

February 7, 2018

Dear Ladies and Gentlemen of the House:

I am writing in support of HB 4104. My daughter Kate was diagnosed with genetic bilateral permanent hearing loss in 2014, at the time she entered kindergarten in Portland Public Schools. She was fitted with hearing aids, where my commercial insurance co-pay required that I pay 80% or \$3,200. I had to pay \$3,200 again when her first set of hearing aids were deliberately broken by an older child on the playground when Kate was in first grade. As she grew, she was fitted with larger ear molds that were not covered by insurance (\$120). The hearing aids were a very difficult adjustment for her, as the school was not prepared for her disability, challenges, and support that she needed. She had an IEP, but the services she needed for support were nearly non-existent. Fifteen minutes a week with a speech pathologist, school psychologist or a hearing specialist in her PPS was not nearly enough. In fact, the school sent her to Pioneer School thinking she had extreme anger and behavioral issues. We both were miserable and she lost the opportunity to learn and grow in kindergarten and first grade because she was in the "learning center" almost every day. She was also bullied and teased because of her hearing aids. I would pick her up from after-care and she would come home in tears. It broke my heart.

Kate needed medical and mental health support, which was expensive. I reached out to Tucker Maxon School for help. They attended our IEP meeting at PPS and explained they "see this behavior in hearing loss/deaf children that struggle in public schools without proper support". Tucker explained that Kate would receive 50 minutes of speech therapy a week, she would be regularly tested by an audiologist, would be fitted with new ear molds as she grew, and would have teachers that specialize in working with children with hearing loss. PPS Special Education was so supportive and agreed to pay for Kate's tuition, which was a first in the 70-year history of the school.

Kate started Tucker Maxon School in second grade. She was so far behind in her academics, and she is still behind in 4th grade. With wonderfully patient teachers, Kate started to blossom. The school offered teachers of the deaf, audiology services, and speech therapy. No longer did we have to chase all over Portland for services that were not covered by insurance but offered at the school. In the beginning, we would have her hearing tested and aids adjusted at OHSU, speech and occupational therapy in North Portland, and a developmental pediatrician and psychologist in Beaverton. All of these appointments were 1-2 times a week late afternoon/early evening. Most of the services were not covered by insurance. Only one provider had 25% of the service covered and I was balance-billed for the remaining 75%. As a single working mother, I paid six to eight thousand dollars out of pocket each year to help my daughter. With these appointments after school/work, most days we didn't get home until 8-8:30 at night. At 5 and 6 years old, Kate was so tired she would fall into bed without supper. We stopped seeing a psychologist because of the weekly \$50 copay.

At the time, I worked for a Medicaid CCO that provided all these benefits to children with hearing loss without cost to the family on OHP. I cannot count the number of times I contemplated quitting my modest job and selling my small house in order to have access to OHP. I grew more and more in debt; I

sold my jewelry, furniture, anything of value to pay off the bills. Sometimes I thought I would marry just to have the second income or better insurance.

We thank Tucker Maxon every day for Kate. I don't know where we would be with the support of Tucker Maxon. During the summer, Kate attends Laurelhurst for YMCA summer camp, and all the old feelings of isolation and insecurity return. The kids remember her hearing aids, and the teasing starts again. She will not wear her hearing aids during the summer as a result. As a single working mom, I depend on day camps that are more affordable than having a nanny or babysitter.

By the time summer is over and she returns to Tucker, she is renewed that she goes to school in a place where she feels safe, supported, nurtured and inclusive. With her services available at the school, we alleviate the traffic and driving in the early evening attending provider visits. I save so much money having these services available that were not covered by insurance that I am able to pay down my debt.

Please reach out to me for further discussion or with any questions.

Sincerely,

Beth Welty

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