

Hello, my name is Debbie Gilbert. I am from Mansfield, in Tioga County. I'm a mother of 6 children, 2 of which are children with multiple disabilities. They are Ronnie, 17 and Jason, 13. They use a wheelchair and neither can speak. They are in diapers. Their food has to be puréed for every meal. There is nothing that they can do to care for themselves or communicate their needs. They need total care for everything.

About 4 years ago, I was diagnosed with moderate to severe Chronic Obstructive Pulmonary Disease (COPD). Prior to that, I was working and had 2 Certified Nurses Aids that came in and cared for the boys while I worked. The boys had been on the MR Waiver Waiting List for about a year. After I was diagnosed with COPD, they were moved up on the Waiting List but I was already experiencing problems at home caring for the boys. I was no longer employed so I lost the help of the CNA's that had been coming into my home. At that time, my boys were both attending Warren L. Miller Elementary School in the Mansfield School District. Doris Sargent, who was the principal at the time, realized that I was having problems and called a meeting between the school and the county to try to get me help. At the first meeting the county said they could offer me nothing as far as getting help for the boys for in home care. So the school asked for another meeting in two weeks to see if they could come up with any new ideas. The second meeting netted the same results as the first meeting. The county said there was nothing they could do to help me. I became increasingly frustrated and very depressed because I had never asked for anything from the county and when I finally felt I needed some help, it seemed like there was no help available for us.

My oldest daughter, Kelly, was being cyber schooled so she could stay home to help care for the boys. She was missing out on a lot because she was needed to help care for her brothers. I started doing research on my own and finally located a place in Scranton called St. Josephs that was willing to take the boys into their residential facility. It was very hard for us to place them there; I did not want to have them out of our house. With the diagnosis of COPD and my mental health concerns from all the stress, I felt this was the only option for both me and my boys.

They were at St. Josephs for about a year. We visited frequently but Scranton is about 2 ½ hours away from Mansfield. I felt the care they received was good but I didn't like the fact that it was an institutional type environment. Every time we left to go home from our visit, everyone would be crying. During the year they were there, they were injured on three separate occasions. After the third incident, I removed them from the facility because I was concerned for their safety. In that year, administrators from St Josephs told me that nobody from Tioga County had ever once visited to check on them, even after the injuries occurred.

So at that point, Ronnie & Jason got back on the MR Waiver Waiting List. Kelly resumed helping to care for the boys until last year, when she moved to a place of her own. Now, my other daughter, Casey, who is 15, has taken over with the caring for her brothers. Initially, when Kelly moved out, I enrolled Casey in Cyber School but it wasn't working for her so she has enrolled back into public school. But for example, today she is here with me because it's impossible for me to bring 2 children with multiple disabilities that are confined to a wheelchair, anywhere by myself.

The boys case manager has been changed for the 3rd time in 4 years. I have given up hope that I will ever get help from the county. It doesn't make sense that while Ronnie & Jason are on the Waiting List, I'm obligated to open my home to multiple case managers for monthly visits when I'm receiving no help. However, when the boys were in St. Josephs in Scranton, they weren't visited once in a year. Everyone tells me that I need to be on the Waiting List, however after I've waited this long, it seems pointless. I feel it's been unfair to both my daughters, that they couldn't be normal teenage girls, due to them having to be caregivers for their brothers. But if it weren't for them, I don't know what I would do. I am unable to lift Ronnie anymore, so simple day to day tasks like bathing him, cannot be done by me alone. Luckily, I have Casey to help me but a 15 year old girl shouldn't have to bathe her 17 & 13 year old brothers.

The boy's father, my partner, does not help with the care. I have no extended family; it's my children and me. Things will only be getting worse from this point.

Casey will be graduating soon and moving on with her life and the boys will only be getting bigger and less manageable for me. I feel at this point, that we as a family are only existing, not living. I want the boys to be in their home with their family where they should be, but for that to be possible, I need help.

Signed,

Debbie Gilbert