

THE DYSLEXIA REVOLUTION

Quarterly Newsletter from The Dyslexia Initiative



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A MESSAGE FROM THE FOUNDERS

Hopefully we are all moving past the crazy weather and into Spring's colorful glory. I mean what a winter that was! I know in my house, and small part of the country where I live, we keep saying things like, I'm sick of this endless cycle of 100 year events happening back to back.

Yet as we move into Spring we also acknowledge that we are at the one year anniversary of this lock down reality. No one knew a year ago that we'd still be here, but here we are. I didn't fathom a year ago what a political firestorm COVID would become. It's been a nightmare reality from balancing children, work, unemployment, virtual or F2F options this past fall, and the overwhelming full stop most parents faced when they realized their children couldn't read, and we aren't just talking about dyslexic children. This time at home has given everyone a major dose of the struggles our children are having in school. Even as the outspoken and aware advocate that I am of all the things my son struggles with, seeing how his written expression was so far behind was a reality that hit me hard and square between the eyes.

It's been an interesting year because parents are demanding more information, more answers, and becoming more aware of the issues facing our children in the educational environment than ever before. While COVID shut us all down, we all faced an awakening about education.

And, after a year, the environment is tangibly shifting as the habit of denial becomes less accepted. It's been a #DyslexiaRevolution in the making, and it is far from over.

-Ashley, Chontae, and Julie



RESEARCH V EVIDENCE, WHAT DOES IT ALL REALLY MEAN?

BY: ASHLEY ROBERTS

A question that comes up a great deal within our community is what is the difference between evidence-based and research-based programs? This is a fair question that deserves a proper answer. Alyssa Ciarlante defines them as:

"Evidence-Based Practices or Evidence-Based Programs refer to individual practices (for example, single lessons or in-class activities) or programs (for example, year-long curricula) that are considered effective based on scientific evidence. To deem a program or practice "evidence-based," researchers will typically study the impact of the resource(s) in a controlled setting, for example, they may study differences in skill growth between students whose educators used the resources and students whose educators did not. If sufficient research suggests that the program or practice is effective, it may be deemed "evidence-based."

Evidence-Informed, also known as Research-Based, Practices are practices which were developed based on the best research available in the field. This means that users can feel confident that the strategies and activities included in the program or practice have a strong scientific basis for their use. **Unlike Evidence-Based Practices or Programs, Research-Based Practices have not been researched in a controlled setting.**

Terms like "evidence-based" or "research-based" are useful indicators of the type of evidence that exists behind programs, practices, or assessments, however, they can only tell us so much about the specific research behind each tool. For situations where more information on a resource's evidence base would be beneficial, it may be helpful to request research summaries or articles from the resource's publisher for further review, but regardless, evidence-based is the preferred method, not researched-based."

That might be clear as mud so let's try this approach from the Child Welfare Information Gateway:

"Evidence-based practices are approaches to prevention or treatment that are validated by some form of documented scientific evidence. This includes findings established through controlled clinical studies, but other methods of establishing evidence are valid as well.

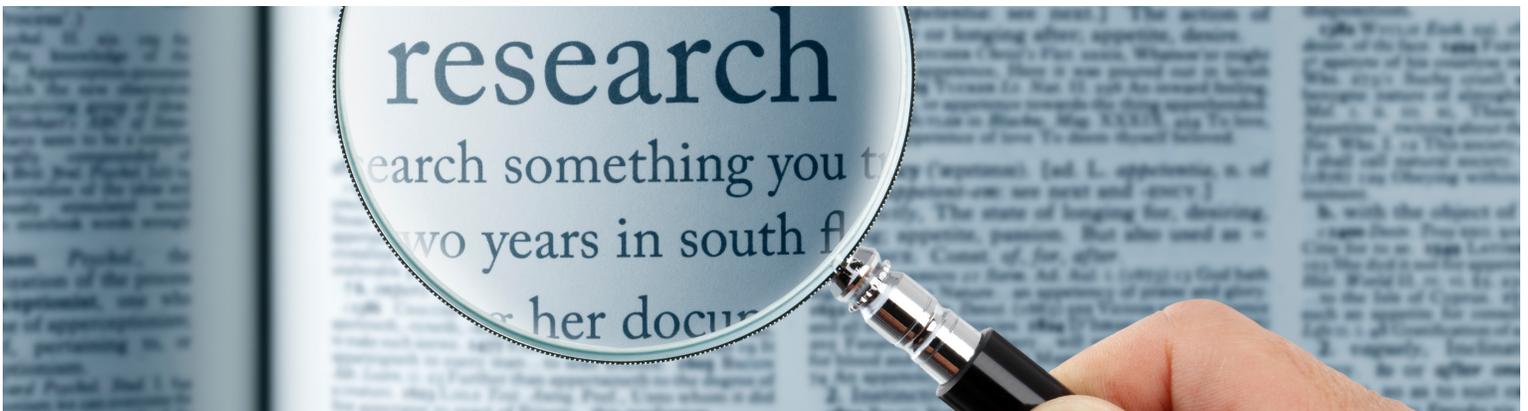
Evidence-based programs use a defined curriculum or set of services that, when implemented with fidelity as a whole, has been validated by some form of scientific evidence. Evidence-based practices and programs may be described as "supported" or "well-supported", depending on the strength of the research design.

Evidence-informed practices use the best available research and practice knowledge to guide program design and implementation. This informed practice allows for innovation while incorporating the lessons learned from the existing research literature. Ideally, evidence-based and evidence-informed programs and practices should be individualized."

And then let's put it through this lens:

- **Science-based** - Parts or components of the program or method are based on Science.
- **Research-based** - Parts or components of the program or method are based on practices demonstrated effective through Research.
- **Evidence-based** - The entire program or method has been demonstrated through Research to be effective.

What this boils down to is that evidence-based is PREFERRED over research-based. Think of it this way, evidence-based means significant studies were performed, with control groups, meeting the criteria of scientific research, and that the results were



repeatable numerous times with minimal variation. Research-based means someone stands on the shoulders of the giants who did the work for the evidence to create something based off of the evidence, but it isn't put through the same rigors. It can be tough and that's a very clear distinction. Research-based programs can be studied until they become evidence-based, but not all are.

Now the challenge is, when being presented with remediation plans for your child, in differentiating between the two, and knowing which one is being used with your child. We at DI are keen advocates in knowing exactly what program(s) schools are using with your child, and while you should ask if it's evidence or research-based, it is also up to you to find that data yourself by calling the publisher. The publisher should be willing to turn over the data, if not, let that be a sign that something is amiss.

Now, in *Overcoming Dyslexia*, Dr. Sally Shaywitz refers to the What Works Clearinghouse for referencing which programs are evidence v research based.

(<https://ies.ed.gov/ncee/wwc/>) "The What Works Clearinghouse is an investment of the Institute of Education Sciences (IES) within the U.S. Department of Education that was established in 2002. The work of the WWC is managed by a team of staff at IES and conducted under a set of contracts held by several leading firms with expertise in education, research methodology, and the dissemination of education research. Follow the links to find more information about the key staff from American Institutes for Research, Mathematica Policy Research, Abt Associates, and Development Services Group, Inc who contribute to the WWC investment."

The issue here is that too many question the validity of WWC. Programs like Fountas and Pinnell and other balanced literacy programs are given high marks, while some well known dyslexia programs are not, if they're even included at all.

So then what is a parent to do?

As stated, get the evidence or research, whichever is available, from the publisher and with an understanding of scientific principles and methodologies, review the evidence with a discerning eye. Ask questions like how many children were in the trials? If it's 5 then the findings can't be very legitimate. If enough children were used to make up a large enough statistical pool then the findings are more valid. This is just an example, but a key one within educational data that must always be at the forefront. Why? Too many papers exist calling programs / data "research-based" when in fact scientific principles and statistical modeling were not followed correctly therefore the data upon which the programs are based is in essence invalid. As you start to look at the data, you will start to see what to look for, i.e. what questions to ask.

But, this brings up an important point that we've had to repeat a few times lately, at DI we do not recommend or back any programs. We are parent advocates, not researchers and we do not possess the expertise we believe is necessary to do so. We defer to the list of approved programs that The International Dyslexia Association has already defined.

References:

"Evidence-Based" vs. "Research-Based": Understanding the Differences, <https://apertureed.com/evidence-based-vs-research-based-understanding-differences/>

Child Welfare Information Gateway, <https://www.childwelfare.gov/topics/management/practice-improvement/evidence/ebp/definitions/>

Evidence Based Assessment, <https://pubmed.ncbi.nlm.nih.gov/17716047/>

ESSA, <https://www2.ed.gov/policy/elsec/leg/essa/guidanceusesinvestment.pdf>

Science-based, Research-based, Evidence-based: What's the difference?, <https://www.dynaread.com/science-based-research-based-evidence-based>



THE FLORIDA BAKER ACT

BY: ASHLEY ROBERTS



Recently I had my eyes opened to a travesty I was unaware of, as I do not reside in a state that has a law equivalent to The Baker Act.

While we will be focusing here on Florida's Baker Act, there are other states with similar statutes. It is important for all parents to know and understand their rights, the laws, and what injustices demand action.

"In Florida, more than 37,000 children are "Baker Acted" each year. That is, in this state, we authorize the involuntary arrest, transport, hold, and psychiatric examination of so many children under the Florida Mental Health Act, known as the Baker Act, that it has become a verb. Even worse, Baker Acting has become a "normal" behavioral management tool for far too many Florida classrooms, schools and residential foster care facilities. Children as young as 5 and 6 are handcuffed and forcibly taken by police to psychiatric hospitals, where they legally can be held for up to 72 business hours in conditions that would harm and traumatize even adults.

Still, schools, residential facilities, and police often decide to subject children to this trauma without first notifying the child's parent or guardian or over their parent's objections, even when doing so isn't necessary for the child's safety. Because of understaffing or the desire to maximize fees, some psychiatric facilities make matters worse by holding overnight and longer than needed these frightened and traumatized children, some of whom they involuntarily sedate."

This reality means that advocates are passionate about not having their children labeled with behavioral issues or "Emotional Disturbance" otherwise known as ED. We've shared some powerful testimonies from advocates of late discussing how the attitude of schools leading with behavior first before looking into what is causing the behavior is so concerning. Please click here for "Behaviors Before Dyslexia" by mother and advocate Lauren Taylor: <https://www.thedyslexiainitiative.org/post/behaviors-before-dyslexia>.

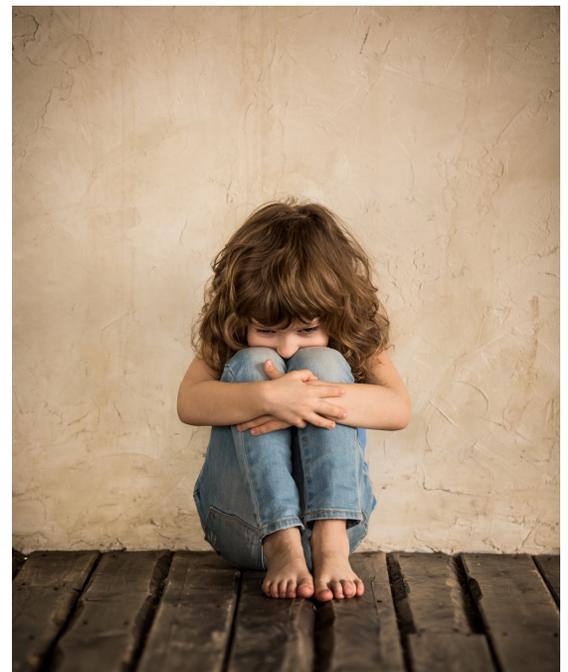
By leading with behaviors in states that have laws like Florida's Baker Act, when the intelligent children have an emotional reaction to their lack of success, what can happen is that the parents lose access to their child while they are locked in a mental facility, against the parent's will, for up to 72 business hours. Now the trauma of undoing educational damage is now multiplied 1000 fold by institutional trauma that will last a life time.

"In each of these instances, the Baker Act is not only an inappropriate intervention, it is a harmful and often illegal one. No child should be Baker Acted for exhibiting a behavior caused by a developmental disability (like autism), because the Florida legislature explicitly excluded such disabilities from the statute's criteria and, more importantly, because developmental and intellectual disabilities are not mental illnesses and, therefore, mental health treatment facilities are not equipped to meet their needs."

"Shawn M was just 10 years old when he faced one of the most terrifying experiences of his young life. To this day, Shawn is still afraid, haunted by the day in 2018 that he was taken from his school by a police officer, caged in the back of a police car, driven away from his distraught father, and held overnight without contact with his family in a psychiatric ward with older children — all because he expressed to a teacher some distress over losing a playground game.

Shawn is just one of tens of thousands of children in Florida on whom the Baker Act has been used at school — even though he did not meet the statutory criteria and his parents strenuously objected — in place of appropriate mental and behavioral health care and interventions in the community.

When he was taken and involuntarily committed, Shawn was a fourth-grade student in an Orange County public school. Shawn, who has autism spectrum disorder (ASD), had been placed in a class for children with ASD, with the goal of transitioning him to a general education classroom over time. Because of his autism, Shawn sometimes reacted strongly to situations that might not have generated the same reaction in other children, but his parents and teachers understood how to de-escalate him in those situations. That all changed one day in early 2018 when he was Baker Acted.



That day, he and his friends were playing a game called the "orange touch," the equivalent of "cooties." Shawn was touched and it triggered a strong reaction. He became upset and said something that a teacher interpreted as meaning he wanted to hurt himself. But there was no reason to think Shawn genuinely and imminently was going to do actual harm to himself. He had no actionable plan for self-harm, engaged in no self-harming behavior, and he calmed down after his initial outburst. However, instead of contacting Shawn's parents or a counselor, the school took the drastic step of contacting the local sheriff's department to take him to a psychiatric facility for involuntary examination and treatment. Even the responding officer wrote in his report that Shawn was "calm and talkative," but he nonetheless continued to Baker Act Shawn based on his layman's diagnosis that Shawn wanted to hurt himself because Shawn allegedly made a reference to jumping off of a nonexistent bridge.

Shawn's dad, Brian, was not contacted until after the school had already taken steps to Baker Act him. When the school finally informed Brian, he raced there as quickly as he could, but it still took him 45 minutes to arrive. To this day, Brian lives with the regret and guilt of being out of Shawn's immediate reach. When he finally made it to campus, he saw the armed and uniformed sheriff's deputy already questioning Shawn in the principal's office. Brian explained to the deputy that Shawn had autism and was not always able to control his emotions, but these kinds of reactions were normal, and he knew how to help Shawn deal with them. He begged the officer to allow him to take his son home, assured them that Shawn wouldn't try to hurt himself, and that he would stop Shawn and care for him if he tried. But the deputy refused, claiming that the law required him to take Shawn to a facility once the school called, regardless of his father's ability to care for him appropriately, regardless of his wishes, and regardless of the fact that his son had a known developmental disability that accounted for his behavior.'

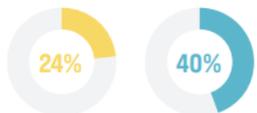
The anecdotes shared with me by fellow advocates of horrific situations in which children have been placed has kept me awake at night. The most disturbing regarded children who were taken to too full facilities and placed in the adult wings of the hospitals where physical abuses then happened to the children at the hands of other dangerous adult patients with diagnosed history of child and sex abuse.

"Involuntary examinations can be initiated by judges, medical professionals, or law enforcement officers. In schools, however, where at least a quarter of the Baker Acts against children happen, they almost always are initiated by law enforcement officers — often with limited and variable training. The standards of evidence and expertise required for each of these actors to initiate a Baker Act differ significantly, and these standards vary in illogical ways"

Additionally, "Unscrupulous facilities can further maximize the number of days they hold a child and, thereby, maximize their revenue, by filing such a petition (the law permits the facility to petition the court to hold the child for more time) to hold the child for longer, then dropping the petition shortly before the hearing is scheduled. This allows such facilities to detain the child beyond the 72-hour window without judicial review. A recent media analysis found that, using this technique, one facility in the Tampa area holds patients of all ages on average 8.8 days, dropping 86 percent of the petitions it has filed before they are heard. Sadly, this traumatizing practice of holding children for days in psychiatric facilities, without medical justification, parental consent, or judicial review, undermines the original intent of the Baker Act itself — to authorize immediate involuntary examinations for individuals who may need emergency psychiatric attention, not to authorize unchecked involuntary institutionalization for individuals who can receive no benefit from such treatment or confinement."

"From the 2001-2002 fiscal year to the 2018- 2019 fiscal year, the percentage of children who were Baker Acted increased 152.6 percent. This explosion in Baker Act use far outstrips Florida's population growth. The rate of involuntary psychiatric examinations of children has more than doubled in the past two decades, from 547 to 1,240 Baker Acts per 100,000 children. Children now make up 18% of all people Baker Acted in the state, with wide variations across counties, from 6.24% in Monroe County to an astonishing 48% in Wakulla County. In the 2018-2019 fiscal year, the Baker Act was used against children 37,882 times — a rate of approximately one time for every 86 children, or 1.2%, of all children age 5 and above. And, at least 30% of those children are involuntarily examined more than once over a five-year period. Additionally, the available data suggests that Baker Act use in schools has increased significantly since the Parkland shooting; though, unfortunately, this data is not consistently available from all schools. The Baker Act is also used disproportionately on Black children; 25% of all children who were Baker Acted were Black in 2016-17 (the last year for which race data was reported statewide), despite Black children comprising only 15% of the under-18 population."

● White Students ● Black Students



Of the children Baker Acted in Palm Beach County in 2019-20, 24% were white while 40% were Black.



Comparatively, the Palm Beach County student population is 33% white and 28% Black.

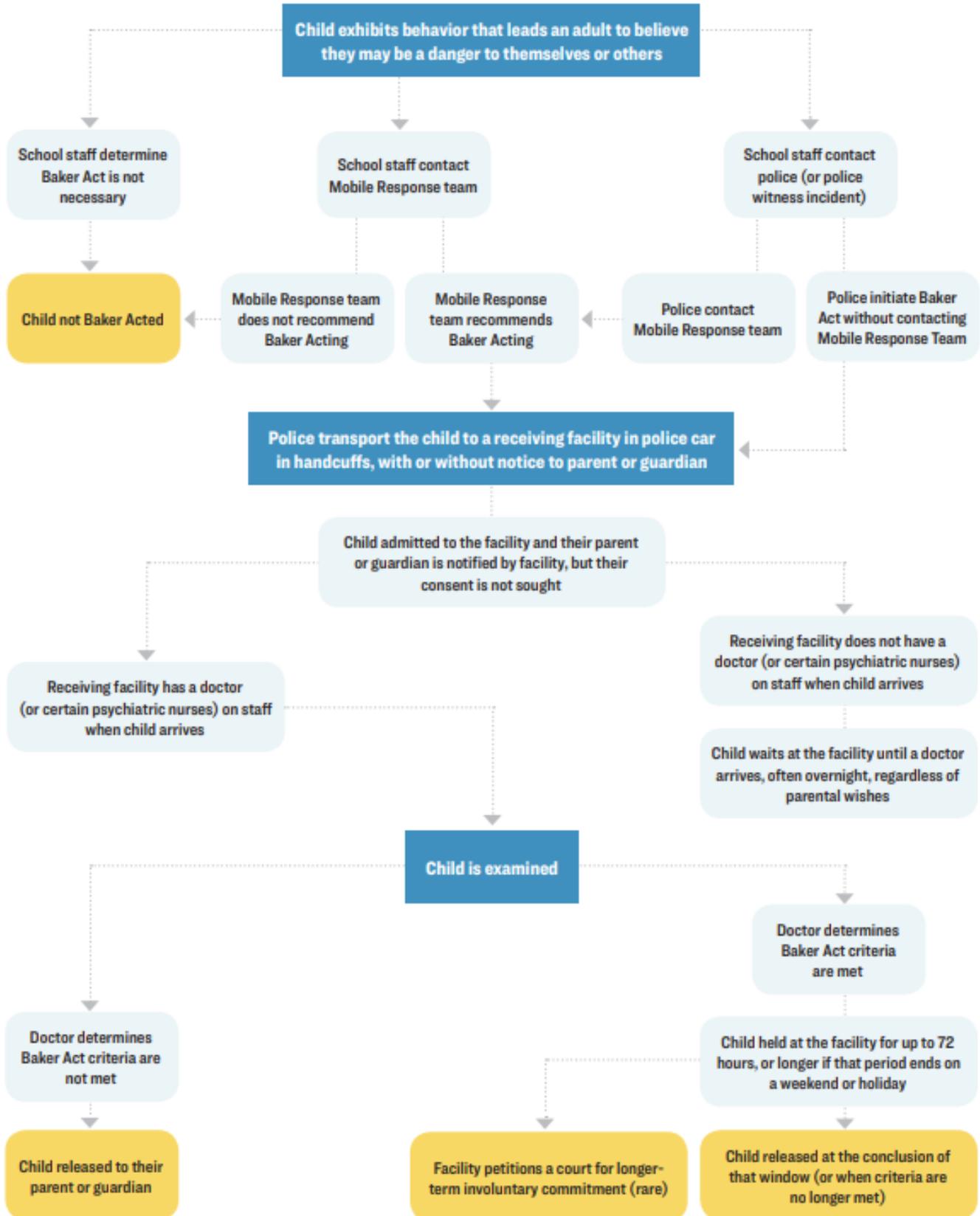
RATES OF EMERGENCY PSYCHIATRIC EXAMINATION PER 100,000 FOR ALL AGES



SOURCE: Gi Lee and David Cohen, Incidences of Involuntary Psychiatric Detention in 25 US States, 7 Psychiatric Services in Advance (2020)

"Black students in the District are doubly at risk of both disproportionately high criminal arrest and involuntary psychiatric commitment by police."

WHAT HAPPENS WHEN A CHILD IS BAKER ACTED?





There is no other way around what is happening, then calling it what it really is, and it is abuse. Parents who abuse their children are reviled by society, yet we pass laws that allow our children to be abused. Further, I'm disgusted at the thought that parents are stripped of their parental rights, unable to stop the criminalization and mental and sometimes physical trauma that is inflicted upon their children from being stopped. All parents can do is try, if they are even allowed, to soothe their handcuffed child knowing they are being taken to hell on Earth and will be returned to them traumatized beyond imagining.

I've written about the pipeline to prison this past October, the link can be found here:

<https://www.thedyslexiainitiative.org/post/the-school-to-prison-pipeline>. What I did not include, because frankly I was unaware, was how laws such as these fuel that transition even further.

So, let me ask the obvious question, how is a child who has been Baker Acted supposed to return to the classroom without complete fear that it won't happen again? The child isn't going to learn any lesson other than complete and utter fear of school, teachers, police, etc., and if the child has challenges such as autism, what guarantee exist that they won't become over stimulated again resulting in the same outcome, just further traumatizing the child? And, if the child has been Baker Acted, how will that fear manifest in their overstimulated, or emotionally wrought brains and emanate?

What is sad to me is once I posted against restraint and seclusion of children within the school environment and the comments were an overwhelming attack on the position I took. In all caps and tons of exclamation marks teachers were demanding to know how they were supposed to discipline children that are out of control that they aren't even allowed to touch. My responses fell on deaf ears but my repeated reply was, what training have you had to deescalate a child and how supportive is your school / district of such trainings? If they're not supportive then have you engaged the parent community to support you and help drive change?

Within my own district I watched a horrifying video of a mentally challenged child who had an IEP that clearly stated that he was allowed to go outside of the building to self soothe and calm down when overstimulated, yet this accommodation was ignored by the resource officer on site and the child was tased 17 times, then arrested. Let that sink in - he was tased 17 times and then arrested. This was one child against multiple police officers. He was a 17 year old boy with the mental capacity of a 4 year old. The officer that did the tasing received a commendation for how he handled the situation. What would have happened if a law like the Baker Act existed in my state? I cannot even fathom such an outcome.

The funny thing is the concept of adolescence is a relatively new concept, originating between 1890 and 1920. Prior to the concept children were viewed as adults and psychologists came out and said that we as a society had to shift away from such a dangerous concept. We know so much more about the development of the brain, challenges that children may live with like learning differences, autism, etc., yet from a scholastic perspective we are demanding our children behave as adults. We treat and judge them as adults, all the while forgetting ourselves what it means to be a child. With ever developing brains and emotions, especially given special circumstances, why would anyone conceive of treating a child in the ways that have become common place under the Baker Act?

It is clear to me this is more about education and training than it is about the children themselves. As it stands the children are victims and parents are powerless to stop their children from being the victims of such negligence and ignorance, because while on the surface it may seem "for the benefit of the child," upon closer examination is the easy button to avoid dealing with a child asking for help.

And, it doesn't matter in what way this is twisted and turned, it is child abuse. Period. #RepealTheBakerAct

Resource for all quotes and graphics :

https://www.splcenter.org/sites/default/files/com_special_report_baker_act_costly_and_cruel.pdf?fbclid=IwAR2yxp82jJcXxiM6QrX_Fv4_3hAXsjAr-FVTRcf-8VzbZ7VgvM1VhNAI4w

STATE OF AFFAIRS

In many states across the country dyslexia legislation is actively being championed.

Everyday people have rallied together to draft laws, are speaking to legislators and trying to unite voters behind these new laws. Do you know what's being debated right now in your state?

Many states enable you to track what's on the legislative docket electronically. You can enter in key words, see if laws specific to those words are listed, and set alerts for yourself. Read the laws and educate yourself. Are these laws worth supporting, or are they worth your informing your representative that they should vote against them?

Have you contacted your representatives about the laws in question? It's pretty easy. You can Google "Who are my elected representatives?" or you can go to sites like <https://myreps.datamade.us/>. You will enter your address and a listing of your representatives will appear, usually with an ability to drill down and find their contact information.

The legislative process is key, and dyslexia laws are critical to the success of our children's educations. Every voice is important to help get laws passed. Your reps are not rock stars or celebrities. They work for you the voter and tax payer. Remember, you're the one with the power. Use your voice for what matters.

And, if you are seeking change, that is possible too. Find your circle of common voices, allies, friends, and do the research about what is needed. The Freedom of Information Act will help you access data to help solidify your case. Have any friends that are lawyers? Have them help you with the language. Reach out to the advocacy groups in your state and form a united front. Submit the bills to your rep and ask them to champion what you've written and get them to the stage of being bills and debated in committee. Know the in's and out's of your particular state legislature and what it takes to get the draft you wrote all the way to a vote.

You can do this! It is possible. Do not be afraid.

When it comes to the denial of dyslexia across our country, we believe it is parents who will lead the way to change.

For a reference of what exists already in the laws, here are a few references:

As of 2018, <https://dyslexiaida.org/dyslexia-laws-in-the-usa-an-update/>

As of 2020, <https://www.dyslexicadvantage.org/dyslexia-laws-2018/?cn-reloaded=1>

The electoral process was designed to be accessed by every American. It is your constitutional right to raise your voice for change, and champion the laws that are meaningful to you.

For us, this is about our children, and changing education for all. Here at DI we do not support balanced literacy, but only the science of reading through structured literacy. We support FAPE, Child Find and ensuring that IDEA is enforced for all children everywhere.

We are suffering a major illiteracy crisis in this country. Knowing how to read is critical to access our society. Reading is the key to self determination, it is a civil right, it is what levels the playing field for all.

Raise your voice!
#DyslexiaRevolution #Vote



ALFABET SOOP

BY: AMY TRAYNOR, OTR, M.A., ATP

A column dedicated to facilitating an understanding of the Universal Design for Learning (UDL) framework and Assistive Technology (AT) and what each might look like for individuals with dyslexia.



It's that time of year again. Birds are chirping, trees are budding and students (and their parents!) are starting to plan for and fret about STANDARDIZED ASSESSMENTS! As a parent, emails have been dropping into my inbox almost daily with announcements, reminders or to-do's for one or both of my children in regard to spring assessments, so I can only assume the same thing is happening to you! Right about now you may be thinking-wait...I thought this column is about assistive technology; why are you writing about standardized assessments? Glad you asked. Administration of standardized assessments on a computer has been taking place with greater frequency year over year. With so many students continuing to attend school virtually, that number will likely increase significantly this year requiring the use of technology to deliver allowable accommodations.

For many of our children, standardized assessments cause worry about going to school and elicit anxiety, both which can create a barrier to learning. Additionally, far too many parents are bullied by campus or district administrators who are providing false information related to standardized assessment. Contrary to what most schools would like you to believe, there is actually federal policy regarding standardized assessments and provisions for opting out. Parents-YOU ARE THE PARENTS and are protected by law that allows YOU to decide if your child takes one of these assessments or not. Please know that as a parent and therapist myself, there is not one "right" answer when it comes to how your child takes a standardized assessment or not, each child is different and even children have different needs from one year to the next. The intent of this article is to provide food-for-thought as you are deciding what is best for your child this year and resources to help support your decision in communicating your choice to your school and/or district.

The Every Student Succeed Act (ESSA) is a federal law with multiple provisions for schools, students and families. ESSA is clear that parents have the right to refuse testing for their child(ren), for any reason, period. While the ESSA does require 95% of students to be tested it also provides individual states options if too few students are tested. So read it again: ESSA recognizes that it is fully the parent's right to OPT THEIR CHILD OUT OF TESTING. Parents should not fear that their school/district will lose funding or their child will not be able to graduate as a result of opting-out or tolerate bullying from schools/districts who are unwilling to recognize these explicit provisions in ESSA. You can find full-text of the ESSA and more by visiting <https://www2.ed.gov/policy/elsec/leg/essa/index.html>.

So you've made the decision to opt your child out of standardized assessment, now what? I am going to make the assumption that as a reader of this newsletter, your child has dyslexia or other diverse learning need(s) that is/are supported by either an Individualized Education Plan (IEP) or 504 plan. If this is the case, your child's campus administrators are most likely making or have made plans for how your child will take the assessment with allowable accommodations, inclusive of staffing decisions. In my personal opinion, I think taking the higher road, one that is respectful to the school/district staff, is the best first approach. You never know if or at what point you might have to enter dispute resolution and when you've consistently been respectful in your communication and willingness to work with the school, it will be much more challenging for you to be portrayed as a "difficult" or "unreasonable" parent. That being said, a respectful parent would recognize that the school is making arrangements to accommodate their child during testing and making staffing decisions accordingly. By letting the school know in writing and in advance that you are opting your child out, you are giving them the opportunity to plan accordingly with staffing, space and equipment needs. Your email does not need to be anything elaborate. In an email to your child's teacher and campus administrators, you can simply state:

"As (your child's name) parent, I do not want (your child's name) to participate in the (name of your districts/state) assessment this year. I wanted to let you know in advance so that you would have the opportunity to plan your staff and other needs accordingly, with the awareness that (your child's name) would not be taking the (name of test) assessment.

If there are additional documents that I need to complete or district procedures to follow, I am requesting that you send them to me via reply to this email."

Personally, while I think you should receive a thank-you-for-thinking-of-our-needs email in response, I doubt you will and, quite possibly, you will receive a phone call in response to your written notification. Take the call, have the conversation, jot down some notes and follow up with another email to whomever called you in which you summarize and capture the conversation in writing. It's always a great idea that whenever you're having a verbal conversation with someone from your child's school/district, to follow up that conversation in writing. Also, if the individual happens to mention a "policy" that prevents what you are asking to happen from happening, request in your email that they provide you with that "policy" in writing. 99.9% of the time, they will not because they cannot, as the "policy" they are referring to either does not exist or is illegal. In some instances sending the email and a possible phone call or email exchange might be the end of it and you gain the "blessing" or at least understanding that your child will not be taking the assessment. In some instances, the school/district may continue to provide you with information they deem valid, but remember, the law grants YOU the PARENT the final say. Depending on your tolerance for banter, it may just be easier to keep your child home on test days and any test make-up days. Another option is sending him/her to school and having him/her write "refused" on the test materials, book and answer form. If your child is given a computer based assessment, have him/her simply skip through the questions without answering (if possible) or select the same random answer for ALL questions and just get through. If you know that your child will be administered a computer-based assessment, I recommend you connect with other parents or contact your state department of education to ask for more specifics about the computer-based assessment so you can prepare your child to refuse accordingly.

So what if you decide to go ahead and have your child take standardized assessments-what considerations do you need to think through? As written earlier, I am making the assumption that as a reader of this newsletter, your child has dyslexia or other diverse learning need(s) that is/are supported by either an Individualized Education Plan (IEP) or 504 plan. Your child's plan contains accommodations that are made in the classroom on "regular" school work or school situations as decided by the committee making the IEP or 504 decisions. Standardized assessment can also be administered with accommodations, but their use is typically done with stricter guidelines according to your specific state and may not include all "regular" accommodations. For example, here in Texas, the Texas Education Agency (TEA) releases "allowable accommodations" and lists them on their website along with different criteria for use and procedures for requesting their use, if applicable. I suspect something similar is available in your state too. Here is where the connection to assistive technology comes into play. If your child has routinely used assistive technology as an accommodation in the academic area in which the standardized assessment will be administered, a similar accommodations that supports the area of need should be provided. For instance, if your child has an accommodation to have text read aloud either by staff or with assistive technology tools such as a screen reader or audiobooks, when and where reading skills are not assessed, the same should be provided in the standardized assessment. In math, this might look like word problems and answer choices; in science perhaps the entire scientific "scenario" and answer choices; in language arts, questions and answers. However, in reading, if reading is being assessed, passages are likely not read aloud but it may be allowable for questions and answer choices to be read. If your child uses supports such as spell check, word prediction, text to speech or traditional word processing for written expression, they might be considered "allowable" or perhaps instead, a human scribe might be used during standardized assessment measuring writing skills.

I implore you to consider to what extent accommodations are provided and used in your child's program, both during the regular school day and during standardized testing situations. As a therapist and assistive technology professional, I am all for accommodations when they are used appropriately. Unfortunately, even when used by committed educators with the best intentions, they can be detrimental to your child's overall academic progress. Please keep reading and allow me to further explain why I think this. The intent of an accommodation is to mitigate the effects of a disability. But what if using the accommodation is providing a false sense of progress or mastery of the content area? What if the accommodations is not being administered with fidelity? Is the accommodation for read aloud support provided but instead of only reading the questions and answers in a reading standardized assessment is the proctor for your child "helping" them and/or the school and reading the entire assessment? Oftentimes when read-aloud is an accommodation it also means that the administration will be in a one-on-one setting. Would anyone really know how the test was given? Or, even if only the test questions and answers are read, how is the material presented? Are their images? Is the language used in and the wording of the questions and answer choices so explicit that an error cannot be made?

Extended time is also a frequently used accommodation for students with dyslexia or other diverse learning needs. Extended time-sounds great, but what does that really look like? If your child has extended time for a standardized assessment, how will you know how long it took your child and how does that relate to his or her peers? Let's take a 3th grade student with a specific

learning disability in basic reading and the condition of dyslexia as an example. This student has excellent vocabulary and background knowledge which support improved overall comprehension, but struggles with decoding, encoding and fluency. Allowable accommodations for standardized assessment include reading questions and answers, extended time and 1:1 administration. What happens when the standardized assessment is administered and the student does well? Does it give the impression that achievement gaps have been closed when they may not have been? Do you know how long it took for your child to take the test? Was it three or four times as long as the "typical" child? Were the accommodations administered with fidelity or was the entire assessment-passage and questions and answers read to your child? If your child does "well" with accommodations, what might happen to the provision of intervention or other supports? Standardized assessments rarely measure the discrete skills in which our children with dyslexia struggle, so are we really measuring progress and mastery of content or are we measuring the mastery of utilizing accommodations? Let's take a language arts/writing standardized assessment example for an 8th grader with dyslexia. This student receives the support of text to speech and spelling support with standard spell check as accommodations both in class and on the state assessment. Poor spelling is one of the hallmark characteristics of dyslexia, so what happens when we negate the effects? Yes, the student can produce a composition without spelling errors, or at least fewer of them, but does that composition imply that there is no longer a deficit in encoding that requires explicit and systematic intervention? Are the grade level expectations truly being met or just the illusion of such? What are the potential consequences of the appearance of mastery when in fact, "raw" skills were just not measured? Will there be an administrator, mediator or hearing officer down the road that will look at the "passing" scores and assume the achievement gap in the discrete areas of deficit have been closed, when in fact there is still a multi-year deficit? As a result of these possible outcomes of taking the assessment, perhaps you may also wish to consider having them take the assessment without accommodations. While this might sound scary and provoke thoughts of possible retention or other "drastic" measures, if your child is on an IEP, retention ultimately is the decision of the committee making the IEP decisions.

For more information regarding retention, please follow this link to a resource produced by Wrightslaw:
<https://www.wrightslaw.com/flyers/retain.promote.pdf>

The decision to utilize accommodations both in the typical school day and during standardized assessments should be thoughtful and not made in haste. Accommodations, inclusive of assistive technology, are excellent for "levelling the playing field" and mitigating the effects of a disability. Accommodations, inclusive of assistive technology, when applied with a broad-stroke approach or without thoughtful consideration to the consequences to a student's progresses, can be damning to future supports, interventions or compensatory education a student may receive.

It hope this has given you food-for-thought around standardized assessments and the use of accommodations. If this leaves you with more student specific questions about your child or one for whom you support, I encourage you to seek guidance from your state department of education followed by your district. There are so many points to ponder and why I say, when in doubt, just opt out.

Amy Traynor, OTR, M.A., ATP: Amy is an occupational therapist, assistive technology professional, and most proud of her role as mom. She began her occupational therapy career in August 2000, committed to success and participation for ALL students in the school setting. Most of her 20 years supporting students in public schools were focused on assistive technology supports for literacy and physical access. As a parent of a child with dyslexia, she has a deep understanding and appreciation for the role technology plays for students who learn differently. Amy recently founded E2 Alliance, LLC, providers for educational consultation, evaluation, advocacy and training. Given her commitment as a parent advocate, the National Center for Learning Disabilities has contracted with Amy to lead their Texas Parent Advisory and Advocacy Council. Feel free to share thoughts or ask questions by emailing Amy at info@e2alliance.org.



COVID REFLECTIONS

This has been a hard year that has tested the temerity of us all.

Personally speaking, as a parent and advocate, I'm experiencing tons of emotions because even for me, this was an eye opening year.

We are all exhausted, worn bone thin by the reality of what we've been through. Some are invigorated. Some are pleading for help. All have had their eyes opened. As parents, whether our children struggle or not, we've seen what our children are exposed to within their school curriculums and most are very concerned. For those of us who have struggling children, we already knew our kids were suffering, but even for some of us, the degree to which they were suffering was eye opening.

Admittedly I knew the GenEd reading instruction was insufficient, and I knew writing was too, but even though I am a writer and have an English degree, I had forgotten how hard it is to learn to write. Watching my dyslexic child struggle with the writing assignments has been shocking, eye opening, and deeply disturbing.

Why that was such a realization was a part of our family's journey on the dyslexia /dysgraphia road and how much of a revelation the concept was that age / grade equivalency could be provided for written expression, not just reading. While that seems perhaps like a "duh" realization, it is not data that is typically shared as dysgraphia isn't something we are collectively discussing nearly enough.

On the public advocacy side, what's been equally amazing and hard (I'll explain what I mean by hard) as an advocate is watching parents across the country also realize how much our children are suffering. As a result they have the same emotions, and so voices have come forth asking for help and joining the fray. What's hard about that is that parents deep in the trenches and advocates have been saying things need to change for years so the mass realization stings, but personally speaking I am grateful for so many coming forward to join the movement and how that adds to the fight for change.

This past year has been remarkable because it feels like a paradigm shift is happening. I'm not the only one who feels it. Many educators, parents, researchers have commented the same thing to me. More people seem to be aware, more questions are being asked, more are coming forward. The ready availability of so many conferences being streamed online and for free was inspiring and people were able to access information previously denied to them purely because they would have had to attend the conferences in person, paying the attendance fees, and / or reading the papers behind the presentations. As for books and papers, we as parents read it all, but that's a lot of data to weed through, and conferences are an ideal platform by which information can be delivered / explained in digestible chunks.

On the flip side, is the information overload dangerous?

Tons of people are engaged in the conversation, but it's not necessarily being moderated, and can that feed the confusion or slow the debate for change? After all, article titles can be misleading and some may jump to conclusions that aren't accurate, and then fuel heated but unnecessary debate. Because of this, we at DI feel an obligation to post relevant, scientifically valid articles and findings, supported by evidence, but not everyone does.

Additionally, with so many voices now a part of the fray, it is important to remember to speak from a place of true knowledge, not supposition. We owe it to each other to not add confusion to this community by sharing what we are not certain of, but to only share reputable articles, and only to share helpful, valid, supported advice.

Also, I caution everyone to remember to speak as you wish to be spoken to. The support within our community is critical to each person's success in helping their child. Kindness and grace are always free and easy to give.

So in this time of continued change, while so many attempt to "return to normal" as companies reopen their offices and more and more children will likely return to in-person instruction in the fall, we must continue the dialog on the science of reading through structured literacy, and how to change education to serve all children, with the goal of finally enabling literacy for all.

Remember, literacy is the key to self-actualization, and that is why it's a civil right for all.



THE PARENT SESSIONS



With an educator's heart and a passion for helping parents and serving the dyslexia community, Marvilene Hagopian, also known as Marvi, and her team of seasoned educators set forth to create The Parent Sessions. Aligned to The Dyslexia Initiative's (DI) ideals that parents, when given the right tools, can indeed help their struggling children, she asked the DI team to host her sessions. We didn't hesitate before shouting, "YES!"

At the time of this publication, Marvi has presented 12 sessions. Her initial series which aired in the 2020-2021 school year is called "Beginning at the Beginning." Each meeting scaffolds previous sessions. The focus of the first series has been on the early childhood years from birth to about 6 years of age. The information is essential for parents who have struggling readers no matter their age. Topics include the following: letter recognition, text awareness, vocabulary development, the importance of background knowledge, and phonological and phonemic awareness.

Each meeting's content is roughly half an hour so as not to overwhelm parents with too much information. The information shared on her PowerPoint slides, PDFs, and recommended links to videos and other websites, round out the deeply informative and empowering sessions. All materials, including the recorded sessions, are posted on The Dyslexia Initiative's website.

One of Marvi's favorite questions to ask at the beginning of each session is "Where is everyone from?" The answers have been astonishing. People are participating from across the United States, as well as countries like England, Australia, Scotland, India, Pakistan, Malaysia, Guyana, and more.

"From the impetus of the idea to have these sessions to where she is now, I've watched Marvi's concept develop and the considerable effort she and her team put into each session. They do not take the material shared in these sessions lightly. They invest significant time and energy into creating well researched, well rounded, and meaningful learning opportunities for parents. We have been so blessed to be able to host such an amazing creation and effort. The response from the community has been amazing. Marvi and her team of experts are truly to be admired for their commitment to dyslexic families." stated Ashley Roberts, co-founder of DI.

I asked Marvi, "Where did the desire to create these sessions come from?" Her answer was something many of us can relate to.

Marvi: "My middle son didn't learn to read until he was 13. I was told in our first IEP meeting, the reason he didn't learn to read was because I hadn't read to him enough. Their expectations for him were that he would become a juvenile delinquent and a high school dropout. I had trusted the principal, teachers, and resource teachers for 7 years. I wish I had not trusted them for so long. My son could neither read nor write at even a first-grade level.

I pulled him out of our neighborhood school and enrolled him in a private school that knew how to teach dyslexic children. One year later, his reading comprehension was at a 9th grade level and he was writing full-page essays. I was so grateful and appreciative of the instruction they provided that I wanted to pay back the kindness and dedication they gave to him and other dyslexic children. Since then, it has been my mission to give back.

I knew other families were not as fortunate, so this became my advocacy. I dedicated my time, energy, and finally my career to helping all children who struggled with learning to read. God willing, all kinds of wonderful things have happened since I started this journey. I was given the opportunity to meet and work with like-minded people, including Marion Joseph, Chief Policy Analyst for former Wilson Riles who was the CA Chief of Public Instruction, Alice Furry, PhD., Director for the CA Technical Assistance Center for Reading First, as well as many talented administrators, teachers, and coaches across the state. I learned the evidence-based reading research and worked at the Reading Lions Center and the California Technical Assistance Center for Reading First. I continue, even after retirement, to have a strong desire to educate and empower parents.

I am so grateful panel members agreed to work on this project with me. If we can demystify what reading acquisition is all about, parents will have the knowledge and confidence to advocate for their children."

Turning to her panel of experts, I asked, "Why were you so willing to give of yourselves to these sessions?"

Dr. Norma Baker: "I got involved because of Marvi. I've worked with both Marvi and Marilyn (Astore) and I respect their efficacy and the work they've done with children regarding reading, so I knew this was a project worth getting involved in despite my busy schedule. It's interesting because I don't personally know anyone with a dyslexic child. However, I have learned that there are many famous individuals that were diagnosed with dyslexia. Yet, went on to be very successful.

Reading is essential to academic success. Children are either readers or non-readers. A child's race, socio-economic status, or gender does not immune him or her from dyslexia. The material Marvi and our team provide in the Parent Sessions can be used by all parents to improve their child's reading ability.

It is really critical that children are reading fluently by the time they leave 2nd grade because of the stereotypical predictability that these non-readers will end up as juvenile delinquents, high school dropouts, and/or in prison.

Reading is my passion, and I am learning a lot about dyslexia and its impact on reading skills from Marvi, our team, and other experts. It's great working with my two friends Marvi and Marilyn as well as the other team members. I wish I could do more."

Michelle Holman: "Having worked with Marvi in the past, I knew, when she reached out to me, that anything she would embark on, any adventure, any endeavor, would be amazing. When she explained her ideas about wanting to teach parents how reading should be taught, I was confident in her knowledge and knew she would be precise in presenting the information. I was honored that Marvi asked me to join her team. I had worked with Marvi and Teri at the Reading Lions Center writing the California Reading First Assessments. We had worked very well together on this high-pressure publishing assignment and I wanted to work with them again.

Having had lots of experience teaching and coaching teachers on reading instruction, I was excited to share the Science of Reading and a systematic approach to teaching reading with parents. After retirement, I continued to follow my passion by tutoring children in reading. When schools closed due to COVID, parents had to take on the role of teacher. They were frustrated and it became urgent to find a tutor. They realized they didn't have the knowledge needed to teach reading and were concerned their children were falling behind. Teaching parents, including many who are homeschooling, has proven to be very beneficial for them and a real joy for me. So, when Marvi said she wanted to create a series called The Parent Sessions, I was thrilled to be included in this project."

Marilyn Astore: "When Marvi mentioned this project, I wasn't sure what it would involve; but I did know that she has always been committed to ensuring that every child succeed in reading and thus in school, as well as in life. As John Mockler, late Secretary for Education in California, stated so eloquently: "Reading is the freedom skill."

Also, I have been privileged to work with Dr. Norma Baker for many years in her efforts to close the achievement gap. When I learned she would be joining Marvi's team, I knew that this effort would result in worthwhile outcomes for parents and their children.

The number of parents insisting on evidenced-based reading instruction has increased exponentially through online networks, such as The Dyslexia Initiative. I deeply appreciate having the opportunity to join Marvi, Dr. Baker, Teri Henning and Michelle Holman in partnering with parents' ongoing endeavors to improve and accelerate their children's achievement as fluent readers."

Teri Henning: "From an early age, reading and teaching was part of family life. When my five siblings and I were in school, my mother accepted a first-grade teaching position. My father was a nuclear research chemist and whenever he was asked to deliver a research report at a conference, or write up lab reports, my mother dutifully edited his work. After she became a reading specialist, she told me he was probably on the dyslexia spectrum. Regardless of his struggling with literacy skills, he had a successful career and so I never equated dyslexia with lack of intelligence. When I began my education, I remember struggling with reading and spelling. On several first and second grade report cards it was stated in the comment section, that I lacked auditory discrimination skills.

My first teaching position was a first-grade assignment in a school that was using Open Court Reading which included a complete, sequential phonics strand. What a revelation it was when I understood and taught the phonics curriculum. By the time my youngest daughter began struggling in kindergarten, I had my reading specialist credential. I had learned about the important role phonological and phonemic awareness and evidenced-based phonics played in successful early reading. Therefore, I was able to help my daughter.

Late in my career, I worked with Marvi and Michelle on the California Reading First Assessment project. After retiring, Marvi and I worked together for 5 years creating and writing an early literacy app called Castle Quest: Becoming a Knight. Its purpose was to provide instruction in early literacy skills along with imbedded and engaging practice games. Unfortunately, neither of us had the knowledge to write the code and produce the animation required to build the app. We were unable to find reliable coders; therefore, we sadly set the project aside.

About a year later, Marvi called and said, "Teri, I have an idea!" She explained her idea and I knew it would be a lot of work, but so important and necessary! Without hesitation, I said, "Count me in!"

All of us who are involved in the Parent Sessions project are lifelong educators who are passionate and dedicated to helping all children become proficient readers. This desire did not stop at retirement for any of us. For me, it's a way to keep abreast of the latest evidence-based reading instruction. I relish the opportunity to contribute and assist parents, their children, and teachers in the necessary reading skills and proven teaching strategies. Many teachers aren't receiving this information in teacher education programs. Marvi's idea of imparting parents with this knowledge is ingenious. I love that she's sharing the Parent Sessions with families all over the world. I can see children's lives changing because of it."

Recordings of The Parent Sessions can be found on our website at www.TheDyslexiaInitiative.org/the-parent-sessions, with the presentations and suggested links, as well as on our YouTube channel.

#TheParentSessions #DyslexiaRevolution

THE DYSLEXIA INITIATIVE YOUTUBE CHANNEL

Did you know that DI is on YouTube? You didn't? What???????

Well, we are. All of our media content is available to stream at any time on YouTube from Dyslexia Coffee Talk sessions, to special interviews we've done, all the way to The Parent Sessions.

We work hard to keep all of our parent friendly content free and so we load as much as we can to YouTube. Go check it out and while you're there, don't forget to subscribe so you are alerted when new content is available.

See you there!

To read more please go to:

www.YouTube.com/channel/UCbHMBvY8QurMgcndafBsHJQ



POETRY CONTEST CALL FOR SUBMISSIONS

Are you a poet? Would you like to participate in our poetry contest?

Yes, it's true! We are hosting a poetry contest!

We are seeking poems that reflect the full landscape of dyslexic people creating vital poetry—that means poems that are formal, poems that are not formal, poems written in languages that are not English, poems that stem from academia and poems that don't. The door is open for those pieces that beg for breath.

Submission is simple. Simply click here:

[https://form.jotform.com/210743890724155?](https://form.jotform.com/210743890724155?fbclid=IwAR0oYoewVLBoFb8CuG5vt6gVLIXoCwf5b5WP5f7CvoZVAzGHizJVgzpVAVw)

[fbclid=IwAR0oYoewVLBoFb8CuG5vt6gVLIXoCwf5b5WP5f7CvoZVAzGHizJVgzpVAVw](https://form.jotform.com/210743890724155?fbclid=IwAR0oYoewVLBoFb8CuG5vt6gVLIXoCwf5b5WP5f7CvoZVAzGHizJVgzpVAVw)

complete the form, and upload your poem.

We will feature selected poems in future newsletters.



DYSLEXIA COFFEE TALK SECOND SEASON HIGHLIGHTS

Dyslexia Coffee Talk is nearing the end of its shorter second season, and I thought I'd take the time to reflect on all things DCT and how exciting of a season it's been for me.

The first season was very aggressive with a session almost every single Saturday morning. Being a mom with an active dyslexic child who needs my support educationally speaking, and in this strange COVID environment, I knew that the pace DCT had in season 1 was not sustainable for season 2. For some reason being home and accessible to my family means they want my full undivided attention when I'm not working, even if they don't give me theirs. Lol! Mom's are just supposed to be there all the time, ready and willing to jump into whatever is needed.

Also, going into season 2, I wanted to shake things up and "go for the big guns" as far as guests were concerned. I knew it was time to reach out to some major leaders in the science and educational arenas and have some really great and helpful parent-centric discussions.



My invitation was simple. To each guest I explained who and what DI is and I said, "hey, it's fantastic all of the conferences that exist and even more exceptional that in this COVID environment all of them are virtual and most of them are free, but most are still full of "educator speak" and I want to focus on the critical topics and aim those discussions at parents." As parents, each of us is in the trenches, working diligently for our children's success, and I believe that it is parents who will be the ones to turn the tide of education in this country. I must say, I aimed high, and I was overwhelmed by the response. All but one of the individuals I reached out to accepted my invitation, and I have to say those interviews were so much fun! Here are some of the highlights.

Faith Borkowsky came back to help launch season 2 as we focused on "A Reality Check on the Intersection of Dyslexia & the Reading Workshop" after the Teacher College Reading & Writing Workshop released their latest "dyslexia" patch.

Dr. Marianne Wolf, author of [Proust and the Squid](#) and [Reader, Come Home](#) graciously took time out of her day and shared with us the fundamentals of how the brain learns to read and what that means for our dyslexic children.

Dr. Louisa Moats, author of [Speech to Print](#), and as I called her, the godmother of SoR, talked about the differences in balanced literacy and the science of reading and how to convert our schools from BL-centric to SoR-centric and what PD should look like for our teachers.

Emily Hanford came on and discussed what inspired her to write about the reading wars and shared information about some of the things she's learned along the way.

Dr. David Kilpatrick, author of [Essentials of Assessing, Preventing, and Overcoming Reading Difficulties](#) talked about so many awesome things it's hard to sum up our conversation. Just watch it and you'll see what I mean!

William Van Cleave of [www.wvced.com](#) and a masterful presenter talked about dysgraphia, handwriting, spelling, syntax and grammar, oh my! I had to go back and take notes after the fact and note down all of the goodness he shared. If you're not signed up for notices from his website I recommend doing so. He has great trainings that are open to parents.

Peter Wright of [www.wrightslaw.com](#), a hero of mine too, explained the differences between 504, IDEA and the ADA and highlighted things for parents to focus on as they advocate for their children. He will be a frequent guest and I cannot wait to have him back on!

And, that's not even all the shows!

Mid-season we also shifted to a single host model with just me, co-founder Ashley Roberts. It is the great content as before only now with just one host. We may have guests co-hosts from time to time, and that will be fun. DI is my baby and DCT is my heart. I am still reaching out to guests and trying to juggle this COVID life as we go back to "normal," whatever that may mean. Stay tuned for still more to come, including season 3!!

xoxo

FAQ'S



It was suggested that we tackle a list of frequently asked questions for our newsletter, and I have to say this turned into a very robust exercise. The suggested questions just kept piling up and we wanted to do right by them. In our mind a true FAQ is a living, breathing list. There are core questions that everyone will ask, and there are more intense questions that one may ask the farther down the rabbit hole they go in advocating for their child. This led to the conclusion that our FAQ's need to be added to our website where they can be edited and grow appropriately. In the mean time, below is a list of the most frequent questions we come across. We hope you find this list helpful.

What is dyslexia?

Per the International Dyslexia Association, "Dyslexia is a specific learning disability that is neurobiological in origin. It is characterized by difficulties with accurate and/or fluent word recognition and by poor spelling and decoding abilities. These difficulties typically result from a deficit in the phonological component of language that is often unexpected in relation to other cognitive abilities and the provision of effective classroom instruction. Secondary consequences may include problems in reading comprehension and reduced reading experience that can impede growth of vocabulary and background knowledge." Children with dyslexia will require systematic and explicit instruction in how to read via Structured Literacy. For more information on dyslexia including a list of signs we recommend further reading here at this link: <https://www.thedyslexiainitiative.org/dyslexia>.

What is dysgraphia?

Per the International Dyslexia Association, "dysgraphia is the condition of impaired letter writing by hand, that is, disabled handwriting. Impaired handwriting can interfere with learning to spell words in writing and speed of writing text. Children with dysgraphia may have only impaired handwriting, only impaired spelling (without reading problems), or both impaired handwriting and impaired spelling." Children with dysgraphia may also have challenges with written expression, meaning the ability to get their thoughts onto paper. Children with dysgraphia will require systematic and explicit instruction in handwriting, spelling, grammar and syntax. For more information on dyslexia including a list of signs we recommend further reading here at this link: <https://www.thedyslexiainitiative.org/dysgraphia>.

What is dyscalculia?

Per Understood.org, "Dyscalculia is a learning disability in math. People with dyscalculia have trouble with math at many levels. They often struggle with key concepts like bigger vs. smaller. And they can have a hard time doing basic math problems and more abstract math." Children with dyscalculia require systematic and explicit instruction in mathematics at a pace that works best for them. For more information on dyslexia including a list of signs we recommend further reading here at this link: <https://www.thedyslexiainitiative.org/dyscalculia>.

What is comorbidity?

Co-morbidity means the simultaneous presence of two or more conditions. Dyslexia has a high comorbidity rate with other challenges like ADHD, dyscalculia, dysgraphia and more.



What is the co-morbidity rate with ADHD?

It is believed the co-morbidity rate between ADHD and Dyslexia is approximately 30%. As with all things dyslexia, the science is always evolving and as the science evolves the data may change, but this is the statistic that has been shared with us from reliable sources.

Is dyslexia inheritable?

Yes, if you, the parent, has dyslexia then each child you have has a 50% probability of being dyslexic themselves.

What is working memory?

Per MedicineNet.com, "working memory is a system for temporarily storing and managing the information required to carry out complex cognitive tasks such as learning, reasoning, and comprehension. Working memory is involved in the selection, initiation, and termination of information-processing functions such as encoding, storing, and retrieving data." William Van Cleave has a great, simplified example of this that he calls the stove top. Think of a six-burner stove and on each burner is a pot. The front three pots are the things you are juggling at that moment, and the back three pots are the automatic processes you don't have to really think about, they just run on their own. A child with a low working memory who is struggling with, for example, dysgraphia, has a lot that they must concentrate on from the legibility of their handwriting to their spelling and then content. Depending on the effort they are putting forth, the content may get less attention because the child is tired by the time they get to the content. Another example is a dyslexic child being asked to take class notes. There's an enormous amount of concentration that has to go into taking notes from looking at the board, listening to the teacher, thinking about what's going to be jotted down, how fast one can do that, what happens if a mistake is made on the notes being taken that require correction, etc. A child with low working memory will struggle with processing all of those various tasks, and will be unsuccessful in taking good notes, thus why a common accommodation is to provide the child with class notes so they can concentrate on what is being said / explained at the time, and not focus on a task that diverts their attention away from content.

What is the difference between balanced literacy and the science of reading?

Welcome to the Reading Wars. This is a simple yet complicated question that I'm going to oversimplify due to the need to be succinct, but what I encourage anyone asking this question to do is to read Faith Borkowsky's book *Failing Students or Failing Schools* which can be purchased from any retailer including Amazon. It is a very good explanation of the history of reading instruction and is easily digestible and a must read for all parents.

Now, to oversimplify, Balanced Literacy is the "compromise" between the Whole Language movement, which asserts that the child must be taught the whole word, not the code to break the alphabetic system down into its components to build upwards to comprehension and fluency, aka, a successful reader. The Science of Reading asserts through decades of scientific data what the pathways of the brain are and how those pathways take in reading, which is a manmade invention approximately 5000 years old. Whole Language asserts humans are born readers while the Science of Reading asserts we must in fact be taught to read this human invention, and that evolution has not made reading automatic. Balanced Literacy is meant to be the compromise where some phonics is taught in Kindergarten and the first half of 1st grade, but no more. The pillars of reading are not adhered to by Whole Language or Balanced Literacy, but only through the Science of Reading via Structured Literacy can a child truly be taught how to read.

To find out more about the science of reading via Structured Literacy please explore this link: <https://dyslexiaida.org/effective-reading-instruction/>.

How do I get started?

First, start by knowing that your child is amazing and so are you. Second, prepare yourself to work hard for the legal rights of your child. Learn all you can about dyslexia, reading instruction via Structured Literacy, and yours and your child's rights under the various laws that protect our children.

Initiate an evaluation for the whole child via the process under IDEA, and be clear about all areas of concern. A good evaluator will adjust their evaluation as they work with your child and may see additional areas of concern. You should submit your request for the evaluation to the school as soon as possible as federal and state regulation timelines allow a specific amount of time before the evaluation must be completed. While you are waiting, explore what programs your district has adopted, find your community, and start asking questions. Remember this is always a learning path.

Lastly, be kind to yourself and hug your child often. Grace, patience and perseverance are necessary in our world. For further information please check out this page where we've linked all of Emily Hanford's very valuable podcasts and a template for requesting an evaluation under IDEA: <https://www.thedyslexiainitiative.org/for-parents>.

Can I specify what program should be used with my child?

Technically, yes, but it is not recommended. The primary reason is, if you as the parent, push for a specific program and it is not the right fit for your child, then the school will be in a "See, I told you so!" position. Push for a gold standard, highly explicit, systematic program, and then monitor the results. If some progress is not being gained in a sufficient time frame (6-8 weeks max), then there is an issue with either its implementation, fidelity, or it just isn't the right fit for the child. A key thing to remember is one program may be AMAZING for one child, and just not work for another. That is not a slam against the program, but the individuality of the child. Therefore, prescriptiveness is key, and why the "individualized" of the federal law IDEA is stated as well. Instruction must meet the individual needs of the child to be successful.

What is IDEA?

IDEA is a Federal law called the Individuals with Disabilities Education Act. Some call it "IDEA" and other refer to it as "The IDEA." The purpose of IDEA is to "ensure that all children with disabilities have available to them a free appropriate public education that emphasizes special education and related services designed to meet their unique needs and prepare them for further education, employment and independent living." It is a special education law, but remember, special education is a SERVICE, not a PLACE.

What's the difference between 504 and IEP?

This is a big question and we've written a lot about this and detailed as much information as we can on our website which can be found via this link: <https://www.thedyslexiainitiative.org/504-v-iep>. On this page we have also included the link to the presentation Peter Wright shared with us on Dyslexia Coffee Talk, as well as a template to request an evaluation under IDEA.

What is an advocate? Where can I find one?

An advocate is a support person who is familiar with the law and the disability with which your child struggles. They are not lawyers. They are there to help you fight for your child's educational rights, and help you get the right identification, goals, etc. We recommend looking at www.COPAA.org for an advocate in your area but note that COPAA does not vet the advocates listed. It is important that you do your own due diligence on the advocate you are considering and seek recommendations. Note too that once you hire an advocate, like any service provider, if you are not happy with that advocate it is ok to move onto a new advocate. We elaborated more on what is an advocate here: <https://www.thedyslexiainitiative.org/post/what-is-advocacy>.

Can I have an IEP and a 504 at the same time for the same child?

Yes, you can, but many will ask why. The concept of 504 is to provide accommodations. The concept of IDEA is to provide accommodations and services. Comorbidity is real so if one comorbid condition is under 504 and another under IDEA then we ask if the team really understands the interaction between the two challenges. If they are not related and comorbid then perhaps one can argue to support both types of services, but it is two different teams, two different sets of paperwork and two different laws, so why go through that? Push for the prevailing challenge to be under IDEA, and all comorbid related challenges and how they intertwine, and be done with it. If the conditions are not comorbid, still list them all under IDEA.

What is an evaluation and how do I obtain one for my child?

Because of the state in which The Dyslexia Initiative founders reside, we feel we must clarify the difference here in a 504 versus an IDEA evaluation. Under 504 a child is given a limited set of evaluations to determine if the child is only dyslexic. Under IDEA the whole child is evaluated to determine not just if dyslexia is present, but other possible comorbid conditions. A limited dyslexia evaluation will not address the question of what other challenges may or may not exist for the child, and therefore remediation, if provided through GenEd, is limited and focused only on one aspect, reading. Dyslexia however is more than just reading, and the probability that at least one comorbid condition exists along with the dyslexia is extremely high. A whole child evaluation allows the parents and the school to tailor services and accommodations to all the child's needs and address all areas of weakness appropriately. Even if you as the parent opt for a 504 plan for your child, we recommend only doing the IDEA evaluation in order to best serve the whole child. A template for the evaluation may be found at this link: <https://www.thedyslexiainitiative.org/for-parents>.

What is a subtest v a composite score and why should I care?

The best way to explain this is to think of your own education. Within a semester you take several tests. Each test is equivalent to the sub-test and the composite score is the average of all those tests, i.e. the final semester grade. We as parents need to care about the subtests because of how averages work which is if your test scores are 57, 95, 96, 72, 92, 100, and 84, then the average is 85.14 or rounded to the whole number is 85. If we are talking about a composite score, then the child is within the average range of intelligence even though they are at the bottom of the range. By just looking at the composite score, an argument can be made that the child is not in need of any services as the child is average, however, this is why the sub-tests are critical. Note the scores themselves. Depending on which evaluation is being addressed, that 57 is highly concerning. As advocates, we would also focus on the 72 and the 84 given the other scores. Clearly weakness exists.

"It is within the subtests that you find dyslexia." – Peter Wright

What evaluations are best for dyslexia?

For this question we will be providing links. This is a complicated question and deserves a robust answer.

Components of Comprehensive Dyslexia Testing; Part I- Introduction and Language Testing

https://www.smartspeechtherapy.com/components-of-comprehensive-dyslexia-testing-part-i-introduction-and-language-testing/?fbclid=IwARowak5IWA2_8ZuGKq9HVDqnVP6KM-_DF3vaK6HnWs-4a6yLhxd7rsmd3JY

Part II: Components of Comprehensive Dyslexia Testing – Phonological Awareness and Word Fluency Assessment

<https://www.smartspeechtherapy.com/components-of-comprehensive-dyslexia-testing-part-ii-phonological-awareness-and-word-fluency-testing/>

Part III: Components of Comprehensive Dyslexia Testing – Reading Fluency and Reading Comprehension

<https://www.smartspeechtherapy.com/part-iii-components-of-comprehensive-dyslexia-testing-reading-fluency-and-reading-comprehension/>

Each diagnostician will do things a little differently and each one is ultimately in charge, but know what the evaluations given are for and how they assess the child, what subtests are within the composite as not all may be used, and what each one measures.

What can I do if I disagree with the evaluation?

If you disagree with the evaluation you have the right to request an Independent Educational Evaluation at public expense. The IEE process is defined in IDEA under § 1415(b) Types of Procedures IEE. We encourage defining your own preferred list, vetting all candidates the district proposes, including a Freedom of Information Act request on the financials to see how much the district paid those individuals in the last school year to determine bias, and know that you do not have to go with the district's desired provider.

They do have to agree though. Recently we became aware of a district who put a mile range that all providers had to fall within, and this is not allowed or supported under IDEA. Familiarize yourself with the law and know your rights. Additionally, we advise to ask the school for their "rules of engagement" to be able to accept the IEE. We have seen districts throw up barriers that were not realistic to reject an IEE which is why we recommend getting the "rules" up front. Remember, for everything that does not seem right, ask them to provide the law and / or policy in writing to support the statement / denial / whatever. If it is not supported by law, then it is not actionable.

Should I write the goals?

Technically yes, you can, but it is not normally recommended. Push the team towards the right goals, but we do not recommend the parent being the author of those goals. You want to understand exactly what your child is struggling with, what the state expectations are per grade, and write goals around those state expectations and struggle, and you want the gains to be quick, to grade level, and be mathematically quantifiable. Progress needs to be real and tangible and be able to be integrated into your child's ability to function in the classroom in correlation to those gains. Remember, a true IEP team is collaborative and equal, always taking the child's best interests into consideration, and striving for true grade level achievement and beyond.

Note, I said not "normally." An extremely savvy parent with the right support team privately can indeed present goals as the parent and team can have a better understanding of what the goals need to be. This is a parent who is fully aware of present levels of performance and fully understands the IEP process and therefore what areas of weakness exist and what targeted goals are essential to helping their child achieve success. Ideally, all parents can reach this level of understanding and then can drive their child's IEP to the levels their child truly needs. However, bear in mind that the writing goals is really a team decision during IEP meeting and parents should bring their ideas to the table. It is often helpful to have written input from their dyslexia private tutors, if this is a possible reality for the family.

Additionally, write concerns in Parent Concern Letter and include deficits you see and goals / things you want to see improvement in so the school now has a paper trail that will need a PWN if they decline. This helps with potential due process and state complaints, should that be necessary down the road.

What is a good goal?

A good goal is one that takes into consideration what the child is specifically struggling on, what the grade level standards are and where gaps in those standards may exist for the child, and are written with the goal of helping the child achieve grade level standards at a bare minimum. Even if the expertise necessary does not exist within the district, it is incumbent on the team provide the right and proper resources to support this child's needs, but note this is the ideal scenario to adhere to FAPE, but it a challenge to actually make happen. Goals should be well written, challenging, but not overtly so, unique to the child's needs (aka individualized instruction), and target grade level success within a short amount of time, ideally one year. Measures for success should be repeatable, and mathematically quantifiable, not subjective. If goals are falling short, or are being achieved quickly, the team should intervene to adjust appropriately instead of waiting a full year to discuss again.

Is grade level achievement possible?

YES! Dyslexia is not a handicap in the sense that the child can either a) never learn to read, or b) only learn to read at early elementary levels. Dyslexia is simply a different way the brain processes information. The goal for ALL dyslexic children should be at a bare minimum grade level achievement, but honestly it needs to be ahead of grade level, if the IQ supports the ability to advance beyond expectations. School goals should be written to grade level expectations in all matters. Anything less is a disservice to the child and not a reflection of their capabilities or intelligence.

How do I know for sure that my child is meeting their goals?

First, all goals should be mathematically quantifiable and not measured against subjective data. Always ask for evidence on how the child is integrating their new knowledge into the everyday classroom and how that new knowledge is impacting their grades (it should be positive). Annual measures via tools like the GORT and others can be graphed and measured to weigh true gains. Also, with each goal report, have the school team show you the 4 out of 5 instances when reviewing the progress against the goals. Anything less is not a full picture and can be misleading.

Can I call a meeting any time I need to even if it's not yet been a year since the plan was implemented?

Yes. Whether 504 or IDEA, you as the parent are the expert in your child. If you have concerns, questions, or desire changes, you are free to call a meeting at any time. It is important to note that a parent is not an equal member of the 504 team, but they are of the IEP team.

What are accommodations and why are they important?

An accommodation is a means of allowing the child access to grade level material by leveling the playing field. Like you would provide glasses to someone who struggles seeing clearly, you would, as an example, give textbooks via audio to allow for ease of access instead of asking a struggling reader to labor unnecessarily through the texts just to complete an assignment.

For a list of accommodations that may help across various classes we have a comprehensive list here:

<https://www.thedyslexiainitiative.org/accommodations>.

What is the difference in an accommodation and a modification?

An accommodation is a means of allowing the child access to grade level material by leveling the playing field. Like you would provide glasses to someone who struggles seeing clearly, you would, as an example, give textbooks via audio to allow for ease of access instead of asking a struggling reader to labor unnecessarily through the texts just to complete an assignment.

A modification is a change to the curriculum, as an example, shortening a 100-question test to 40 questions, or 5 essay questions to 1 or 2 that may be done orally versus written.

People tend to use the words interchangeably, but they are two very different things. For a list of accommodations that may help across various classes we have a comprehensive list here: <https://www.thedyslexiainitiative.org/accommodations>.

What is assistive technology?

Per IDEA, "an assistive technology device is defined as "any item, piece of equipment, or product system, whether acquired commercially off the shelf, modified, or customized, that is used to increase, maintain, or improve functional capabilities of a child with a disability." This means that it can be low tech, e.g. graphic organizers, or high tech, e.g. speech to text.

The key to AT is that it must truly meet the individualized and prescriptive needs of the individual with the need. The severity of dyslexia as well as the combination of comorbid conditions, and what those specific conditions are, make each individual unique.

For the unique individual, some tools are just going to be better than others.

For more information please explore this link: <https://www.thedyslexiainitiative.org/assistive-technology> as well as our newsletters for "Alfabet Soup," an article by OT, ATP Amy Traynor where she shares a vast amount of helpful information regarding assistive technology.

Our newsletter archive may be found here: <https://www.thedyslexiainitiative.org/newsletter-archive>.

Should I let my child's school continue to use balanced literacy strategies with him / her in the regular classroom or tell them to stop?

As advocates what we would advise is no, you should not allow balanced literacy strategies to be utilized with your identified dyslexic child. First, it's critical to understand what curriculums are being used in the general education classroom, and that information is publicly available from all districts under the Freedom of Information Act; and second, it's critical to understand, if the curriculum is balanced literacy based, that aspects of the program will contradict what your child is receiving in remediation.

Remediation will (should) truly teach the code of the language, while balanced literacy can (and usually does) utilize poor reading strategies like guessing at words and using pictures to guess as well. We recommend, if your child is identified with dyslexia, to state that the child will only utilize the strategies provided in remediation and no conflicting strategies will be used with the child. Balanced literacy strategies are difficult to undo once engrained, and you do not want to create confusion in the child's mind about which strategies are right or wrong, but support what we know is scientifically sound.

What is due process? Is that my only recourse?

Under IDEA (2004), due process is a formal set of procedures for resolving conflicts between the school (or district) and parents (or the equivalent, as recognized by IDEA) regarding the child's rights to special education related to "identification, evaluation, or educational placement". In other words, due process ensures that children with disabilities and their parents are guaranteed rights to conflict resolution regarding the provision of a free appropriate public education (FAPE) (20 U.S.C. §§ 1414-1415). We have an article that explains more here: <https://www.thedyslexiainitiative.org/post/what-is-due-process-why-do-we-need-it>.

No, it is not your only recourse. One can file a state administrative complaint, a complaint with the Office of Civil Rights (OCR), and / or a complaint with the Department of Justice (DOJ).

Is it true that if I file a complaint I'm just being difficult and not cooperative with the school?

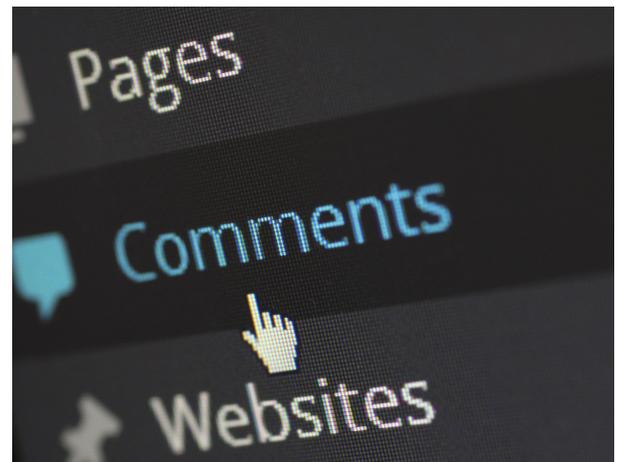
No, this is not true. This is a prevailing belief to keep parents from filing complaints. Complaints are a necessary part of the process and a right of the parent. A complaint may be met with a due process hearing filed by the district against the parent, if the district disagrees with the judgment or purpose behind the complaint, and while that is a risk, it is not a frequent occurrence.

Complaints are an effective tool to gain clarity and the necessary forward momentum for our children when the applicable law is not being properly applied.

THE "POST"

Oh dear "post," what, oh what shall I say about you? All the things, that's what.

As a parent and a public advocate I've spent years walking a fine line so teachers don't feel attacked by my words or actions. As the head of a nonprofit dedicated to educating and empowering parents we walk this line with great awareness. Despite our best efforts, the admonition that we're "bashing teachers" occurs quite frequently. In the last year I, and others like me, came to the realization of how unbalanced the scales are in regards our positions as advocates. We cannot talk about the pain our children are experiencing every day, both mental and physical, without that being teacher bashing. The reality is that we as parents and as advocates have to talk about the damage that is being inflicted through poor curriculum choices and through the denial our children face of their learning challenges, or we are not really discussing the abject and absolute damage and trauma that is the denial of dyslexia and the belief that our children are not able to be educated to grade level.



Now, I'm pro-teacher. We have a teacher on our board of directors and personally speaking in every IEP meeting I've ever attended I have not once attacked a teacher. Please note I've been screamed at, shamed, and more by the educators sitting on the other side of me, but I've not once raised my voice, called someone a name, or shamed them for their actions, or inactions, as regards the remediation of my child.

Having said that though, it is well past time that we address the inequality of the situation before us. Before I do I have one more thing to say. In my constant attempt to be seen as pro-teacher, which again I am, every now and then I post something to DI that it meant to be pro-teacher, seeing it as pro-teacher, yet I lose sight of how the trauma of denial has directly impacted families, and for that I take full responsibility and apologize.

So, recently there was a post that went "viral" within our community. Myself and many others shared it and the reaction was mixed and heated, and rightfully so. What's funny is when I first saw it I didn't like it. I had to watch it a few times and then against my better judgment, to be pro-teacher, I shared it. The backlash was swift and while I was at first defensive, I quickly started to rethink that position, and so I watched it again. In case you haven't seen it, here's the link:

https://www.tiktok.com/@ottimecasey/video/6935242398100507909?_d=secCgYIASAHKAESMgow%2FTeK1m3uYBfDN17B5GlcnEltde1wiJ7gWAnpToQCYBI3inFltwHckA5akl7joQwfGgA%3D&language=en&preview_pb=0&sec_user_id=MS4wLjABAAAANL7e6G6zLonZIBHDKWHE84MCsAHzf33UX4h_ZObtd8qhtBSIQDoUrjgASjUkJVoo&share_item_id=6935242398100507909&share_link_id=3D3D7761-4E6C-4FBA-82E4-9539120F337A×tamp=1616535466&tt_from=copy&u_code=dh9bcj5ee7flb4&user_id=6934075420892546054&utm_campaign=client_share&utm_medium=ios&utm_source=copy&source=h5_m.



So, seems nice right? Well, the truth is it isn't. Why? Because parents don't want you to sit across from us thinking nice thoughts about how we aren't alone and how it's ok to cry. We don't need a video of you crying with a tearful song behind it with words saying what good parents we are. The reason the parents at the meetings are upset isn't because their child has dyslexia, the reason the parents are upset is because they are asking for help and being met with repeated and systematic denial, which isn't the teacher's fault, unless the teacher refuses to speak up.

In this situation your good thoughts are not helpful. In the scheme of things the help our children need and are legally entitled to, while being met with systematic denial makes the well wishes are empty words and nothing more.

I get that teachers hands are tied thanks to the political environments inside of schools demanding their complete submission otherwise they can be met with ostracism and worse, termination, but here's the cold hard truth, We need the teachers to stand up and defend the legal rights of our children. Sitting silently, watching, afraid, helps no one, and most especially not the child. The very real and undeniable trauma our children face due to the prejudice against them for being dyslexic by the very

educational system meant to educate them is not something any of us should sit quietly and allow to happen. The situation at hand needs to infuriate everyone. The injustice is overwhelming, just look at the numbers, and it is not just our dyslexic children that are suffering. The NAEP scores, and by the way the NAEP is an accommodated assessment, shows very real and damning facts about the state of US education.

I've said all of this before, but I'm going to have to agree that posts like this TikTok post, without real action behind it, isn't a balm, it simply inflicts more pain. One friend of mine called it gaslighting. The truth is a lot of parents were harmed by the sharing of this post. That harm speaks volumes to the trauma that exists within our community.

"We must all work in harmony with each other to stand up for what is right, to speak up for what is fair, and to always voice any corrections so that the ignorant become informed and justice is never ignored. Every time a person allows an act of ignorance to happen, they delay our progress for true change. Every person, molecule and thing matters. We become responsible for the actions of others the instant we become conscious of what they are doing wrong and fail to remind them of what is right." — Suzy Kassem

"Don't be afraid to speak out. Your human rights story could be the inspiration that opens the window to someone else's awakening. Let's draw open the curtains together." — Janine Myung Ja

We need your voices too. Our alone will change the world, of that you can be sure, but it would be really nice for everyone if your voices joined the cacophony ours is making.

And, this isn't teacher bashing for the record, this is the reality we are facing, and truth is necessary to move forward. It must be ok for teachers to defend students who are struggling, and speak on behalf of the children, and work hand in hand with parents for real change.

#DyslexiaRevolution



2021 DYSLEXIA ART SHOW CALL FOR SUBMISSIONS



CALLING ALL ARTISTS!!!

The 2021 Dyslexia Art Show is in it's planning stages for the month of October and art submission has begun. Have you seen the last two art shows? They were breathtaking with so many great pieces from artists of all ages.

All mediums are allowed for submission.

Form submission is via this link:

https://form.jotform.com/203004751979155?fbclid=IwAR1bodqNI7sE3JXV-4N6p68jL_7jeNC3OojNSHwBlq6zMJHli1zF0gO5F9o

BE A PART OF THE REVOLUTION

At The Dyslexia Initiative we have some state and regional chapters, and are always looking to expand our community of support and voices for change. Right now there are two ways to join the revolution.

- 1) Join one of our existing state / regional chapters and be a part of the conversation. Whether you're in Texas and wish to join the Houston, Katy or North Texas groups, or you're in Arkansas, Arizona, California, Georgia, Illinois, Michigan, Missouri, Nevada, New Jersey, New York or South Carolina and wish to join, we have groups for you. The groups are meant to discuss state and regional matters, laws, districts, etc. and unite for change. These groups exist for you, everyone out there, to combine your voices, find your allies, and work together to save our children.
- 2) Is a state you live in not listed already? Are you a dynamic individual, passionate about structured literacy, dyslexia, equity for all children? Would you like to join our corp of volunteers, working together to support change within their respective states? Well then, reach out. We'd love to hear from you!

Be a part of the #DyslexiaRevolution!



Don't forget to subscribe for updates like our newsletter and more on our website, www.TheDyslexiaInitiative.org.

