2/11/2025

Honorable Representative Rob Nosse

Chair, House Committee on Behavioral Health and Health Care
900 Court Street NE, Room 453
Salem, OR 97301

Dear Representative Nosse,

My name is Marisol Levick, and I am the parent of Reed Levick, who has been diagnosed with Down Syndrome, Autism, and Apraxia (difficulty with speech). I am writing to express my strong support for HB 2023, which aims to establish health insurance coverage for applied behavior analysis (ABA) therapy for individuals with intellectual and developmental disabilities, ensuring the same coverage as for autism spectrum disorder diagnoses.

Reed is a 12 yr old boy. He is full of energy and he loves to be with his favorite people, which tends to be the family. We are a family of 5 which includes my husband and Reed's two older siblings who are 18 and 16. Our family is very close, we enjoy doing things together from outdoor walks, to meals, watching sports, playing games and just simple daily life activities. We noticed early on in Reed's life that many of those things, which required a willingness to be in new environments, around people he might not know, or taking on tasks he might not be familiar with caused him great discomfort. I'd call it anxiety. He would often "shut down", which meant sitting or laying down wherever we were: a store, the doctor's office, a public pool, a sibling's sporting event, a restaurant, unable to get up to even leave the place where he was so unhappy. Due to limited speech, he could grunt to show displeasure and eventually learned to readily and heartily shout the word No! to get his point across. When he was small we could scoop him up and make a quick exit but as he got older and bigger, we had to wait him out, which could take hours. You can imagine that these frequent protests made family outings or activities difficult and eventually not worth it. Over time, our motto became "divide and conquer" meaning when we needed or wanted to do things, we selected who would go and who would stay home with Reed. That meant that other than a family walk in the neighborhood, activities outside the home with Reed, with all 5 of us went from few to none and his own experience out in the world became extremely limited. If I were to go into what it was like for him to go to school, and his inability to access learning even though he is very capable of learning and retaining knowledge, this letter would become a book. I can go into that another time. Its suffice to say, his frustration was palatable as was ours.

Over the years we saw doctors who suggested just about everything to help him, which we tried. Maybe there was a physical ailment causing him pain? We had full exam's, blood work-ups, ultrasounds - nothing. Maybe he had poor nutrition? We added supplements, vitamins, expanded his diet - little improvement. Maybe he would benefit from developing more independent skills in physical therapy, occupational therapy, speech therapy? We did those, there were small gains in simple words. Nothing sparked real change in Reed's behaviors and overall development until one doctor explained that many behaviors associated with Down Syndrome were similar to those in Autism, Reed seemed to exhibit many of those and that a diagnosis of Autism would give us access to more therapies and help for him. He was the first doctor to mention the similarities in this way. We were told by others the similarities were very common, but he was the first to say we could access more help if they were enough to have a dual diagnosis. So we were referred for an Autism evaluation and at approximately 9 years old, Reed was diagnosed and we began ABA therapy.

Intensive ABA therapy has been the key so far for unlocking our son's abilities, interest, and engagement. Over time we have seen behavioral change ranging from him being a kid who needed someone to tell him it's time to go to the bathroom, remove his clothes for him, wash his hands and basically do it all for him - to now, initiating when he needs to go more and more often, disrobing and putting himself on the toilet, washing his own hands, basically becoming more capable and independent at the task each day. He has begun to replace "shutting down" and freezing up in a situation with asking for "more time" or "help" with his speech device when he's not sure what to do. He is also showing that he understands numbers, the alphabet, has some basic reading skills and an incredible memory. I feel like he could eventually be ready to do school again and be successful.

Reed is currently receiving an intensive ABA schedule of approx 30 hours per week at the Estuary Center. A speech therapist comes in every other week to work with him on learning to use his speech device and everyone working with him learns how to use it as well. In our case, and due to his Autism diagnosis, this is covered by health insurance. Without that coverage, we certainly could not afford the level of help he's getting and would not see the results we're seeing. In our case, I wish we had access to ABA therapy much sooner, at the age of 3 or 4 when we first noticed his regressing skills and increasing anxiety and behaviors. I try not to think about where he might be with his current skills and development if he hadn't spent 5 years retracting into himself, coping and laying down behaviors that were not helpful to him in the long run, while we didn't know how to help him. I'm grateful for where we are now with the access to ABA therapy that he has and I'm very hopeful for where we are headed with his continued involvement. Our family has high hopes for Reed and all the things he is learning to do every day.

HB 2023 is an essential step in ensuring equitable access to ABA therapy for all individuals with intellectual and developmental disabilities. I urge the committee to vote in favor of HB 2023 to help families like mine receive the support and services they need.

Thank you for your time and service to the state of Oregon.

Sincerely,

Marisol Levick
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