

THE DYSLEXIA REVOLUTION

Quarterly Newsletter from The Dyslexia Initiative



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A MESSAGE FROM DI

This is going to be a very personal and introspective issue. It is also the last time it is going to be so. I ask that you bear with me for this one issue, then we will return to our regularly scheduled programming.

DI has been undergoing some fairly radical change, and in the razing and rebuilding of what was versus what will be, some things need to be said.

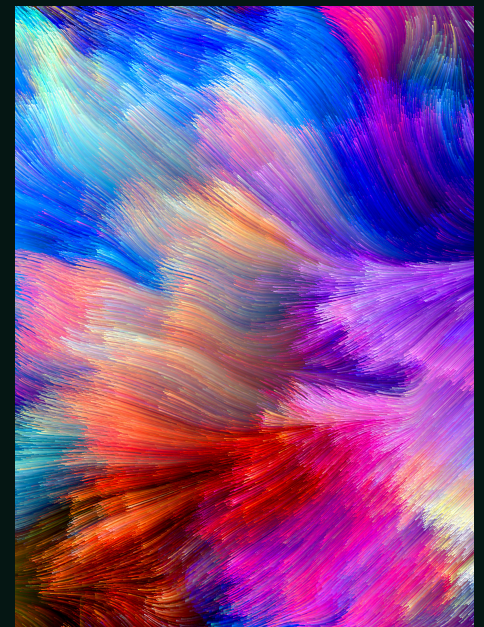
Before we can get to that, we are using this opening section to issue a very public apology.

Dear Mrs. J. Putnam:

On November 16, 2021, your words were used without your permission on The Dyslexia Initiative: Texas group in the posting of an OSERS letter regarding dyslexia instruction in the state of Texas. I did not handle the situation with any amount of grace, respect or apology. You deserved better and for every aspect of the situation, from plagiarizing your words to treating you poorly, I am deeply regretful and humbly apologize. There is no excuse and you were justified in your outrage.

I vow that no such action will ever occur again.

-Ashley



TRYING TO CHANGE THE WORLD

The Dyslexia Initiative has been unusually silent this past year. Yes, we've posted some great articles from some amazing guest writers, put out some memes, shared articles and hosted a shorter season of Dyslexia Coffee Talk than normal, but our total output has been less than in prior years. Even The Parent Sessions, while tackling much more complex topics, due to that complexity had a shorter run than in it's first year.

This organization has also undergone significant change, and within that change, I've searched for clarity, for purpose, for the spirit to keep going.

While this is a non-profit organization, to date we have not functioned like a non-profit. We are not a true corporation in design, attitude, or effort. We've always just been a group of moms trying to help shed some light on dyslexia and advocacy and little more.

But, therein lies the challenge, both good and bad, with consequences both positive and negative.

See, when you're just a bunch of moms without a real remit then personalities, ideas, convictions get in the way. Feelings reign and within those feelings sometimes people get stomped on. This is dangerous because everyone that is here is so because they have a struggling child, and perhaps were and possibly are struggling themselves. Within that struggle every person exists within some stage of coping. Per the work of Rick Lavoie, of whom I am a major fan, the stages of being a special needs parent is similar to the stages of grief, except there are more of them, and a person can exist in more than one stage at a time. Additionally, a person can move back and forth across the stages, meaning that just because someone gets to acceptance doesn't mean they will stay there. They can easily slip back to any of the multiple stages and struggle once again to find solid footing.

What we as a community are not very good about is understanding someone else's pain, even when we claim that as our personal hallmark. I don't say that as a bad thing because our personal pain is very real and within that pain, sometimes we cannot see or understand someone else's. That's just life.

Additionally, it is almost impossible to create real and genuine relationships with people on the other side of the computer. We try, and sometimes we think we do, but real genuine connection is challenging at best without face-to-face, in-person connection. If you're an introvert like me, it's easy to believe these connections are real. I at least have come to depend on them, thinking people I've never met in person are my actual and real friends, but that's almost never been true. The lack of face-to-face interaction leaves a gap of understanding where we cannot connect, not really, and therein lies a core problem.

Even for someone whose face is out there, it's sort of like thinking you know a TV personality from the role they play, but the truth is it's a glimmer, a perception, an idea, a need fulfilled or not fulfilled. It's not real. Social media can exacerbate this as we each paint a picture of who we think the other person is, but it's not a genuine connection, which is why real life is so much better.

So, given that, how do we form genuine tribes? How do we rise above the perception of what exists and create real change? How do you affect change when each person is also fighting their own battle, and whose journey is also in a different place, and within a different stage of coping?

Those are answers I know I personally seek, and those questions sit at the heart of my current journey.

Here are some problems, both for our community and for myself, as I both see them and have personally run into.



Problem 1: Public. I personally never wanted my face out there. I never wanted people to know my name. I never wanted anyone to put two and two together and send me a friend request because I was the voice behind DI. I just wanted to write. I kept my personal blog as innocuous as possible so people wouldn't know my name or have any idea of roughly where I lived. The problem was I had some ideas and some people who encouraged those ideas, and that ended up giving me the courage to start Dyslexia Coffee Talk, then BAM! my face is out there and so is my name. Eventually I got used to that, so then the longer I was out there the bolder I grew with my writing, and I wasn't afraid to place a byline on my articles or memes, consequences be damned. Some people didn't like that so how do you reconcile that? When you've been put out there with support and find that support withdrawn because of the very thing they encouraged you to do, where is the balance?

Problem 2: Perception. As an introvert who likes to write it's easy to create what seem to be real relationships over social media and assume people are my friends. As already stated, the problem is a lack of genuine connection with whom you're "friends" with, so it is simply a perception of someone. The consequence is that creates little understanding of a person's flaws and if there's no understanding of a person's flaws there's no willingness to forgive when someone acts in a way that is less than the perception of how they are supposed to act. Now, compound this by being someone who is seen within the community as a supportive advocate, and when that human being messes up and isn't supportive then there is retribution, and as someone who isn't and wasn't prepared for that reality, then how do you reconcile that gap between the perception and the real person, especially since perception reigns therefore consequences can be severe?

Problem 3: Connection. How do you reconcile the lack of connection and the need for a support group / a tribe when there is a certain perception that may or may not be in any way accurate? How do you maintain a support group when your journeys are at different stages and each of you are in various stages of coping? How do you move in and out and through as a cohesive unit when this is purely emotional? How do you reign in your emotion and be what people want you to be when you are still just a parent, and you still have a child whose educational rights you are fighting for? How do you keep that from influencing how you behave, what you say, what content you produce, how you engage with others, etc.?

Problem 4: Trauma. Whether we want to acknowledge this or not, this is a journey of trauma. Period. Some people are better than others at coping with the various trauma, or at least they're good at pretending like they are. As a parent and as an advocate, the farther I travel this road, the more aware I become of the trauma in all of its various forms, as well as people's abilities and inabilities to cope with it. Now, that's not a damning statement in any way, trust me. Trauma is a beast and coping isn't always possible. What I came to understand though was that if I was going to be true to advocacy then I needed to shed light on the trauma. Some people don't like that, don't want to see it and certainly don't want to hear it. As the DI organization fell into radical change, what I ran into was the idea that by talking about trauma I was abandoning the hope on which DI had been built, and I disagreed strongly and still do. If we are to be true to our community, we need to give voice to the trauma.

Problem 5: Honesty. One thing I'm adamant about is being honest with the community about what is and isn't. Vision therapy = snake oil. Balance literacy = illiteracy. The science behind how the brain learns how to read = literacy. Denial = trauma. \$220 billion + a year = the annual cost to the citizens of this country due to illiteracy. A great teacher skilled in SOR = a child who will learn to read and rise above current educational expectations. Some of that doesn't necessarily align with the idea of a positive message or with hope. The facts of the battle in front of us aren't all roses, unicorns, rainbows, and sunshine. This is a fight. A real and serious fight with major opponents with billions of dollars behind them, political connections and heavy hitting lobbyists. This is a serious fight entrenched in emotion on both sides. This is a fight against pedagogical ideals that were engrained in universities across the country to young impressionable altruistic children as they entered adulthood, and we are challenging the very ideals with which they were engrained. This isn't easy, nor is it going to remain easy, but that doesn't mean we shouldn't have hope, that we should give up, or that we shouldn't engage. Yes, for some people this is too big of a fight, and they just need to protect their children and we as a community should provide all we can in the ways of real and genuine support to everyone out there because not everyone can fight. Honesty is hard. It sucks hearing it too. There's a reason it's a value and that's because through honesty we can shed light in the dark places and bring about change. Again, that doesn't mean it's easy or pretty. That doesn't mean you won't get bloody. That doesn't mean you won't emerge without scars. Yet, none of that means we shouldn't fight back. If we don't then we perpetuate the damage and allow it to continue for other children, generation after generation.



Personally speaking, I refuse to discuss politics, especially on social media, and I despise it when people post memes during elections that state "your silence means you agree," because it's usually about aligning or not aligning with their political opinion; but with this issue, as it's universal, shouldn't be politically based, and is therefore fully non-partisan, once you understand, and not everyone can see the illiteracy crisis facing our country, silence does mean we are allowing it to continue. That does not mean that we have to each stand up and scream at the top of our lungs, but it does mean we have to at least be aware of the platforms our candidates are campaigning on and use our vote to try to make change, and this goes all the way to the school board level where your vote can have a great impact on the direction of your school district and it's literacy.

Problem 6: Voices. Some people either want to control who represents our community, or how pretty those voices may be. The farther I go down this path, the more outraged I am by that idea. The first issue is the primary voice is female, white, and upper middle class to wealthy. These are the parents for whom private tutoring, advocates, lawyers and the time to go testify in front of their state legislature is an option. This is less than 1% of the total community, and therefore not representative of the community as a whole. Yes, I absolutely fall into that bucket, and I am wholly and completely aware of my opportunities and blessings.

Dyslexia and all the D's are fully and completely non-discriminatory. Learning challenges do not pick and choose across gender, race, languages, or socioeconomic strata.

Additionally, nice wealthy white women have been playing a very nice game for decades, and to be fair not much has changed. Why? Those voices, no matter how altruistic they may be in their advocacy, are not representative of the community as a whole. The community needs all voices from every gender, race, language and socio-economic strata to speak up. That means some are going to be offended by their perceptions of how some people should speak or behave. Some people are going to have to move past their perceptions of who should represent the community and open their eyes to the POWER that other voices are going to have.

But, this also means providing empowerment to the community as a whole so that all voices feel able to speak up for change.

But here's the thing, I try very hard to only speak from my perspective, for my family, for my child, for myself as a parent and advocate, and not for others. I cannot speak to someone else's story. That is not my place. I can speak to statistics. I can share articles. I can create memes. What I cannot do is be someone else's voice, and I've never tried to do that. When I do speak and say "parents" I am referring to the comments and questions DI has received, the messages I've received personally, the conversations I've had with various people, etc. I refuse to assume someone's story, and I won't pretend to be the voice for the community. That's never been my place.

Problem 7: Allowing others' perceptions of me to impact my advocacy. This has been my greatest struggle because I take things very personally, and since I have anxiety I am really good at running things in my head over and over again for years. I've never been good at letting things go or forgiving myself for my mistakes. I'm hard enough on myself so when people shape a perception of me and then use that construct against me in some way I don't know how to handle it. The sad thing is if I'm going to be out here as an advocate then that's a reality I need to get used to. Goodness knows my husband keeps begging me to develop a thicker skin so I stop being so overwhelmed by emotion when things go awry.

That being said it's time to explain some things.

This newsletter opened with a public apology. Some people told me not to do that, but I felt it was the right thing to do. I mistreated someone, and while the probability of that person ever actually seeing that apology is slim to none, I needed to put it out there. I made a mistake and I need to own it. That may destroy my credibility and that of DI, but if that's the price I'm willing to pay it.

Next, I have been the primary contributor, creator, writer, and financier behind DI from the beginning. While a non-profit corporation, it is in name only and is unfunded except for my personal checkbook. I don't say that to generate a woe is me sort of vibe or ask for donations because I don't want them. I do it because I feel the content is important to the community. Period.



Sadly, the DI board and I recently fell out and as a result, they resigned. I hold them no ill will and wish them the best, and hope they do for me as well. What I will say is that from my perspective, and they will disagree, the falling out was based on certain misperceptions of who each of us are and are not, as well as our individual roles within the community. The falling out was also under some false ideas of what we were pretending DI was versus what it actually is. Additionally, it became clear our paths were diverging based on where we are in our advocacy for our own children and our own stages as special needs parents.

Regarding DI, while it is a non-profit, it is so in name only, because we've yet to develop it to the place we want it to be for the community. What it really has been though is just a bunch of moms posting some stuff and creating original content. The actuality is we were pretending to be something we aren't yet, and some of our own people couldn't and wouldn't see that, myself included. The sad part is on the brink of transforming into something that could create real and lasting change as a true organization, personalities and perceptions got in the way and the end result is what continually damages our community and our ability to advance and make real and lasting change.

This leads us back to Rick Lavoie and his idea of the 12 stages of being a special needs parent. Why? Because as a community we have to get over ourselves as individuals to create change. Why? Because advocacy and creating change isn't and cannot be just about the self, but for all within the community.

We are all going to get mired down in our own journeys. That is frankly unavoidable. Truly. One bad IEP or 504 meeting can easily send someone over the edge and into a massive depression for months on end. Lord knows I'm still reeling from a disastrous IEP in October and coming to terms with both my anxiety and the fact that I have been in a massive depression has NOT been easy. Exacerbate this with a complete lack of understanding, sympathy or respect from some people I considered to be friends and well, that's a recipe for disaster.

And, don't get me wrong. I'm not crying victim or asking for sympathy. I'm a big girl. I've coped, I know I'm not blameless, and I've pulled up my big girl pants, and am carving my way forward, one step at a time. I am talking about this not to create drama, or say woe is me, but for one very particular reason...

I really want our community to rally together and create real change, and to do that we need to learn to be way more kind and understanding of each other, give each other a hell of a lot more grace than we ever do, and recognize our own concerns and weak moments for what they are, forgive ourselves and each other, lock arms and DEMAND UNILATERAL CHANGE!

That is going to mean getting into some pretty uncomfortable situations with people we might not normally talk to, allow new and different voices to cry out for change, shatter some pedagogical ideals, both on the opposing side as well as our own, and not rest until all voices are represented, and we never give up until change is achieved.

I don't need to be there either. At some point my voice will fade away. My words won't be relevant anymore. My personal trauma will be too much for me to keep going.

But I hope DI in some form, with or without me, is there, even if just in spirit.

To conclude, this is the last personal article anyone will see from DI. I'm going to keep writing, keep creating, but my personal voice versus the direction in which I hope to carry DI need to be two separate things. I cannot transform this into the org I pray it will be without doing so. I need to be separate. I need to be a wife and a mom. I'll never stop being an advocate, and I'm not yet sure what shape that is going to take, but I'm looking forward to finding out.

For you, I wish you nothing but the best. Stand strong. Be introspective. Be brave. Embrace others. Embrace change. Don't be afraid of uncomfortable change. It's ok to let go of certain ideas and ideals. It's ok to break some perceptions. Life will move forward, and if we truly want change, then this is what we must do...together.

I'm always here, standing with you.

-Ashley



THE 12 STAGES

BY: ASHLEY ROBERTS
ORIGINALLY PUBLISHED NOV. 19, 2019

You have heard of the stages of grief when dealing with death, but have you heard of the 12 stages of emotion for the special needs parent?

Eleanor Westhead and Rick Lavoie came up with strikingly similar theories at approximately the same time. I've had the great pleasure of hearing Rick Lavoie speak and found the stages of being a special needs parent to be rather profound, and in my advocacy life, learned that it bears so much truth.

I have said before that I have found far too many instances in various community support groups of mistreatment of fellow parents. This emanates in a variety of forms.

A parent can ask what seems to be a seemingly harmless question, and in the course of responses you will see anger, arguments, condescension, shaming, compassion, kindness, and more. Upon entry into the dyslexia community on social media I quickly stopped commenting or questioning on anyone's post because there was always someone quick to argue, shame, etc., and that wasn't something in which I wanted to engage.

My least favorite responses were the self purported experts and how condescending they could be. I always wanted to comment and state that they had clearly forgotten how vulnerable one is at the beginning of the journey. It's not the parents fault that upon entrance one is not automatically gifted with vast knowledge and a doctorate in the subject of dyslexia. People need to ask questions in a safe space and be treated with courtesy and compassion.

Fast forward to 2018 and I partner up with two amazing women and we create The Dyslexia Initiative. In the course of having the pages and the variety of posts we have done, occasionally we get comments that cause us to pause and ask each other, what is the appropriate response here? It's usually Chontae who speaks and says, "Clearly this person is commenting from a place of great pain."

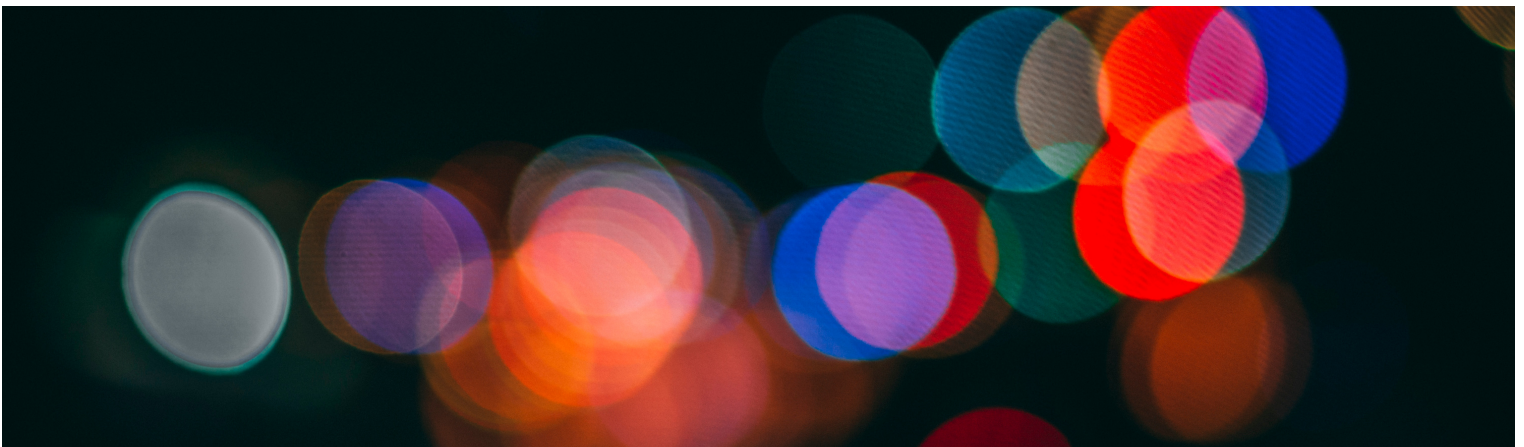
I love her empathy. Truly. Her ability to see through things is a real gift, and I love and cherish her insight. It always makes me pause, recall Rick Lavoie's speech, and remember why we are here to begin with, and what it is that we hope to achieve.

Over the year that we have had The Dyslexia Initiative, our message has become as equally about sharing information to help educate and empower, as it is about the human spirit, gratitude, beauty, kindness, forgiveness, compassion, and unity. In the journey that is dyslexia, these emotional aspects are just as vital to surviving this road as it is to life itself.

Regarding the stages below it's important to note that you can be in more than one stage at a time, that you do not travel through the stage only once, it is not like grief in that way, and that once you get to acceptance, there is no guarantee that you will stay there. Think of the stages as an endless slide with twists and turns, ups and downs, and loop de loops.

There is also no set order like grief, and no time limit for each stage. It is possible to get stuck in a specific stage and stay there for a significant length of time.

So I share the stages with you below, as well as the specific language that Mr. Lavoie qualified them with, so that you can see them for what they are, recognize them in yourself as well as in others, and consider them at all times when speaking with other parents within the dyslexia community, as well as special needs parents at large.



Denial

Nothing is really wrong; That's the way I was; Wait 'til next year

Bargaining

We'll move; We'll change schools; Send him to camp; Send money

Anger

Those doctors, teachers, etc. don't know anything; I hate this school, neighborhood, kid, etc.

Flight

Let's try this therapy; We're going from clinic to clinic

Guilt

Too long in the playpen; I shouldn't have worked; I should have used cloth diapers; Am I being punished?

Blame

You baby him; Not from my side of the family; Those f*****g teachers

Envy

Look at my sisters kids; It's not fair; Why me?

Isolation

No one really cares; No one understands this kid except me; Circle the wagons

Mourning

Imaging how great things could have been; If only....

Fear

Maybe it's worse then they're telling me; Will she ever marry? Work? Be independent?

Depression

There is no hope; I feel so inadequate; Where have I failed

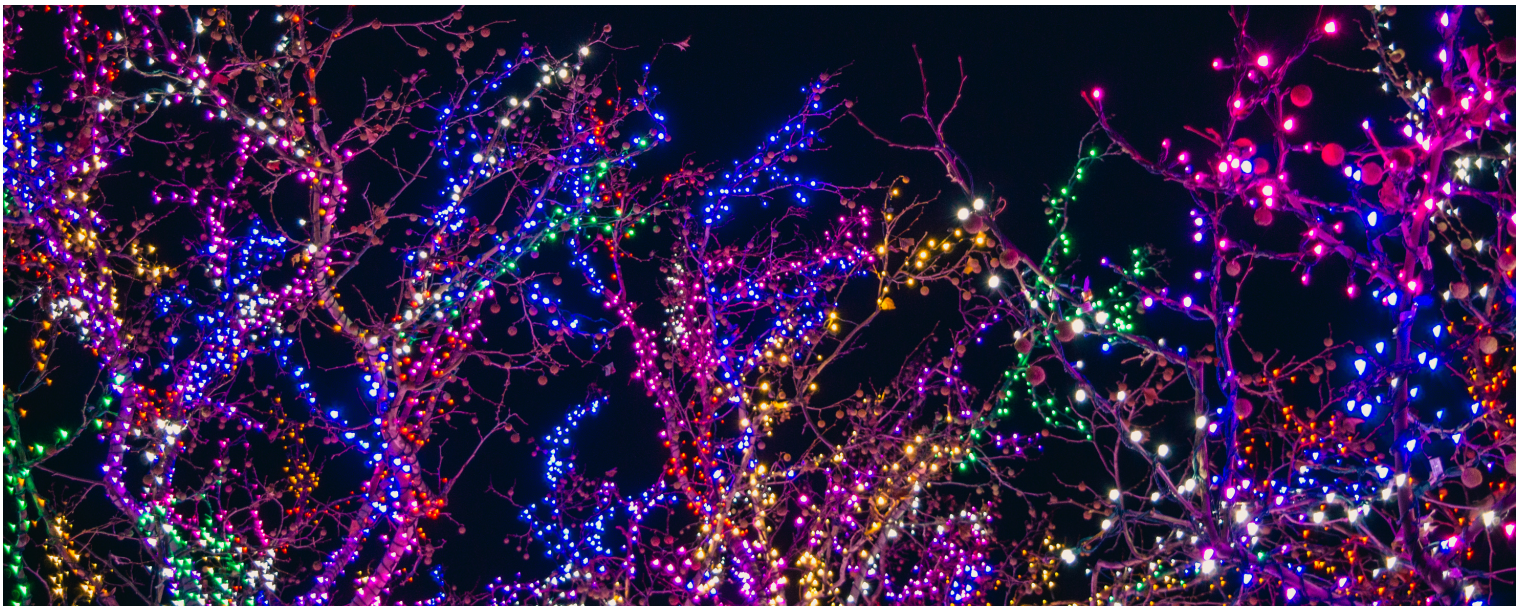
Acceptance

Let's get to work; Child orientation approach; Let's work together

Bearing all of this in mind, please always be kind and show compassion. As we all know, the journey is hard and the pain is very real, for our children, as well as for ourselves.

I also encourage you to read Mr. Lavoie's books, and if you ever get a chance to hear him speak, I promise it's worth it.

#PhoenixRising because this is the #DyslexiaRevolution!



DYSLEXIA MYTHS & URBAN LEGENDS

Myth:

Dyslexia cannot be diagnosed until the child is in 3rd grade.

Fact:

Professionals with extensive training can accurately diagnose dyslexia as early as age 5.

The sooner a diagnosis is made, the quicker your child can get help, and the greater chance you have of closing the educational gap. Be aware of the signs for dyslexia before 3rd grade. A combination of a family history of dyslexia and symptoms of difficulties in spoken language can help identify a vulnerable child even before he/she begins formal schooling.



Myth:

The child can't be dyslexic. They've made it through the lower grades just fine. Now they're just being defiant and refusing to do the work.

Fact:

Dyslexic children are excellent compensators. They will use clues, memorize as much as they can, guess at context using the habits of poor readers like using picture clues and more, but in the higher grades when picture cues go away and they are required to read to learn, not learn to read, the tools they use to compensate will not help them any longer. Additionally, holes that exist in their understanding of the alphabetic code or issues with fluency will impact their comprehension of text and they will begin to struggle. A child or adults age is irrelevant in the diagnosis of dyslexia. Starting as young as 5, children can be diagnosed, and unidentified children and adults can be diagnosed at any age.



Myth:

More boys than girls have dyslexia.

Fact:

Boys' reading disabilities are indeed identified more often than girls', but studies indicate that such identification is biased. The actual prevalence of the disorder is nearly identical in the two sexes. So why are more boys sent for testing than girls? It's because of their behavior. It seems when boys in first, second, or third grade can't do classroom assignments or homework, they get frustrated and act out their frustration. Parents and teachers notice that behavior and then try to figure out why they are behaving that way -- by sending them for testing. But often, when girls in first, second, or third grade can't do the work, they tend to get quiet, move to the back of the room, and try to become invisible. So they don't get noticed as early.



Myth:

Dyslexic children will never read well, so it's best to teach them to compensate.

Fact:

Individuals with dyslexia can become terrific readers with the proper instruction. It is important to identify a child early in his/her school career in order to discover any problems and engage in proper instruction / remediation as young as possible.



**Myth:**

Retaining a child (i.e., holding them back a grade) will improve their academic struggles.

Fact:

According to several institutions (i.e., The U.S. Department of Education, The American Federation of Teachers and The National Association of School Psychologists) and their extensive research, there is no benefit to retention because it has never improved a student's academic struggles. This is especially true if the method of instruction, e.g. the use of balanced literacy, doesn't change. Repeating the same unhelpful curriculum will simply harm the child's self esteem.

Myth:

We acquire a majority of our phonological awareness from language rich environments.

Fact:

Regardless of how language and literacy rich your environment may be, phonological awareness must be explicitly taught. Phonological awareness is the ability to recognize and manipulate the spoken parts of sentences and words. Examples include being able to identify words that rhyme, recognizing alliteration, segmenting a sentence into words, identifying the syllables in a word, and blending and segmenting onset-rimes. The National Reading Panel report states that explicit phonological awareness instruction is highly effective for developing phonological awareness in children, which in turn prepares them to read words and comprehend text.

**Myth:**

Accommodations are a crutch, and the child for whom they are made will become lazy.

Fact:

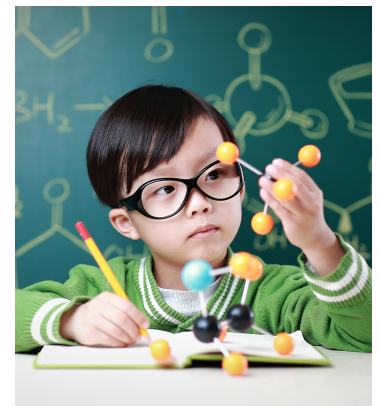
Accommodations are not an advantage; it is an attempt to level the playing field whether it is a standardized test, class work, or homework assignments, however accommodations should NOT replace high quality, explicit instruction based on the scientific data for both reading and writing, otherwise it's just a thing given to a child to enable a school to claim they're helping, when in reality they're not.

Myth:

Children with dyslexia are just lazy. They should try harder.

Fact:

Research has shown, via fMRIs that those with dyslexia use a different part of their brain when reading and working with language. Dyslexic people show a different pattern of brain function when reading: underactivity in some regions, overactivity in others which, according to researchers, accounts for the difficulty they have in extracting meaning from the printed word. The findings provide evidence that people with dyslexia do not lack intelligence and are not lazy or stupid. Their brains just work differently. Lack of awareness about this disorder has often resulted in the child being branded as 'lazy.' If students with dyslexia do not receive the right type of intervention they often struggle in school -- despite being bright, motivated, and spending hours on homework assignments both academically and emotionally.



Myth:

Smart people cannot be dyslexic or have a learning disability.

Fact:

Dyslexia and intelligence are NOT connected. Many dyslexic individuals are very bright and creative who will accomplish amazing things as adults.

**Myth:**

Balanced Literacy curriculums like Units of Study and Fountas & Pinnell are appropriate curricula to teach a child how to read.

Fact:

The empirical evidence is clear that "Balanced Literacy" curricula are wholly inadequate and only teach children the habits of poor readers. Children who arrive at school already reading or primed to read may appear to do well under these curriculums, but only compromise 36% of the total student population. The remaining 64% however will need additional practice opportunities in various and specific areas of reading and language development. The failure of these curricula is most severe for children who do not come to school already possessing what they need to know to make sense of written and academic English. These students are not likely to get what they need to read, write, speak and listen at grade level.

**Myth:**

Gifted children cannot be dyslexic or have a learning disability.

Fact:

Dyslexia has no correlation with intelligence. Many dyslexics have very high IQs and have gone on to accomplish outstanding things in their lives. Many famous authors, researchers, lawyers, politicians, financial giants, and others from all different professions are dyslexic.

**Myth:**

A child's fluency in reading isn't as important as their comprehension.

Fact:

A child's fluency in reading is key to the child's ability to properly comprehend the text and to become a highly skilled reader. Fluency is a key part of Scarborough's Reading Rope, but more importantly fluency is not simply how fast a child can read text. Fluency must be obtained at each strand of the rope in order to progress forward and ultimately achieve overall text fluency. Without achieving text fluency, the child will be a more labored, slower reader than necessary, requiring more critical thinking to comprehend text. When we ignore the importance of fluency, we deny the child all of the developmental skills necessary to achieve true reading skills. Again, this is not how QUICKLY a child can read text. Speed is not fluency. Instead fluency is when a text reader can take all of the strands of the rope and effortlessly pull them all together to read and understand text.

