

Hello, my name is Annette Lambert, I am here today speaking on behalf of my 14-year-old son Alexander Cooper.

Alex is compassionate, honest, funny, and a wonderful young man who has some outstanding skills, including drawing, telling jokes, and helping others.

He has a strong interest in history and aspires to one day become a historian. Alex also faces many challenges as a result of Fetal Alcohol Spectrum Disorder (FASD)\*\*, which was caused by his birth mother drinking alcohol during her pregnancy.

School has always been a challenging environment for Alex as it is for many children with disabilities.

FASD makes it very difficult for him to sit still, pay attention, ignore extraneous sensory information, process verbal instruction, socialize, critically think, and learn.

Despite these challenges, there have been times during Alex's nine years in school when he has thrived because of teachers who understood his unique abilities and needs and were able to provide the right support, proving that he is able to enjoy school and learn in an enriched environment.

This year we relocated to Jefferson County and Alex began attending a new school. Despite proactively providing the principal at Elton Gregory Middle School, StepUp (transition school), his case manager, and all stakeholders a copy of Alex's IEP and BSP three months prior to school starting; they reported they did not have time to read them and therefore they were not prepared for him entering their program.

This lack of support led to Alex having a major meltdown during his first week of school.

In addition to not being prepared, the school administrators and staff clearly viewed Alex's actions as behavior problems rather than the symptoms of a brain-based disability.

As a result, Alex was expected to "make things right" in the school community and was not allowed to return to class on several occasions until the principal determined what the correct restorative action would be (i.e., working in the garden or with the maintenance person, writing a paper and addressing the entire class.)

These activities are above his skill level, and a simple apology was not allowed.

On another occasion, **Alex was secluded from peers and adults** (adults per his request we were told) for 2 days. The seclusion is considered a skill-building exercise by the principal.

**No child should ever be forced into seclusion while in school.**

After asking and being denied returning to his classroom several times, Alex had another meltdown.

Due to a lack of inclusion and interaction with adults and peers, Alex slept most days while in school. His IEP was not being followed which led to several traumatizing incidents. Culminating in a critical incident where the school involved the Redmond police department and Juvenile Justice. Profoundly demonstrating that the administrator and staff misunderstood Alex's disability and treated him as a behavioral problem that needed to be punished, instead of a child that desperately needed help.

Due to the lack of support and being unable to emotionally navigate this harsh environment, Alex has not been able to attend school since November 17th.

This school district does not have the proper resources for neurodiverse students, especially those requiring fixed schedules and high structure.

All of this has impacted him in such a way that he now shows several symptoms of severe PTSD if school is even mentioned.

In the two and a half months since he has not been able to attend school, he has only left his room for bathroom breaks and two short-planned outings. We are concerned about potential self-harming behavior, and he has been on suicide watch.

This experience has also impacted my husband and I in several other ways.

We are exhausted by the constant need to repeat ourselves while advocating for him. Now that he is no longer in school, we face the added pressure of having to change our work schedules to be home to care for him, and since we are not licensed teachers, we have had to learn how to help him learn and grow in his home placement.

At the beginning of January, the Redmond School District promised us that we would be provided with a in home tutor for Alex. But they have NOT supplied us with a tutor.

This experience has been a huge financial burden for our family as we adjust our employment schedules, buy educational supplies, and pay attorney fees to advocate for Alex. The lawyers' fees alone have been over \$20,000 this year.

**As a parent this is what I believe we need to see from ODE and School Districts statewide:**

- Enriched learning environments for all children with disabilities.
- Annual continued education by school staff on disabilities such as FASD and ways to best support children with neurodiverse learning styles.
- A shift in how educators and administrators think about disabilities – all children with disabilities want to learn – and must be empowered to do so by educators meeting children where they are at and recognizing that learning is not one size fits all.

- School staff and administrators should collaborate with families and their teams on creating a positive learning environment for all children with disabilities. Families are all too often not heard and dismissed.

Thank you for your time.

Annette Lambert

Alexander Cooper's Mother

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\*\*Although underdiagnosed, studies estimate that one in 25 people (4%) in North America have some fetal alcohol effects. To provide some perspective, FASD is more common than Autism, Downs Syndrome and Cerebral Palsy combined (Flannigan, Unsworth, & Harding, 2018). Other studies show that in specific vulnerable subpopulations including children in foster care, involved in the correctional system, special education, specialized clinical settings, and Aboriginal populations, the incidence of FASD is 10-40 times higher than in the general population (Popova, Lange, Shield, Burd, & Rehm, 2019).

#### References

Flannigan, K., Unsworth, K., & Harding, K. (2018). The Prevalence of Fetal Alcohol Spectrum Disorder. CANFASD. Retrieved from <https://canfasd.ca/wp-content/uploads/publications/Prevalence-1-Issue-Paper-FINAL.pdf>

Popova S, Lange S, Shield K, Burd L, & Rehm J. (2019). Prevalence of fetal alcohol spectrum disorder among special subpopulations: a systematic review and meta-analysis. *Addiction*. Jul;114(7):1150-1172. doi: 10.1111/add.14598. Epub 2019 Apr 29. PMID: 30831001; PMCID: PMC6593791.