

To the powers that be!

I wanted to write to you and give you a personal insight into how the funding from I/DD program services, in particular the K Plan, have impacted our family. My daughter was born after a normal pregnancy and delivery in 2002. We were thrilled to welcome this sweet girl into the world and had every expectation that life would go forward "as normal" in raising this child. About 6 months later, our daughter began having seizures and she has continued to have daily seizures ever since. These seizures are documented as marks that fill pages and pages of tracking in our journey to find her some treatment or relief from her seizure disorder. I can honestly say we have covered the gamut of just about every treatment that exists out there and continue to explore the varied services and treatments that exist in helping her to decrease or stop her seizure activity. To say the least, this is very time consuming.

Both myself and my daughter's father work full time. We also parent our 14 year old son who has his own array of needs and activities. Our immediate families live in different states so needless to say, supports are a valued commodity to us. And not just any support but healthy, educated, and trained support to handle our daughter's seizure activity and even more importantly handle the behavioral and volatile emotions that come with seizure disorders. A snap shot of these behaviors include intense self harming and harming of others. The after math of these behaviors involve holes in the walls, broken chairs and other household items, bite marks on arms / legs, concussions, bloody noses, running out into traffic, opening car doors in the middle of the highway, pulling hair, yelling and screaming. You get the picture. The stress of these behaviors involves parents (i.e. me) crying, feelings of overwhelm, intense anxiety and a feeling of helplessness. There were many times that hospitalization or treatment facilities were considered but thanks to our own training and the supports of the I/DD services we have been able to keep our daughter where she belongs which is at home.

The other side of this picture involves the most courageous girl who despite daily seizure activity and emotional melt downs continues to go to school every day and manage through the daily activities despite her highly sensitive nature and reactivity. She shows true remorse and sadness after she explodes which we all know is due to the activation of her fight / flight nervous system reaction. She continues to come back every day and work hard in her class to develop basic social and life skills. When her body is calm and her brain is functioning more typical, she is funny, caring, concerned and very loving.

This is the back story. But what I really want to share with you is about the services and supports that have literally pulled us through and saved thousands of dollars in hospitalization fees not only for our daughter but potentially for us as well as we were beginning to lose our own mental and physical health well-being in this journey.

This unexpected turn in our lives has thrown us into the world of parenting a differently abled child. We were not prepared for this adventure. We continue to walk along this path with new insights and experiential training. I can clearly say that we would not be functioning as well as we are now without the supports of the K plan and I/DD services. These services provide us with community supports and resources that connect us with other parents who are struggling with similar issues. This connection

with others help us to feel supported and not so alone. Our case manager provides us not only with resources but she is an advocate who we can trust to know our family's unique story and the needs that accompany our particular adventure. The biggest of all these supports is the caregivers that give us respite so that we can take a break, get some exercise, re group, plan, organize, reflect, schedule appointments, connect with "normal" life, eat slowly, look at the sky, drive without worry, read a book, take the time to talk with people and look at them in the eye, make a phone call, go to therapy, and the list goes on. It is the ability to do these "normal" activities that pull us back from our own mental / physical health collapse.

Due to the age of my daughter we have not yet reached the other valued services that will help support her transition towards self sufficiency. However, the importance of these services is constantly in my mind as we begin to plan for the future. The I/DD services that will help us to create a safe living and work environment for her will be essential. If her seizures do not stop then continued services with caregivers will be essential. Affordable health care is a priority as the impact of her seizure activity is unpredictable and unknown.

I recognize that the financial landscape is changing and programs are being combed to determine whether or not there is a need for cuts or funding. However, the funding needed to continue I/DD supports are essential. I write this letter not only for our family but for all the other families who may not get the time to send their words of experience. To parent a differently abled child is an experience that no one can truly get until you have been there. The normal things we take for granted (i.e. driving in a car) become a focus for problem solving when a child's needs are greater than the typically functioning child. This consumes a great deal of energy for parents who are tasked with not only just caring for the special needs of their child but who are put in roles of supporter, advocate, researcher, cheerleader, creative director, social manager, protector, and teacher for the community who have little experience with differently abled children.

I am hopeful that your experience and understanding of this beautiful population of people will impact your consideration and decisions about future budgeting for these services. Thank you for your work and service in these matters.

Sincerely,

Holly Lohmann
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