

My name is Sherrie Petty. My six year old son, Maguire, is autistic, I work for Eagle Mount of Helena, a non-profit organization that provides recreational activities for persons with disabilities.

A few years back, before I was aware of Maguire's disability, I provided respite care for a 70 year old man. Alma didn't speak; he could not express himself in any way. For the three days he spent at my house, Alma sat on my couch and rocked and twirled his shoe laces. The only time Alma left my couch was when I took him to the bathroom, bathed him, took him to the table and fed him, or took him to his room to sleep. I wondered often what was going on in this man's mind. I didn't think that he understood much about what was going on around him. But then, when I was least expecting it, he would look at me with these piercing blue eyes of his, and I was reminded of the soul trapped in Alma's body, just wanting to be released.

Not long after meeting Alma for the first time, we started to learn the extent of the learning delays that my son, Maguire, had. The few words that he had learned gradually disappeared. Desperately trying to find answers, we'd had several experts examine him by the time he was 20 months old. The day the reality sunk in that my son was going to be disabled, I looked at him and didn't recognize him anymore. The boy upon whom I had placed all my hopes for the future was gone, and I wondered in my bewilderment who this boy was before me. Ashamed at the thought, I tried to believe our situation was different from those of the parents of the *other* children in the pre-school group we were attending. But after five years of struggling to understand what was going on with my son, the truth was plain and undeniable. My son is autistic. We were not going to find the miracle that was going to cure him, we just had to face the truth and move on.

Because my son has both language and sensory issues, it has been recommended that he have speech therapy two to three days a week, and ideally occupational therapy one to two days a week. When my father died and left us with a generous inheritance, we spent over \$10,000 out-of-pocket on speech programs one to two days a week. We also spent money for some recommended medical testing, but could not pay for any occupational therapy. Our entire household income at the time was less than \$20,000 a year. I wished I could have save that money for my other children's college education, but I couldn't go without spending it on my son, especially if there was any chance it would help.

Now, the nest egg is gone. My husband's group health insurance has a \$10,000 annual deductible, which means we will likely never have our insurance pay for services for my son. When I went searching for independent insurance which could possibly offer better medical coverage, my son was automatically refused coverage because he is autistic.

If I were to personally pay for three speech visits and one occupational visit a week, I would be paying \$1,600-\$2000 a month, between \$19,200-\$24,000 a year, almost half of our total income. Maguire qualifies for and is on the waiting list for Intensive Services that is offered through the State and Family Outreach, which would include a Medicaid waver for my son. With the State's current budget for disabilities, we don't expect to receive these services anytime in the near future. These services would be a tremendous

blessing to our family. I wouldn't be concerned about how we were going to cover Maguire's medical and dental expenses or how he could receive the recommended therapies. We could get help in hiring trained aides to help him continue to progress where we are not able to be with him.

When I talk to parents with disabled children, I am astonished by the reasons insurance companies, schools and other services use to deny services to people with disabilities. One reason is that they if they don't quickly see improvement, benefits are not achieved. Services then meet their demise through the age-old process of cost/benefit analysis. I am here to testify that improvement does occur in children like Maguire. It is often agonizingly slow in coming, but it does come! Unfortunately, each set back, including loss of services, delays or even eliminates the progress.

But is that a reason to stop fighting for the souls that are trapped in bodies unlike ours? I quote from a song written by Rachel de Azevedo Coleman that she wrote about her own child with CP, "you'll shine, you'll shine, in your own time." We can't give up on these kids because they don't follow our time table. We have to stick with them, acknowledging each tiny step of progress they make, and give them time to find their way.

I was reminded of this when I saw my Maguire perform in his Christmas program this last month. When they stood him up with all of the other first graders to sing, I thought, "this isn't going to be good, he is going to lay down on stage as everyone sings around him." But he didn't. As I wept silently alone, I watched him stand proudly with the other kids and do many of the actions to the songs with his fellow students, something I would have never expected of him. He proved to me that day that he is capable of so much more, if we just keep working to help him meet his potential.

And what does my narrative have to do with Alma? Alma grew up in a day without early intervention, without the knowledge that we have today of what can happen if we work with our disabled community, instead of letting them sit in a corner and rock all day. The battle we have before us is to not let the physical and mental struggles of these people prevail. If we continue to help them by understanding and meeting them in their world, they will come to want to be in ours. We can't stop fighting or let these souls become forever entombed in the bodies that are failing them. With money and resources, we can give them a better life. That is our duty, as fellow souls of this human race.