GARRETT HEURTEVANT

Shared with House Appropriations Committee on April 9, 2013

My name is Kristi Heurtevant and I am here today to share my family's story with you and to ask for your support in funding an additional 200 New Opportunities Waiver slots.

My husband, Marc, and I live in Sulphur, LA, and are the parents of two children -- Vivian, age 8, and Garrett, age 7. Garrett has autism and sensory integration disorder. He is non-verbal and also walks on his tip toes making mobility difficult. He needs help with all of his daily activities and has no sense of danger, requiring constant care. I am 42 years old and my husband is 49. We had Garrett when we were a little older not knowing that our lives would become so complicated.

Our typical day starts by 3:00am because Garrett doesn't sleep through the night. I change and bathe him, and change his bed linens, then prepare breakfast. Since he doesn't talk, Garrett looks at or points to his food choice; if we get it wrong, he gets aggressive. Unfortunately we have 18 holes in our walls where he has broken through the sheet rock. This can happen at any time.

Some days we are out in the rain or heat at 4:00am to jump on the trampoline to regulate his sensory needs. I get him ready for school but I have to be careful to keep the same routine and watch for his cues. Any deviation will make him upset. If he is still angry on our ride to school, his sister has often become a target for his attack.

Our evenings consist of a lot more of the trampoline. Of course I have to supervise. We watch the same movies over and over and Garrett may get angry if we choose the wrong one. I have to keep a constant eye on our toilet, because Garrett likes to flush everything. We had to buy double-key dead bolts for his security as he will take off any opportunity he gets. During bath time, I have to help him in and out of the tub. This might not sound like much, but he weighs 90 pounds. Chasing around a wet child who does not understand danger or modesty has made our lives interesting. It also pays a toll on me physically. At bedtime we have a routine. He will take me to his room when he is ready. No matter what I am doing, I have to stop. If I don't, it will be impossible to get him to settle down for bed. Hopefully once he is down I can help my daughter with school work and take care of the house. I sleep in the living room to be available when he wakes up. If he has to spend too much time looking for me he tantrums.

Garrett's need of my constant support and supervision prevents me from obtaining a job. A typical parent could hire a sitter or a day care, but with Garrett this is just not possible. With no natural supports, all his care is left up to me.

NOW services would allow me to do things that other parents may take for granted like spending quality time with my daughter or husband and getting more than 3-5 hours of sleep. It would provide Garret with a PCA and offer me some time for respite and taking care of myself. I need to have surgery and I can't as long as I have to physically lift and transport Garrett. I have put this off for the past 6 years.

Despite the challenges of raising a child with special needs, Garrett has taught us that a person should not be identified by a diagnosis. He has shown us that a spontaneous hug can bring an adult to tears. He has taught us to slow down and to experience the joy of every moment and that communication is more than words.

We have been on the NOW waiting list for a little over 5 years and know that we have years more of waiting ahead. We are afraid that this prolonged wait may force us into having to choose between our two children. We might have to send Garrett away if we never got help. Since we are both older parents the possibility of Marc or I having medical problems gives us added fear. If either of us became sick there would be horrible choices that we would have to make.

I’m asking you please to fund the 200 additional NOW slots. Although we won’t get one of these slots, other families who have been waiting longer will be helped, and we would move closer to the top of the waiting list. Thank you.