

HF 1626 WRITTEN TESTIMONY

Establishing permanent increases in reimbursement rates for qualified early intensive development and behavioral intervention providers.

I am the grandmother of a delightful 3 1/2-year-old girl named Lucy. Because I worked in early intervention for 15+ years, have a son with autism, and served on the Autism Society of MN board for many years, I noticed signs of autism in Lucy when she was still a baby. I shared my thoughts with her parents, and we decided to observe her development and seek help when and if needed. We were able to accommodate to meet Lucy's needs until she was almost 2 years old, when her sensory needs and extreme anxiety began to overwhelm her.

Lucy's parents asked her pediatrician for referrals, and she began receiving occupational therapy and counseling. Both the occupational therapist and the child psychologist agreed that Lucy was probably autistic. Over a year later, Lucy has maxed out on the therapy her insurance will allow without an autism diagnosis. During that time, Lucy's parents called multiple places for an autism assessment, most had waiting lists that were already full. The places that took her name for their lists have still not had an opening to schedule her.

Early intervention should be EARLY—we are years from providing help when parents realize that help is needed. Lucy is lucky; because her mom and grandma have experience with accommodations for her autistic uncle, we understand autism. That said, Lucy deserves individualized supports from an autism professional, not recycled ideas that worked for her uncle. Families without our history, knowledge of autism, private insurance, ability to articulate concerns, and tenacity to frequently call to seek openings have an even greater battle. Families are forced to go without evaluation and services, and then must take the first available opening, whether or not the agency is the most personally, culturally or geographically appropriate for that family.

This legislation will provide permanent funding to help providers maintain the capacity to serve children who are currently sitting on waiting lists instead of getting the help promised with the development of Early Intensive Developmental/Behavioral Intervention services.

Please support HF 1626.

Sincerely,

Jean Bender, Lucy's Grandmother
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Saint Paul, MN

Tom and Jessa Williams, Lucy's Parents
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