

Hello, my name is Cari Pagan, mother of 10 year old Nina. Nina was born with Lennox Gastaut Syndrome, refractory epilepsy, non verbal, autism, PICA and intellectual disability. Nina regularly sees a GI specialist, neurologist, developmental pediatrician, speech therapists, behavioral therapists and occupational therapists. Nina doesn't understand much of the world around her. She doesn't know what is safe and what is not. She needs help eating, bathing, dressing. She is making progress with toilet training but it takes A LOT of practice, repetition & help for her to learn skills. She will require substantial support her entire life. Our primary focus in life is caring for her and increasing her quality of life and skills for independence. It's takes 110% of our time and effort. Nina's Dad and I both work in the medical field and have to miss work regularly when Nina has a major medical or behavior issue that no one else is willing to or capable of handling. My husband easily loses 1/3 of his annual income from having to call in to work under FMLA. Nina is aggressive to herself and others when in pain, distressed or frustrated. She has almost no ability to communicate her needs and wants. We are working toward her learning to use an iPad to help her communicate but she is not there yet. She is getting bigger and now her Dad is often the only person who can physically manage and keep her safe when she tries to climb, run away or get into unsafe situations. Nina requires many special safety adaptations and equipment to keep her and those around her safe. A special car seat, locks for all appliances & cupboards, alarms and specialized locks for doors, video monitors to detect seizures and toileting supplies. She has broken doors, windows and numerous household items when agitated. We're currently saving for specialized fencing for our backyard as she's scaled and climbed over our fence and run into the street when one of us has had to run inside even for only a minute or two.

When Nina is sick, constipated or otherwise distressed she is calmed by car rides. It's often the only way to stop her incessant head banging and help her regulate. There have been days when we drive 6 hrs or more as well as hours throughout the middle of the night. It is expensive and exhausting.

Both my mother and mother-in-law have historically helped us care for Nina but as she gets bigger and stronger and they get older and less capable it's becoming impractical and unsafe. We are signed up with 4 agencies looking for caregivers and have had 3 candidates. One who quit after seeing the high level of care Nina required and two others that had mental health/addictions issues and were unstable. Nina qualifies for 391 hours a month of caregiving but we are lucky to use 40 with the one reliable, competent and professional caregiver we have. There is a crisis level shortage of caregivers for this high need vulnerable population. Nina's father became a DSP for Nina in 2021 and it has made a world of difference for our family. Prior to this we would rack up credit card debt trying to pay the expense of Nina's specific foods, therapies, sensory needs and safety modifications in our home with continual lost wages from missing work to care for her.

It's extremely difficult to find a competent and trustworthy person to bring into your home who is a good fit with your child. Now with the national employee shortage it is impossible. Allowing parents to be paid care givers is a life changing support for child and family. For many parents it will be the saving grace that allows them to keep their child safely in their home rather than considering alternative living arrangements which can be emotionally damaging to the child, parent (s) and more costly for the state. We like many other parents have had less hospital visits since being able to be a paid care giver and home to more closely manage our child's medical needs.

Please help our children to receive the support that has been deemed necessary for our their health and stability but is unable to be provided without parents being allowed as paid caregivers. It is vital to our family surviving and our children progressing.

It is my request that advocates and leadership in Oregon stand up for our children and support our families. You truly can make a difference in the lives of disabled children and their families who are already giving beyond what they have and can for their child.

Please consider what a difference you can make for families who live a life with so much struggle and hardship.

Thank you,
Cari & Dan Pagan
Nina's Mom & Dad

Sent from my iPhone