it and that she could work full-time and provide for herself, but but this is not the case. However, she lives a quality of life that she could not have without the CFI waiver. She is able to attend one college course for semester is currently majoring in visual arts working on her art degree. She should be allowed to have the quality of life as it is she relies on very little financially to pay bills and Medicaid and CFI waiver allows us to live together and for me to provide her personal service care that she needs so that she can have a quality of life as a 22 year-old adult disabled client. If Medicaid funding gets cut in New Hampshire, I will be forced to work a full-time and a part-time job outside of my home instead of just the part-time job. This will leave my daughter without any care alone and suffering. She will spend days unable to cook clean get her medication's get to doctors. Her quality of life will suffer. Her condition requires continuous treatment that I have to travel and take time off work to get her to and without this it will progress and she will be bedridden and pain unable to move. Without Medicaid funding, her quality of life will suffer, her physical condition will suffer, it will progress and she will deteriorate and possibly not survive without all the medical treatments and interventions that I'm able to provide for her and the doctors I can get her to and the assistance of daily living I give her as her personal care Provider. I also have the support of my company and my other coworkers who all work as caregivers to clients as it is a tough but very rewarding job. However, caregivers need support as well and being able to be paid for this position and have a company that supports me as well is vital to both my mental health as well as my client. The support receive allows us to live the best life we can and provide Emma with the best treatments and daily care so she has the best quality of life that she can while suffering from these terrible conditions.

Sent from my iPhone

