

Removing Barriers: Changing I.D.E.A. Regulations to Reflect the Neuroscience of Dyslexia 5/2018

For far too many, receiving the services that enable learning, based on learning disability, like dyslexia and other SLD conditions, particularly learning to read, is a quagmire of diagnostic, educational, and legal-regulatory roadblocks. Consideration for new qualifying categories or more scientifically accurate definitions of SLD conditions is needed to improve access to services. This brief sets out to explain why the faults of the current system need to be clearly understood, by parents, policy makers and educators.

What is causing delays or denial of services and what can be done?

Specific Learning Disability (SLD) Category -

The single most frequently used category for eligibility to receive an Individualized Education Plan is the Specific Learning Disability Category of I.D.E.A. regulations.¹

It might seem counter-intuitive to think that this category, under which so many qualify, frequently requires a delay in services that results in intervention after the optimal developmental time for most effective services. It is also the category that results in the denial or exclusion from services for people who have a disability and a need for Individualized Education Plans based on subjective and unsubstantiated regulations.

On behalf of Decoding Dyslexia Massachusetts, as trained reading therapist and as a licensed school counselor in Massachusetts who has seen these regulations cause harm to students by confusing, delaying and denying services, I would like to present reasons for regulation review.

The regulations that concern me are particular to any student needing services under the category "Specific Learning Disability" including anyone with:

*a disorder in one or more of the basic psychological processes involved in understanding or in using language, spoken or written, that may manifest itself in the imperfect ability to listen, think, speak, read, write, spell, or to do mathematical calculations, **including conditions such as perceptual disabilities, brain injury, minimal brain dysfunction, dyslexia, and developmental aphasia.***

¹ https://nces.ed.gov/programs/coe/indicator_cgg.asp SLD accounts for 35% of the total and speech or language impairment the next largest at 20%. That combines to more than half of IEPs are attributed to some "language" based disability. Only SLD conditions are subject to the additional quagmire of waiting for "good instruction" and "exclusionary factors."

See 20 U.S.C. §1401(30) and 34 CFR §300.8(c)(10)

The strongest argument to request clarification and revision of regulations imposed to meet the qualifications in this category, SLD, **is in the research and advancements of the neuroscience and the knowledge of how cognitive development and language development impacts the skills and knowledge needed for for listening, thinking, speaking, reading, writing, spelling and mathematics.** There are two aspects of the regulation that work counter to current scientific knowledge in both identifying and in best practice early effective intervention.

What the current regulations require -

The current regulations for conditions in the category of specific learning disability require that:

a. to be identified under this category the student must have “experienced good instruction”; and

b. to be identified under this category the student must survive the subjective scrutiny of the “exclusionary factors” (cultural, economic, linguistic, visual or intellectual reasons for the current failure to learn).

These regulations, often reduced to a flow chart in districts across the country, were likely intended to ensure that those receiving services were in fact students with disabilities. (Please see the linked example taken from a current Massachusetts Department of Elementary and Secondary Education (DESE) Website.)²

However, since these original regulations were adopted, **there has been a great deal of additional scientific knowledge about the neurobiological and genetic basis of some of these conditions.**³ For example, dyslexia research has clearly advanced through neuroscience, and we are certain that students with dyslexia have neurobiological markers at birth and arrive to kindergarten already at a significant

²<http://www.doe.mass.edu/sped/iiep/sld/SLD3.pdf>

³Norton, Elizabeth S., Sara D. Beach, and John D. E. Gabrieli. “Neurobiology of Dyslexia.” *Current opinion in neurobiology* 0 (2015): 73–78. *PMC*. Web. 31 Mar. 2018. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4293303/>

disadvantage from their typical non-dyslexic peers.⁴ Likewise a student with aphasia also is already at a serious disadvantage before reading instruction, and waiting for a typical process to be experienced is waiting for children to fail.

SLD conditions, like dyslexia, impact *language* and include disorders in “psychological processes involved in understanding or in using language, spoken or written, that may manifest itself in the imperfect ability to listen, think, speak, read, write, spell, or to do mathematical calculations”⁵. **The “impact of the disorder” is present before formal reading instruction, at birth. Waiting for good instruction to fail⁶ before identifying the condition prevents the most efficient course of action.** Targeting intervention for those underlying language skills, or targeting initial reading instruction to meet the needs of students with deficits that impact language, reading, writing and even math in a more appropriate method for that specific SLD condition (including but not limited to dyslexia) is much more effective when done before and during initial formal reading instruction.⁷ But current reality, largely based on regulatory and other roadblocks to services particular to SLD, shows **most students** with dyslexia and other SLD conditions, though identifiable or at risk, **are not formally categorized for evaluation until 3rd grade or later when their peers are already reading to learn**⁸. For example the Dyslexia paradox as defined by Dr. Nadine Gaab⁹ describes this concern, because to be evaluated for a disability and qualify in this category; reading, and initial learning to read years have passed and instruction has failed. Even though many of these students received expensive programs and schools start the response to intervention process, they do not do so with the identification of the specific SLD disorder, and intervention is based on what product or services the

⁴ Ozernov-Palchik, Ola, and Nadine Gaab. “Tackling the ‘dyslexia Paradox’: Reading Brain and Behavior for Early Markers of Developmental Dyslexia.” *Wiley interdisciplinary reviews. Cognitive science* 7.2 (2016): 156–176. *PMC*. Web. 31 Mar. 2018.

⁵20 U.S.C. §1401(30) and 34 CFR §300.8(c)(10)

⁶ <https://www.gse.harvard.edu/news/uk/16/06/fixing-failure-model>

⁷ For example phonemic awareness is not reading, but a foundational language skill needed to develop reading skills. Targeting a noted deficit in this skill helps students. (cite Ola)

⁸ See Figure 1 from Massachusetts where you can see, students by in large, are not evaluated and provided services until after the developmentally appropriate “learn to read years” which are ages 5- 8 grades K-3.

⁹ <https://www.ncbi.nlm.nih.gov/pubmed/26836227>

school provides rather than the needs of the student based on the scientific structure of language and the needs of the student with a disability. The optimal time according to the same studies mentioned above and many like them, is during the “learn to read years,” those very years, grade K-3, yet schools hands are tied by flow charts and misconceptions and schools are waiting for kids to fail. The paradox being; by the time we identify the condition, dyslexia or any other SLD, we have missed, or deliberately let pass, the optimal time for intervention. **Current regulations ensure that intervention will be more costly, less effective and less efficient for reading. An additional negative consequence of this delay is that it guarantees that access to challenging grade level curriculum, is reduced or more complex without third-grade reading proficiency continuing to impact learning through out the rest of the school years across curriculum.**

Take the example of dyslexia: Since published research studies clearly indicate students with the neurobiological indicators of dyslexia exist a birth, and also NIH studies show that accurate screening¹⁰ is valid reliable and efficient as early as age 4 and 5, before formal reading instruction, waiting for failure is punitive rather than supportive.¹¹

This research and knowledge of the neurobiology of dyslexia should be considered so that the regulations:

- a. **no longer require failure first** but rather more closely adhere to “Child Find” and identify students at risk or “with suspected disability.” Students with pre-existing processing deficits can be identified early with valid and reliable screening reading assessment that adhere to the criteria for screening defined in I.D.E.A. Based on scientifically based reading research (SBRR), identification through valid screening before reading instruction is highly valid and accurate and enables early effective intervention. Developmentally, early intervention targeting the areas of deficit that can be identified in screening is much more effective and efficient in improving reading outcomes.

¹⁰ Screening definition 20 U.S.C. § 6368 (7)

(B) Screening reading assessment

The term “screening reading assessment” means an assessment that is—

(i) valid, reliable, and based on scientifically based reading research; and
(ii) a brief procedure designed as a first step in identifying children who may be at high risk for delayed development or academic failure and in need of further diagnosis of their need for special services or additional reading instruction.

¹¹ ***Get the info from Ola or Nadine to make sure this is correct.***

and

b. do not use “exclusionary factors” that have no basis in scientific reality and can be more accurately determines with valid reliable data. The specifics of each disability, and scientifically based indicators should be determining qualification, **not culture, language or economics.** Factors such as these appear to be significant in school readiness and student literacy outcomes, but that impact is separate from and in addition to any conditions that is based in biological or neurological conditions that impact language and learning.

Waiting to Fail

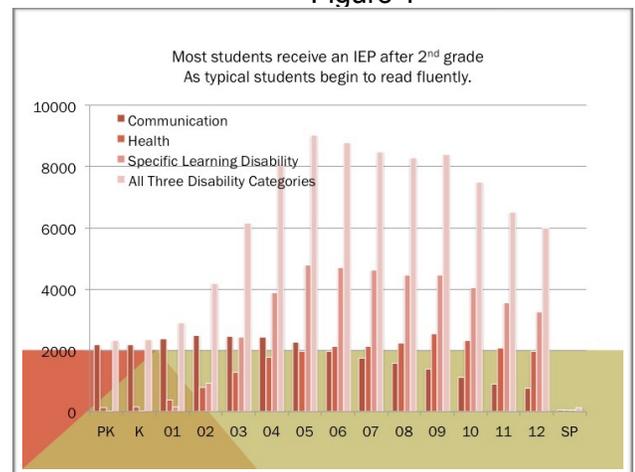
Waiting to ensure “good instruction” as part of a process seems counter to the screening definition provided by Congress: **“a first step in identifying children who may be at high risk for delayed development or academic failure and in need of further diagnosis of their need for special services or additional reading instruction.”**¹² It appears that the intention of screening, is to find and address known risks and reliably apply targeted interventions.

The current regulations for SLD are the foundation on which of the quagmire of diagnostic, educational, and legal roadblocks stands. How can this be in keeping with the intent of the law?

- A. For no other disability category are services delayed or denied based on waiting for “good instruction”.
- B. For no other disability category are services delayed or denied based on subjective exclusionary factors.

Review what the research tell us?

Figure 1



¹² 20 U.S.C. § 6368(7)B

- Students with disabilities that are grouped under the Specific Disabilities category arrive at school, like other students with disabilities: the disability already exists. We may not see it, but it is there.
- Learning - particularly reading, writing and mathematics - will be impacted by these disabling conditions, before failure. Not recognizing it early will virtually guarantee failure. When screening as defined in I.D.E.A. is implemented early, indicators of SLD conditions like dyslexia should receive I.D.E.A. defined Essential Components of Reading Instruction based on I.D.E.A. defined scientifically based reading research as early as same age peers are learning to read, not waiting until typical instructions and interventions have failed.¹³
- Interventions and direct systematic instruction targeting dyslexia, dysgraphia and dyscalculia, are most effective early, before and during initial instruction not after optimal developmental time for developing the underling skills or after failure. Likewise early interventions will also help other students whose developmental language abilities are impacted by other conditions listed in the SLD category. Nobody should be excluded from scientifically based reading instruction including more exposure as needed.

Comparatively, consider a student who arrives to the district and is blind. There is no requirement that “good instruction” take place prior to acknowledging and designing services without consideration of the student’s disability, blindness. The student is identified, provided with an Individual Education Plan for reading instruction in Braille, accommodated for access to curriculum as needed. Braille is an alternate “textile code” for reading, a speech-sounds to tactile code based model that replaces the typical speech-sounds to printed text based model used in general education. It would be absurd to exclude any child from the services known to be successful and in common use for blind students because of the regulatory exclusionary factors required for SLD.

Comparatively, consider a student who arrives to the district and is deaf. Reading, which by definition connects speech sounds to printed text, is much more difficult for students who are hearing impaired or deaf. Spoken language is the underlying skill for reading and consideration for an Individual Education Plan for a deaf or hearing impaired student would not require “good instruction” in the general education for reading take place before services in both American SignLanguage langue and

¹³ 20 U.S.C. § 6368(3)(4)(5)(6)(7)

reading, based on the needs of the student and the known evidenced based methods before IEP services begin. It would be absurd to exclude any child from the services known to be successful and in common use for deaf and hearing impaired students because of the regulatory exclusionary factors required for SLD.

Finally, consider the student with dyslexia. This student arrives to the district and appears typical, yet has an “invisible” neurobiological difference in brain structure¹⁴ that puts that child at a significant disadvantage for learning to read. This child, based on genetics and biology, arrives less equipped to adapt to printed text and has a high, well researched risk of reading failure. Yet regulations require that this child experience the typical “good instruction” during the developmentally critical years of “learning to read.” These students need specialized instruction as soon as possible and targeting their actual needs, yet statistically speaking, the overwhelming majority of these students are not identified and receiving instruction specific to their disability until after “good instruction” and in most cases after the developmentally appropriate “learning to read” years are passed. In addition to the wait, a significant number are excluded, even after the wait for “good instruction” based on their family’s culture, economic condition, first language or language differences, or intellectual abilities. The regulations appear to and in practice regularly require these students to find some other qualifying category or go without and Individualized Education Plan. When placed in a different category, they are less likely to receive the scientifically based instruction specific to the actual neurobiological condition or specific learning disability they have, since it is unidentified.

In many cases, it is not that teachers do not know the child is not at pace with peers. However, in practice trial and error, a misconception that kids will somehow “grow into it” or need more time before being “labeled” has compounded the difficulty in identifying students with SLD. Identifying a student with an SLD is the last resort with exclusions rather than a way to ensure a free appropriate education.

Methods of instruction can and do impact the severity of the struggle. When the typical instruction is structured to “be systematic and explicit” based on the Essential Components of Reading Instruction (ECORI) defined by the National Reading Panel, reading interventions for students may be more naturally imbedded in inclusion with

¹⁴ Raschle NM, Chang M, Gaab N. Structural brain alterations associated with dyslexia predate reading onset. *NeuroImage*. 2011;57(3):742-749. doi:10.1016/j.neuroimage.2010.09.055.

<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3499031/>

Norton ES, Beach SD, Gabrieli JDE. Neurobiology of Dyslexia. *Current opinion in neurobiology*. 2015;0:73-78. doi:10.1016/j.conb.2014.09.007.

<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4293303/>

additional individualized support. But when typical instruction is based on other theories like balanced literacy or whole language with implicit and in context learning, students with SLD need to be placed in a separate environment that instructs using explicit and systematic teaching based on ECORI. Products and services for reading, and teacher training greatly impact the experience of these students.¹⁵

Clearly the delay in identifying and in targeting services cumulatively delays reading success, and access to the general curriculum. The delay also has a progressively negative impact on the social emotional development of students. Students who are behind their peers are aware that they are not keeping up, in their ability to access grade level work and their ability to participate equally.

Updating the SLD regulations and significant clarification based on the scientific facts and common sense would require that students could be identified as early as the current prevailing research allows for valid and reliable identification. Currently for dyslexia this is at age 4 and 5. Regulations should be specific enough to require updates and guidelines for states and districts to have written policies. Many state dyslexia laws are based an attempt to rectify the the problem we are discussing. A clear federal regulation would support that these local regulations are based in research and allow for future developments.

In addition to the problem of “waiting for good instruction” rather than following the Child Find and I.D.E.A. screening definitions more closely the regulations are more difficult for any student that can subjectively be excluded by the “exclusionary factors.”

The Exclusionary Factors create a nearly insurmountable additional barrier to the already precarious quagmire between a disability based need for services and access to those services for the populations that are already most vulnerable to academic failure, people with low income, cultural or linguistic differences and those with intellectual challenges. These reasons for exclusion are in many ways subjective and in every way irrelevant to being identified as a person with a disability. For example, dyslexia is a neurobiological difference that impacts learning to read, and there is a confirmed scientific basis for understanding the neurobiology of dyslexia; how are cultural, linguistic, economic or intellectual differences relevant to this fact? Those factors can impact a child, and school readiness, but those factors do not negate or exclude the indicators of SLD conditions like dyslexia.

¹⁵ Seidenberg, Mark, *Language at the Speed of Sight: How We Read, Why So Many Can't, and What Can Be Done About It*, 2017-01-03, ISBN 13:9780465019328

The result of these exclusionary factors can not be underplayed. Even when over time the students "excluded" from services under this category, SLD, eventually receive an IEP under some other category, the services they receive are not in light of the actual disability and not informed for best practice based on the knowledge of the disability that actually impairs them.

Race-minority, language minority and economically disadvantaged students are much less likely to be identified through the specific learning disability category, and therefore receive no disability services or services based on some other category that will not point to the same interventions, simply based on subjective circumstances or culture. ¹⁶Are students whose academic challenges are the result of disability in any other I.D.E.A. qualifying category subject to this subjective and irrelevant exclusion?

I have personally witnessed this in IEP meetings. The student has every indicator and cannot read on grade level but the team will insist that based on the exclusionary factors they "**can not**" qualify under SLD and therefore also are not eligible for SLD based placement in the language based learning program? Scholars like Nicole Pattern-Terry Executive Director of the Urban Child Study Center Georgia State University has research that shows that low income struggling readers are often "excluded" from the dyslexia services (under represented) in Atlanta, only to be identified later as needing an IEP, but not receiving dyslexia services. ¹⁷

What can be done?

This category of students, those that have the underlying conditions listed under the category Specific Learning Disability, regardless of their ethnic, linguistic, or economic differences need a more clear and equally accessible path to services.

1. Remove the subjective and discriminatory barrier to services that results from "Exclusionary Factors".
2. Honor the goal of Child Find and remove the criteria that "good instruction" must fail first before identification.

¹⁶ Morgan et al 2015 Also see work of Nicole Patton Terry

¹⁷ Dr. Patton-Terry – Issue Differences Among African-American Students
<http://dyslexiafoundation.org/tdfc-ucla-2018-dr-patton-terry-issue-differences-among-african-american-students/>

Note: identification through screening and at risk measures does not “require or mandate special education” but it can **inform instruction** including targeted early Tier 1 or 2 instruction. Because there is a continuum and some students may have more severe or co morbid conditions there will be some students who do qualify for services early in the most foundational of skills, phonemic awareness. Identifying if deficits are based on for example, poor phonemic awareness or rapid automatized naming speed, (both can be validly and efficiently measured for all populations) will be a policy more focused on real needs and inline with the science of reading. In this way “good’ informed instruction based on identified deficits has a chance to be successful before reading failure. The optimal time for intervention is early and during instruction and waiting for failure delays identification and reduces the possibility of “good instruction” meeting the child’s needs at the time that same age peers are also learning these skills.

3. Define and qualify a category to represent students with scientifically known neurobiological disabilities that impact processing the skills of reading, writing and mathematics. Dyslexia, Dysgraphia and Dyscalculia are specific disabilities that like all disabilities, may or may not impact the ability to learn to read, write and do math and will impact learning differently based on what intervention is used and when. When these disabilities, like all disabilities, do impact the ability to learn, they require specialized educational plan to enable learning. They do not benefit from being termed “Learning” disabled. Once reading, a student with dyslexia may not need an IEP, but only accommodations of extended time. Some will not even need that. Early identification should be clearly encouraged and based on current scientific research for each disability.

IDEA definitions clearly state for example: Phonemic Awareness is the first Essential Component of Reading Instruction (ECORI).

A deficit in this area can be identified validly and reliably based on the definition of screening in IDEA. “Waiting to fail”, delaying assessment and delaying targeted services costs more by requiring more expensive and longer duration of special education. But the larger cost to consider is the experience of students and teachers as they work hard, but reading remains a struggle, without the foundation for success.

If the available scientifically based reading research tells us that all students for whom reading will be difficult, benefit from early intervention, but the design of that intervention varies and is not one size for all, then it is critical to identify not only the condition and the area of reading development that is in need of more explicit instruction but also to clarify the methods are consistent with the Essential Components of Reading Instruction in a systematic and explicit way.

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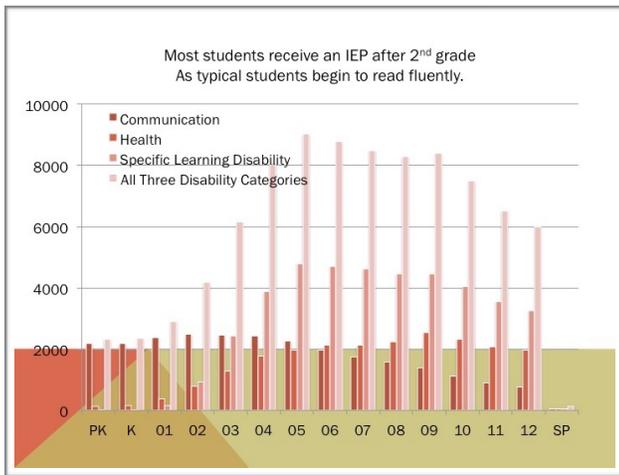


Figure 1