

Advocating for a Child With Dyslexia Within the Public Education System

Raising a child with a learning disability can feel lonely and overwhelming at times. Parents may find it stressful to navigate the systems designed to support struggling students in public schools. They may become disillusioned with their child's school or teachers when progress is slow or the recommended interventions prove unsuccessful. These feelings of confusion and frustration are common. However, uncertainty often subsides once parents gain confidence in their understanding of the laws and policies designed to support individuals with disabilities in both general and special education settings.

It is helpful for parents to also realize that a disconnect does currently exist between dyslexia—the most common type of learning disability—and reading research and many of the widespread educational practices that are popular in classrooms. This “research to practice gap” can complicate advocacy efforts, making it difficult for parents to know if the supports and services being offered are actually evidence based and proven to be effective for students with dyslexia. While advocating for their own child's individual needs, many parents feel they are also engaging to a certain degree in system-level advocacy to raise awareness and improve the types of reading interventions and assessment practices used by their schools.

Preparing to Advocate for Your Child

Research has shown that early identification and intervention is key when it comes to treating dyslexia. Therefore, parents need to request a meeting with their child's teacher as soon as they first notice an issue with the child's learning. Parents should bring samples of their child's work illustrating the issue they are observing and begin

by sharing their concerns. They should ask the teacher to share any literacy screening and benchmark reports. They can ask if the teacher has any concerns about dyslexia, but they should not be surprised if the teacher is not familiar with or comfortable with using the term. Parents should focus on asking for information on their child's reading development and whether their child is progressing normally or showing signs that are atypical. This meeting and all other phone calls or face-to-face discussions should be followed up with an e-mail restating what was discussed and agreed upon for next steps. This will establish a timeline of documentation for the child's records.

Building Knowledge and Identifying Resources.

It is very helpful for parents to build their own knowledge base about dyslexia and its impact on their child. The parent's perspective and input will provide important details about how dyslexia is specifically presenting itself in the child. The more parents know about the characteristics of dyslexia, the more they will be able to express specific concerns over their child's progress and to ask important questions about the programming decisions being made for their child at school.

There are many informative books, documentary films, and websites with online resources dedicated to helping raise awareness about dyslexia. The International Dyslexia Association (IDA) has a series of fact sheets, like this one, available for download on many topics related to dyslexia. There are also IDA branches in many states, as well as other school- and community-based parent groups focused on learning disabilities, where parents can meet other families and talk to educational experts.

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Getting Organized. Documentation is a critical component of effective advocacy. It is vitally important that parents set up a system for organizing their documentation from the very start. Collecting and organizing the child's information can be as easy as buying a three-ring binder and regularly adding documents in chronological order or creating tabbed sections to further categorize information.

Parents should include the following:

- Report cards and progress reports
- State assessments
- Educational plans, such as an individualized education program (IEP) or Section 504 plans
- Screening, benchmark, and progress monitoring reports
- Evaluation and assessment reports
- Samples of homework assignments and homework logs
- Samples of class work, tests, and quizzes
- Letters and e-mails from school staff
- Records/logs of phone or in-person conversations

Understanding the Systems of Support in your Child's School

It is also important for parents to become familiar with how their child's school identifies struggling readers and provides needed interventions. Local, state, and federal policies all play a role in these systems, so parents will need to ask questions about local district or school policies as well as seek information on state and federal education statutes. State parent training and information centers provide good resources—and often training—on federal laws and state special education policies and regulations as well as information on educational terminology. When parents understand their rights and the jargon used in the education system, they are better

prepared to take an active role in their child's education.

Response to Intervention (RTI) Models. Many states and schools use systems of universal screening and tiered levels of support to identify struggling learners and to provide a range of general education interventions. These models can be very effective at delivering timely, effective support when evidence-based screening tools and reading interventions are used. Parents should ask specific questions about the screening process, their child's screening results, the intervention program chosen to align to the child's individual needs, and the progress-monitoring data documenting their child's rate of improvement on skills such as decoding accuracy or reading fluency. RTI cannot be used to deny or delay a child's access to a full, comprehensive assessment if a learning disability is suspected. At any time, parents have the right to request that their child be assessed for special education services. If the child is not making progress, or the progress is too slow to effectively catch the child up to grade level, parents should ask for this comprehensive assessment in writing.

Special Education Services. The Individuals with Disabilities Education Act (IDEA) is a federal statute that ensures students with disabilities are provided a free appropriate public education (FAPE) that is designed to address their individual needs. FAPE refers to special education and related services that are provided without charge under public supervision. Students found eligible for special education services under IDEA are given an individualized education program (IEP) and guaranteed certain procedural safeguards, such as the right to file a complaint and request a due process hearing, to ensure they are provided FAPE.

The Special Education Cycle

An important part of IDEA provides parents with the right to participate in their children's education. It also outlines a special education

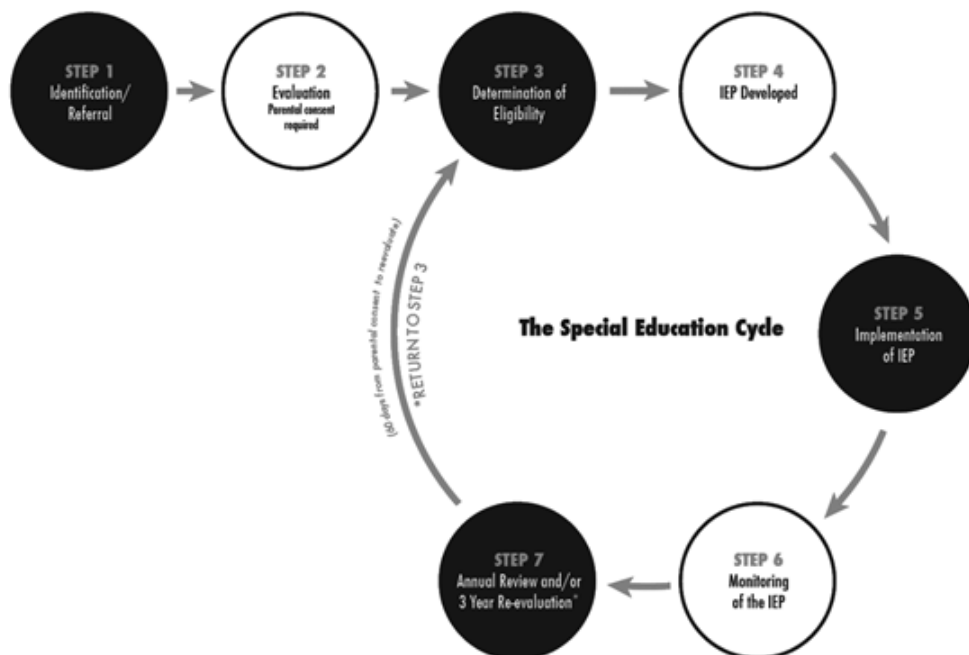
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cycle. Parents of children with dyslexia should become well-versed in this cycle and understand what their rights are at each stage. These rights will vary by state but must align with IDEA.

Step 1 – Identification/Referral. After discussions with school staff or implementation of a reading intervention, a parent or teacher may suspect dyslexia and feel it is time to make a referral for special education evaluation. Parents should take care when making this referral request themselves, to do so in writing and to include their child’s teacher and relevant administrator. In this written request, parents should be clear in stating their concern of a disability impacting their child’s education and their desire to initiate an educational evaluation to determine eligibility for special education services. IDEA requires that all areas of suspected disability be evaluated, so it is important for parents to list all areas of concern they have related to dyslexia. For example, a parent may list concerns with phonological processing, letter-sound associations, decoding, spelling, word identification, and/or fluency. A team of school staff will review the referral, gather additional information, and decide if an evaluation is warranted.

Steps 2 & 3 - Evaluation and Determination of Eligibility. An evaluation is a comprehensive look at the child's abilities, strengths, and weaknesses by qualified professionals. It provides information about the child's educational needs and may be guided by the information provided by the parents during the referral stage. When parents have shared specific areas of concern that are characteristic of dyslexia, an evaluation should include testing that targets those areas in order to determine if special education services are necessary to meet the child’s needs.

After the evaluation, before a child can receive special education services, the child must first be found eligible as a student with a disability under IDEA according to state guidelines. This determination happens at an eligibility meeting where results of the evaluation are reviewed. Eligibility requires more than simply identification of a disability. There must also be evidence that the child requires special education services in order to benefit from the general education curriculum. It should be noted that a child with dyslexia may not always qualify for special education services.



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Dyslexia falls under the IDEA eligibility category of specific learning disability (SLD), and each state or district may have its own criteria for determining eligibility under the SLD category. Parents should become familiar with the process in their state and district to understand the impact on their child's eligibility determination. Also, dyslexia is not its own eligibility category; therefore, schools may use the broader SLD label rather than the more specific diagnostic term *dyslexia*. Parents should not be overly concerned by the use of the term *SLD* as long as the description of the child's areas of need are accurately documenting their child's profile of dyslexia. However, parents can share with their schools that the U.S. Department of Education, Office of Special Education and Rehabilitative Services, clarified in a 2015 Dear Colleague Memo that "there is nothing in IDEA that would prohibit the use of the terms dyslexia, dyscalculia, and dysgraphia in IDEA evaluations, eligibility determinations, or IEP documents."

Parents also have the option of requesting an independent educational evaluation (IEE) during these stages. An IEE is an evaluation by a qualified person who is not employed by the school district. If a parent does not agree with the results of the district's evaluation and its interpretation, that parent is entitled to ask for an independent evaluation at the district's expense. When obtaining an IEE, parents should seek the services of professionals well-versed in dyslexia. A school district must consider any IEE, including private evaluations paid for by parents, when making decisions regarding a child's eligibility or special education program. However, a school district is not required to accept the evaluation report or incorporate any of its recommendations in a child's IEP.

Steps 4, 5 & 6 - Individualized Education Program (IEP). An IEP is a requirement for a student found eligible for special education services under IDEA. The IEP is a written statement describing the specially designed

instruction and related services required to meet the child's needs such as Structured Literacy™ instruction and assistive technology tools. Parents and their child with dyslexia are members of the team that develops the IEP along with school district staff.

One of the considerations when developing an IEP is ensuring that a child will be in the least restrictive environment (LRE), which means that the child will be educated with non-disabled peers to the maximum extent possible. After the IEP is developed and an appropriate placement has been determined for the child in the LRE, the IEP is implemented with instructional strategies and supports. Parents must collaborate and communicate with teachers and school staff often to ensure that the IEP and placement are working well for the child.

Step 7 - Annual Review and/or 3 Year Re-evaluation. The IEP must be reviewed and redrafted at least annually and can be revised prior to that if there is a need. Every three years, the child must receive updated evaluations to determine if the child remains eligible for special education services.

Civil Rights Protection. Section 504 of the Rehabilitation Act of 1973 is a federal civil rights law that protects individuals with disabilities from discrimination. Under Section 504, children with disabilities may receive accommodations and modifications to ensure that they have access to an education and are not discriminated against for reasons related to their disability. Some children with dyslexia are served under Section 504 plans when it is determined that they need certain accommodations and modifications, such as accessible instructional materials or extended time, but do not need special education services in order to benefit from the general education curriculum. These children do not have same procedural safeguards or protections available to children with disabilities and their parents under IDEA.

Balancing Your Rights and Responsibilities

While it is vital that parents have a strong understanding of their child’s educational rights, it is equally important that they understand their responsibility to participate in the process as an active, collaborative partner. Demanding specific services by quoting laws and citing state regulations may be tempting, but these practices can send school staff into defensive positions and break down avenues for communication. Parents can set an example by focusing the team on the child’s specific areas of strength and weakness, by explaining why certain services or instructional practices are needed, **and by consistently maintaining a child-centered perspective in all interactions.** Procedural safeguards are available to help resolve disputes if needed, and parents have the option to enlist the help of a trained advocate or education attorney if communication breaks down and disagreements cannot be resolved.

When advocating, parents should keep the big picture in mind—preparing their child for a fulfilling, productive adult life. This will require not only reading remediation services and accommodations but also the cultivation of self-advocacy skills. As parents work with school staff to secure these services and supports, they should look for opportunities to teach their children how to appropriately communicate their needs to others, how to feel confident in who they are as learners, and eventually how to become their own best advocate.

Resources

- Center for Parent Information and Resources: <http://www.parentcenterhub.org>
- Council of Parent Attorneys and Advocates: <http://www.copaa.org>
- Decoding Dyslexia: <http://www.decodingdyslexia.net>
- National Center for Learning Disabilities: <http://www.nclld.org>
- Center for Appropriate Dispute Resolution in Special Education: <http://www.cadnetworks.org/>
- National Center on Improving Literacy: <https://improvingliteracy.org>
- Understood: <https://www.understood.org>
- U.S. Department of Education IDEA: <http://idea.ed.gov>
- U.S. Department of Education 2015 Dear Colleague memo: <https://www2.ed.gov/policy/speced/guid/idea/memosdcitrs/guidance-on-dyslexia-10-2015.pdf>
- Wrightslaw (special education law and advocacy): <http://wrightslaw.com>

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