03-19-09 SB09-244 Testimony

Rebecca Betancourt 4651 S. Jason Street Englewood, CO 80110 303/832-2575

- My name is Rebecca Betancourt and I live in Englewood, Colorado. Thank you for the opportunity to testify today on behalf of the Autism Insurance Bill.
- I am the mother of a 4-year old son, Aden, who was diagnosed with high functioning autism when he was 2.
- As first time parents, we didn't understand the behaviors we were seeing in Aden, but our instincts told us something was off, and our observations were corroborated by his teachers at his early learning center.
- I am fortunate to be employer-insured with Kaiser Permanente. When we took our concerns to Aden's pediatrician, he immediately ordered an evaluation. We really credit Kaiser for this.
- But, when we received the diagnosis, we had no idea what we were in for. Aden's medical report said he would benefit most from more than 20 hours of a combination of speech, occupational and behavior therapies a week approximately 240 hours a year. Yet, Kaiser only covers 40 hours a year of speech and occupational therapy combined, and Kaiser does not provide for any behavior interventions.
- So, we were forced to begin cobbling together services for Aden ourselves—not fully guided or monitored by his pediatrician.
- We scrounged up every financial resource available to meet those medical recommendations—drying up savings, borrowing from family, seeking out any kind of community funds. We have spent approximately \$20,000 out of pocket to ensure that Aden receives what he needs to succeed.

- I think anyone could understand that it is simply unacceptable to have to "cobble" together medically necessary treatment out of pocket when you already have insurance.
- How did we do it? Since our funds were limited, we sought out and recruited students interested in working with kids with autism from universities and we hired a therapist to train and monitor the students. This has taken us enormous amounts of time, flexibility, self guidance and commitment to make it work affectively.
- But, after cobbling together two years of intense early intervention, the transformation in Aden has truly been astounding.
- Just only a year ago, when he was three, he was nearly non verbal, unable to withstand or understand natural social interactions with another child.
- Today, he is a socially curious, talkative and expressive little boy.
- As a parent, to know that our son, despite the challenges autism presents, has every opportunity and possibility to be a functioning adult and productive member of society, is priceless.
- We would not be in this positive situation had we not been insured to receive an early evaluation. But, once diagnosed, then coverage for appropriate treatment fell off the map. We wished that our insurance offered not just the evaluation and diagnosis, but ways to fulfill the full spectrum of medical treatments recommended in the diagnosis report.
- Some therapy for high functioning kids like Aden can take place at home with us. Often parents just as much as the kids need specific tools on how to work and communicate with their autistic children.
- So, for example, one way insurance companies can help parents meet some of these medical recommendations is by offering comprehensive educational programs that train the parents and progress is monitored by their doctors.

- This training would be in the same vein as other educational programs I've seen offered by Kaiser, like "learning to live with diabetes," or "managing a life with cancer" or instructional classes for new parents, like "daddy bootcamp." There are booklets published in the pharmacy lobby touting myriad programs offered by insurance companies, but there are none for parents who have children with autism.
- So, while we were fortunate to have the resources available to us to provide Aden with services on top of what our insurance covered, we know that others are not as fortunate.
- I wish Aden's tremendous progress could be the same for every child on the spectrum. But each child is different and has their own needs and progresses at their own pace. And those needs and that progress should be covered and monitored by their doctors.
- It truly is a team effort to help people with autism, and it's about time insurance companies stopped sitting on the sidelines and joined that team.
- I implore you to support SB09-244.

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