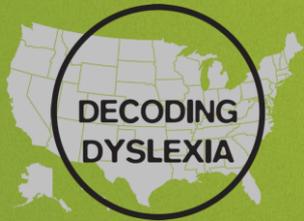


"Family Dyslexia Cost and Support Survey"

The common *thread*



December 15, 2015

Powered by  SurveyMonkey

Background Information

This survey was created for parents and guardians of children with dyslexia.

WHY? We often hear from families from across the country with similar stories. They struggle to secure effective instruction and support for their children with dyslexia in public schools. Often families pay out-of-pocket for private tutoring alongside special education and other services because those services are not meeting the needs of their children. We created this survey to help gain a clearer picture of the costs that families bear in order to meet the educational needs of their children with dyslexia. **All children are entitled to a free and appropriate public education** – including children with dyslexia.

HOW WILL THE DATA BE USED? We will use the data to increase awareness of dyslexia and to illustrate that many families are funding education outside of their local schools in order to ensure that their children learn to read. We may also share the summary data with our policy makers.

DATA COLLECTION and LIMITATIONS. This is an informal national survey created by Decoding Dyslexia Oregon. The survey was distributed to Oregon families from April 13th to July 6, 2015. This Oregon survey was copied to create a national survey for families from all States. The national survey was shared via social media (Facebook) from May 15th to August 3, 2015. The two surveys were combined for this report. The combined data shows the largest majority (19%) of responders were from Oregon. We hypothesize that the Oregon survey received more exposure because, in addition to Facebook, the Oregon survey was shared via email to over 2000 Oregon contacts. These surveys did not capture demographic data with the exception of income. The majority of responders reported above the 50th percentile in average family income. Therefore, families of lower average income are not well represented in this survey. We acknowledge that there may be some duplicates but not enough to change the aggregated summary results. Also, no families from Oregon responded to the national survey. We asked for financial expenses incurred over a five year period from single or multiple children families. In the open-ended responses, some families indicated that their child/children was newly identified with dyslexia and they had not yet incurred many costs. Therefore, in some instances the financial cost reported is lower than expected. In addition, 'average yearly cost' might have been a better measurement. With awareness of these limitations, ***we share it with you.***

947

Total Responses

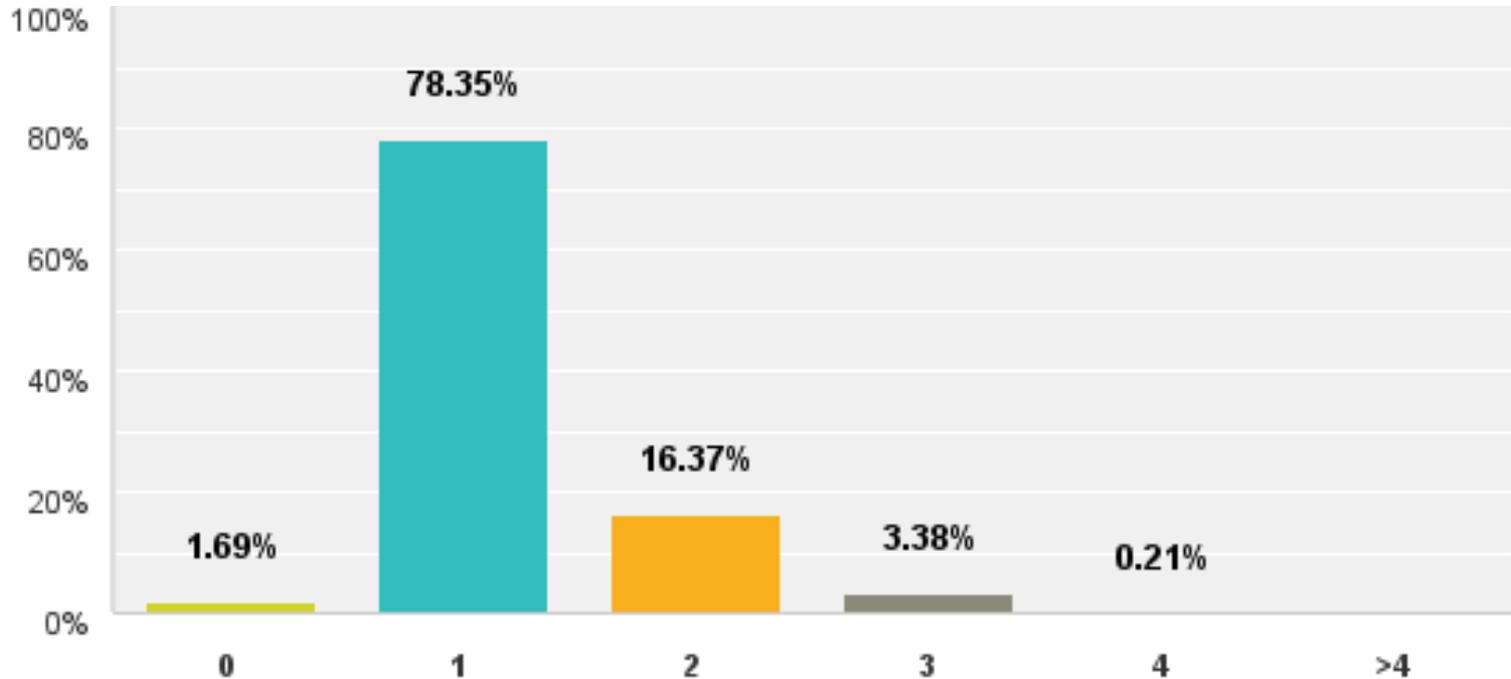
Date Created: April 13, 2015

Date Closed: August 3, 2015

Complete Responses: 813

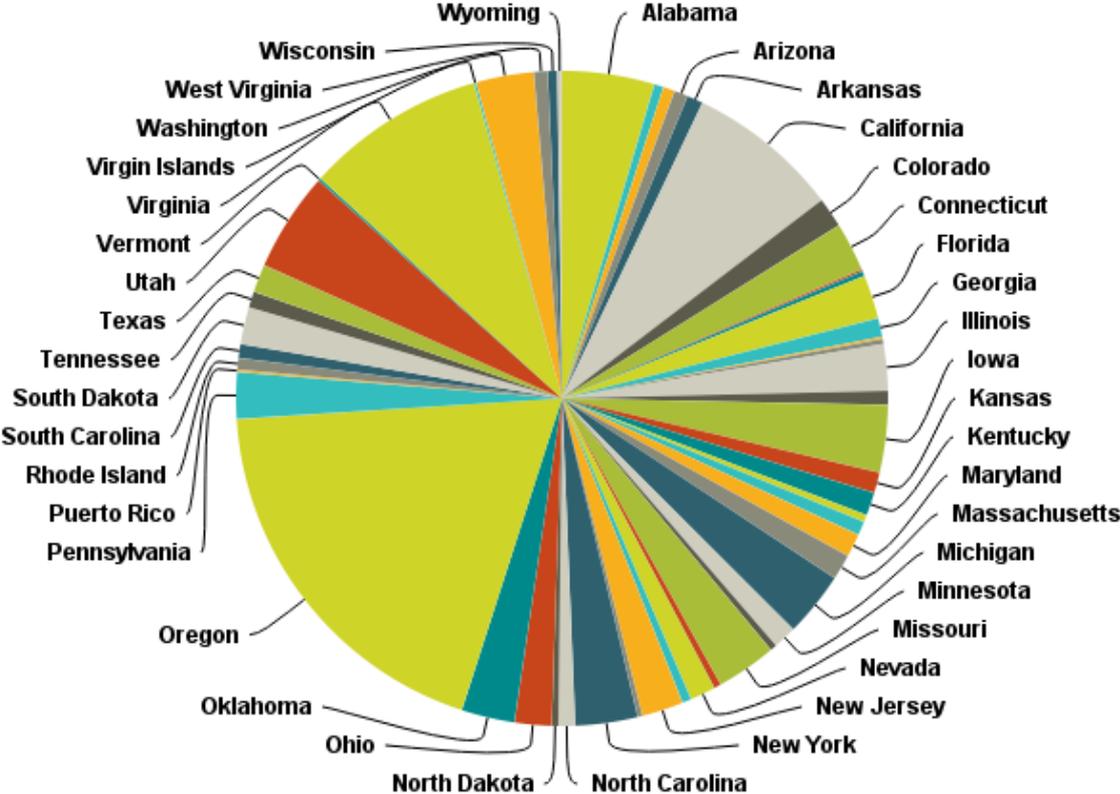
Q1: How many children in your family have been identified WITH DYSLEXIA?

Answered: 947 Skipped: 0



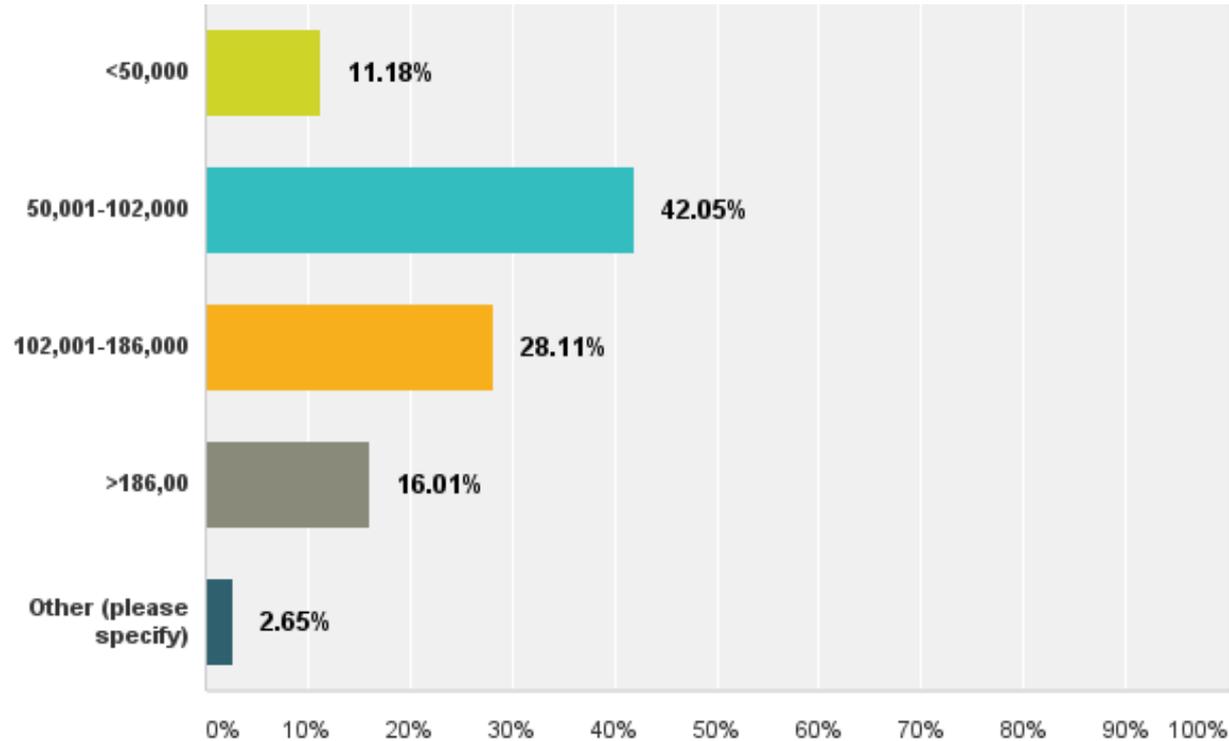
Q2: Where do you live?

Answered: 873 Skipped: 74



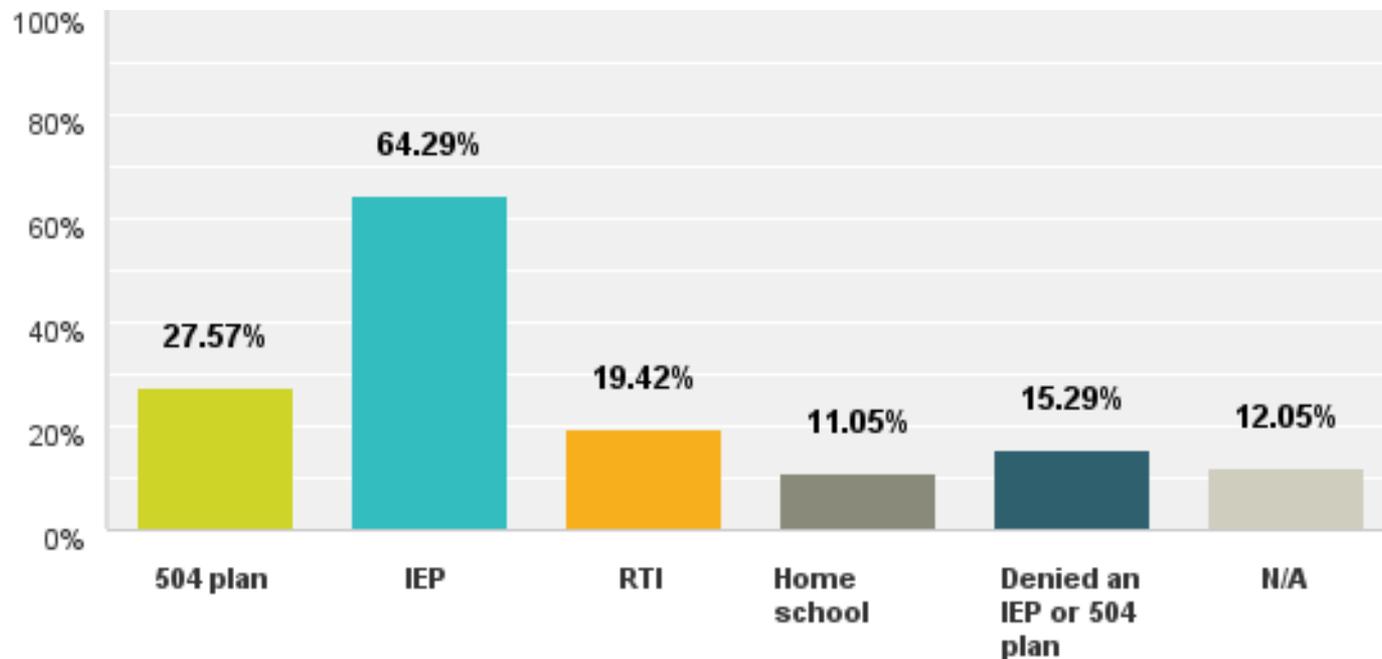
Q3: What is your approximate average household income per year (in dollars)?

Answered: 868 Skipped: 79



Q4: Within the last 5 years, did any of your child/children have an IEP, 504 plan or participate in RTI program or other alternative learning plan?

Answered: 896 Skipped: 51



Q5: Within the last 5 years, did any of your child/children have an IEP, 504 plan or participate in RTI program or other alternative learning plan?

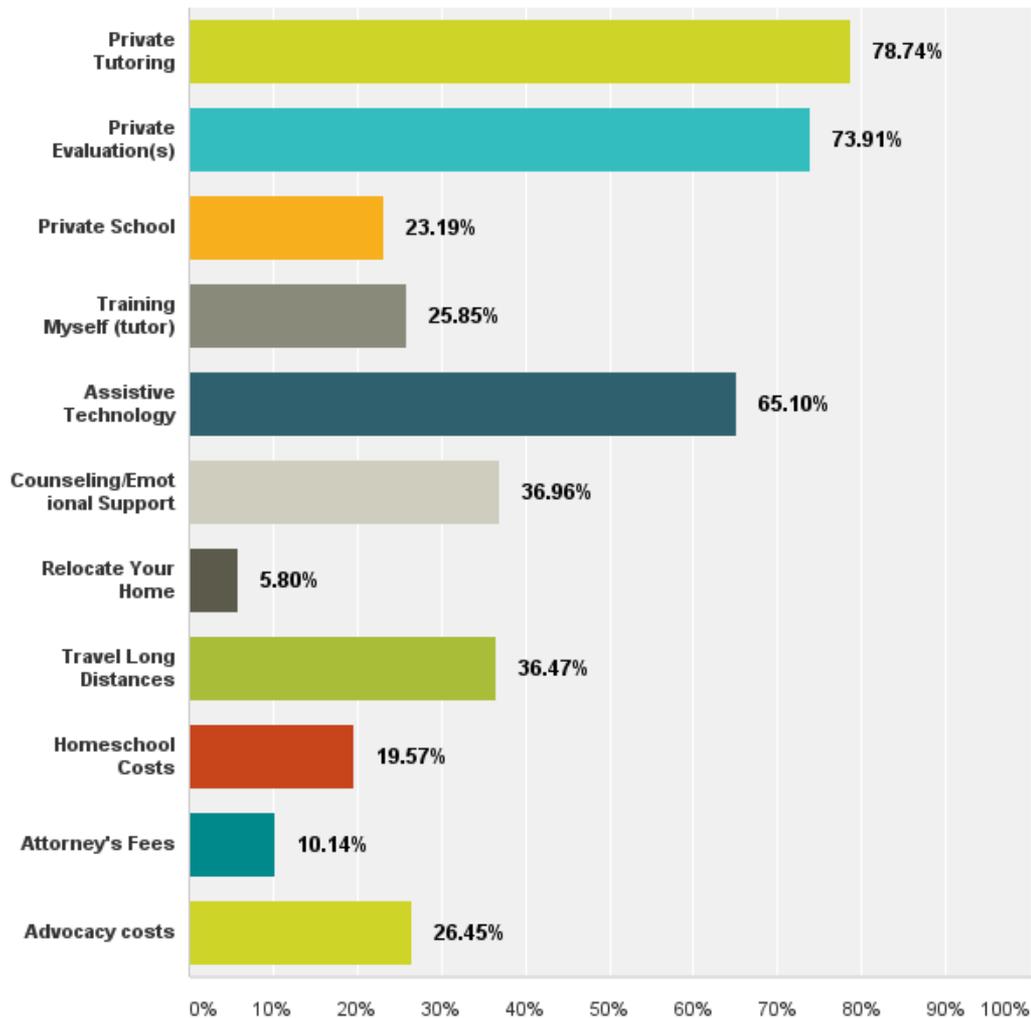
Below are several open-ended responses under “Comments”

State	Comment
Iowa	In process of testing, which we have to pay for because she does not qualify for testing even though there is a family history and she has classic warning signs. The state will only test once she is 3 years behind grade level.
Kentucky	We also pay for private tutoring because the school will not use an Orton-Gillingham approach.
Michigan	Had an IEP but took him off as he was not getting any intervention and it was just for accommodations and extra help. We decided to do a 504 as we are providing him with his intervention outside of school.
Oregon	IEP for Specific Learning Disability was initially denied until I provided an independent assessment.
Virginia	Attended private school when public school couldn't address his needs.

Q5: For the past five years:

Please indicate all ways that you financially supported your child/children with dyslexia.

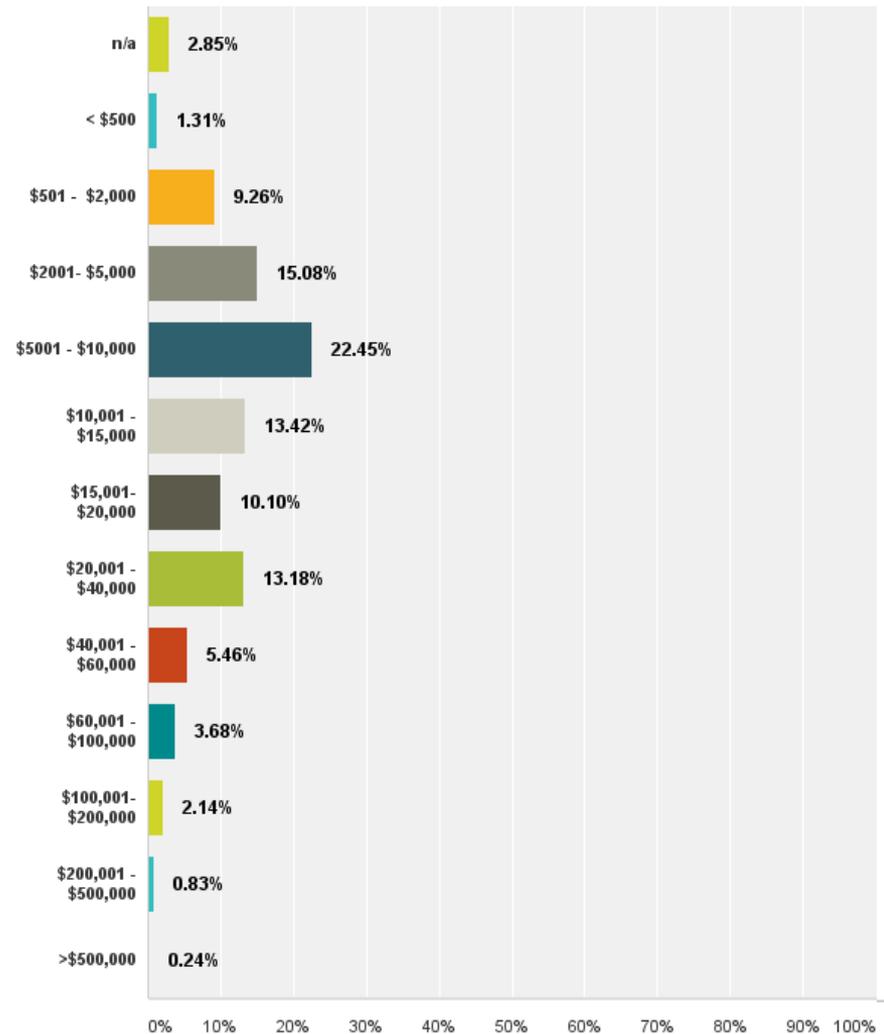
Answered: 828 Skipped: 119



Q6: For the past five years:

Please estimate the **TOTAL** financial contribution your family made to assist your child or children with dyslexia.

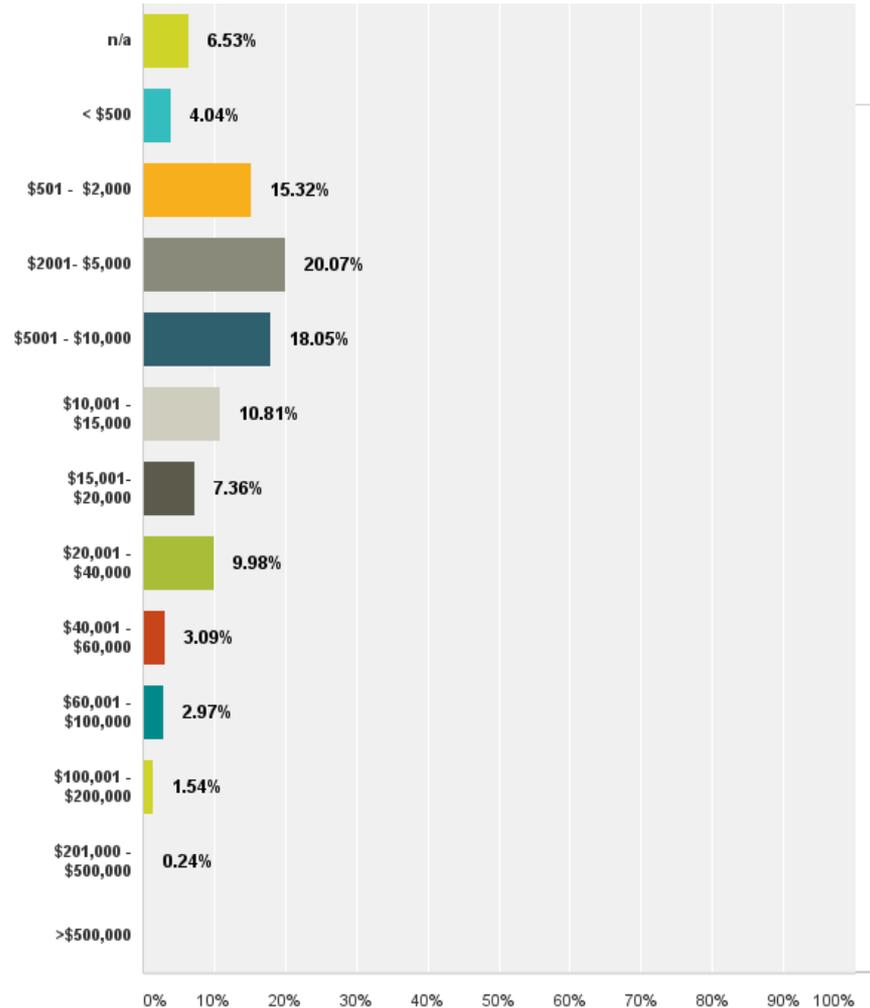
Answered: 842 Skipped: 105



Q7: For the past five years:

Please estimate the financial contribution your family made for INSTRUCTION SERVICES ONLY. (tutoring or private school)

Answered: 842 Skipped: 105



Comments: What is the common thread?

The last question of the survey included a comment field. Below are examples of the additional information families shared.

State	Comment
Alabama	Private dyslexia tutoring has become so expensive that instead of the recommended 2 times a week, we have had to drop to 1 time a week.
Arizona	We have been unable to find a certified tutor in our city.
California	Single mom with no support. I receive help from public assistance and I work. I beg and barrow from friends. I use assistance money to pay for FAPE. Something is very wrong in our country. I am dyslexic. I made the same school that did not teach me to read, teach my children.
California	Wish we could afford specialized tutors or programs, but they are beyond our means.
California	We will have to send him to a private dyslexia school next year which will cost almost 20,000 dollars per year.

Comments: What is the common thread?

State	Comment
Colorado	We received the diagnosis 3 weeks ago--the testing was approx. \$650, he needs tutoring x2/week at \$80/time, so \$160/week.
Colorado	Paying OG tutor three times a week. Cost continues to accumulate.
Georgia	Very concerned as we anticipate \$300 month just for tutoring.
Iowa	Best money we have ever spent and I am just thankful we had it to spend.
Massachusetts	My child attended a private school, funded by the school district.
Michigan	We were on a long waiting list but blessed to be able to have a tutor through the Children's Dyslexic Center. Free tutoring, we just pay for gas and parking.

Comments: What is the common thread?

State	Comment
Nevada	My child was just diagnosed 5 months ago. Spent \$10,000-\$15,000 since then.
New Jersey	We do Wilson tutoring 3 times per week at \$50 per session. The school is going to pay for this starting in Sept.
New York	I have spent nearly \$10,000 on a private tutor for my son. He Skypes with her 3 times per week because there are no local tutors that specialize in teaching dyslexics how to read.
Ohio	No money available to pay for more tutoring, or I would in a heartbeat.
Unknown	We had to stop because we could not afford the cost.

The common *thread*. . .

Sixty-four percent of the families responding to this survey had a child(children) on an IEP. Almost 79% of families seek private tutoring to supplement their school experience.

Families reported the most common ways to support their child(children) with dyslexia were securing private tutors and evaluators and the use of assistive technology.

We found some families have the means to pay out-of-pocket for private instruction. Other families seek training to become tutors themselves. Many families feel fortunate to find creative ways to secure low cost instruction outside the school setting.

More often, the cost families bear were thousands of dollars, especially when families enrolled their student in a private school or relocated the family to find services.

The common thread is the patchwork of diverse ways families are finding and securing appropriate instruction and support for their children with dyslexia in public school.

Discussion . . .

Dyslexia stakeholders and organizations have reported that families often augment their child's education because not only do schools fail to offer evidence-based instruction for their children, but schools are reluctant to reference or use the terms dyslexia, dyscalculia, and dysgraphia in evaluations, eligibility determinations, or in developing the individualized education program (IEP) under the IDEA. This year alone, 20 States proposed or passed laws to improve resources for students with dyslexia in public schools. In response to recent letters of concern from disability organizations, on October 23, 2015 the United States Department of Education's Office of Special Education & Rehabilitative Services issued guidance to states and schools in a "Dear Colleague Letter" clarifying that there is nothing in the IDEA that would prohibit the use of these terms.

Dyslexia is a learning disability that is neurological in origin and known to run in families. Dyslexia makes it difficult for individuals to learn how to read, write and spell. According to the National Institutes of Health, as many as one in five students has dyslexia. However, teacher education programs typically do not provide coursework on dyslexia that would enable teachers to identify dyslexia and use effective strategies to teach these bright and capable students. Students with dyslexia are often misidentified as unintelligent or "lazy" and fall through the cracks. This survey seems to confirm that certain families, with the resources to do so, can change the trajectory for their children by paying for services outside the school system. This is costly for those who *can* afford it. And for those who cannot, you can imagine that there might be an equity issue that no-one is talking about.