

Chair Shields and members of the Committee:

My name is Karen Ploof and I am the mother of a child with autism. My son was diagnosed at age 3; he is now 14. Although information on the internet was far less organized back then, what we did find consistently insisted that we take two actions immediately: the first was to implement a Gluten-Free/Casein-Free diet, the second was to implement an in-home ABA program. We put him on the GFCF diet immediately and began the hunt for an ABA provider to get us started on when would prove to be a confusing, frustrating and expensive program. Nathan was almost 4 by the time we had our in-home program in place. We began to see improvement in social, academic and communication skills almost immediately.

We placed Nathan in a private school that allowed us to integrate ABA practices as well as more traditional therapies like Occupational Therapy, into the classroom and throughout the school. During the seven years he attended, Nathan's education and development activities remained under the direction of our ABA consultant. Tuition and therapy cost our family approximately \$35,000 per year. In 2010, we lost our primary source of income, forcing us to find alternative placement.

Nathan is now enrolled in a Beaverton School District Structured Resource Center classroom, staffed and equipped to work with children on the spectrum. By the time school began, Nathan had been home the entire summer, with no therapy because we could not afford it. We were dealing with daily self-injurious tantrums that left his arms bleeding and his face bruised. I spent months working with Kaiser medical staff to find a way to stop the tantrums. As soon as we could afford it, I began a search for an ABA consultant with experience working with children in their teens, who were exhibiting self-injurious behavior. I was unable to establish a treatment plan until late September, when I met Jennifer. Jennifer and I began the process of identifying Nathan's triggers. In cooperation with school staff and his OT, we observed, documented and analyzed Nathan's routines, looking for a way to avoid the outbursts. While the school staff worked to get Nathan into a daily routine of academics and the OT worked to get Nathan comfortable with his body and his environment, Jennifer worked with Nathan to help him learn to control his emotions. She did this by teaching him to self-identify his feelings and by showing him how he can control his environment. Within two weeks we saw a decrease in tantrums. At this time, Nathan attends school regularly and his tantrums are, on average, once or twice a week, less injurious and shorter in duration. Therapy has taught Nathan to remain calm long enough to allow us to talk him down. He is learning to tell us when he is under stress and needs to take a break or to leave an uncomfortable environment or to go home. He has learned to tolerate sensory overload for longer periods of time because he has begun to understand that he has some control over his environment and continues to build his arsenal of tools to manage the discomfort he experiences every minute of every day. While ABA therapy alone could not achieve the results we've seen over the past months, teaching Nathan that he has the ability to control himself and his environment is crucial to his health and safety. It is also crucial to his ability to participate in other activities, including attending school. It is also crucial to our ability to prepare him to enter adulthood and to achieve even a semblance of independence.

On 5/29/2012 I received a referral for ABA services from Kaiser Permanente. As was standard practice at the time, the referral was denied and I began the process of appeals. I submitted a request for an IRO

on 9/18/2012. The external review was done by Medwork, who denied my appeal on 10/16/2012. A review of the denial showed that the IRO did not comply with the administrative rules governing conduct of external reviews.

- It cited as “evidence” only two documents, neither of which meet Oregon’s standards of evidence as defined in OAR 836-053-1325(4)(a).
- It did not include the qualifications of the reviewer as defined in OAR 836-053-1325(6)(c).

I filed a complaint with the Department of Consumer and Business Services and continued to pay for Nathan’s ABA services. This week I received a response to my complaint. A review of Nathan’s case found that Medwork failed to provide an acceptable IRO. The Department of Consumer and Business Services states that it “will be working with Medwork to assure that they provide complete and thorough reports in the near and long term. Failure to take appropriate corrective action could result in termination of Medwork’s contract with the State of Oregon.” While I commend the department for taking action against Medwork, under current law, neither I nor the State of Oregon has recourse to have Nathan’s case reviewed again by a more reputable IRO provider.

During the period between filing my complaint and receiving a response, Kaiser Permanente made the decision to provide ABA coverage where need is demonstrated. The ABA referral for Nathan was re-submitted and approved. Kaiser began covering Nathan’s ABA therapy in October. We have requested and received two extensions, both approved based on progress reports for the past period and treatment plans for the next period. Nathan’s progress is undeniable. I am immeasurably thankful that I chose to enroll in the Kaiser medical plan and not the alternative insurance carrier’s plan. If I had made that one decision differently, Nathan’s ABA treatment would likely still be in jeopardy, and our family suffering the financial consequences, because his IRO was assigned to an organization that was found to be superficial and sloppy.

ABA therapy is effective in the treatment of autism. Some families have the financial resources to provide it on their own, most do not. The appeal process is a good one, and has proven its value. But in Nathan’s situation it failed because the an organization who pledged to provide a thorough, un-biased review failed. SB416 would give the Insurance Division the option of reassigning a review to a new IRO if the first IRO fails to comply with the law and administrative rules, as happened in my son’s case. Please allow the Insurance Commission to ensure that families who are already fighting a daunting battle, get a fair chance to provide the ABA therapy crucial to their child’s future by passing SB416.

Karen Ploof