

Critical Issues in Serving Children with Developmental Language Disorder

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McGregor Financial and Nonfinancial Disclosure

- Salaried scientist at Boys Town National Research Hospital
- Research funded by the National Institute on Deafness and Other Communication Disorders
- Research funded by the National Science Foundation
- Receives honoraria for CE courses and seminars
- Receives financial compensation for reviews of grants from the NIH
- Non-salaried faculty member in the Faculty of Health Sciences at the University of Sydney
- Non-salaried Professor Emerita at the University of Iowa
- Serves as a reviewer for peer-reviewed journals

- Founding member of DLDandMe.org
- U.S. representative to RADLD.org (Raising Awareness of DLD)



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Map

<p>The problem</p> <ul style="list-style-type: none"> • Definition of DLD • Prevalence of DLD • Evidence that children w/ DLD are underserved • Some reasons why • Some consequences 	<p>Some solutions</p> <ul style="list-style-type: none"> • Identification • Awareness and understanding • Advocacy
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WHAT IS DLD?



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DLD =

Significant deficits in the comprehension and/or expression of spoken language

Other terms:

- Specific language impairment
- Language delay
- Language learning impairment
- Primary language impairment
- Developmental dysphasia
- Developmental aphasia



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DLD is a neurodevelopmental disorder



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The neurodevelopmental disorders are a group of conditions with **onset** in the developmental period that can persist into adulthood. –DSM-5

Other neurodevelopmental disorders:

- Intellectual Disabilities
- Autism Spectrum Disorder
- Attention-Deficit/Hyperactivity
- Specific Learning Disorder
- Tic Disorders
- Developmental Coordination Disorder

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DLD is a communication disorder



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Communication disorders are a group of conditions characterized by difficulties in speech or language severe enough to pose functional problems in academic, professional, or social settings -DSM-5

Other communication disorders

- Speech sound disorder
- Fluency disorder
- Social communication disorder

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Other communication disorders

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DLD is a disability recognized under IDEA



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IDEA requires schools to provide special education and related services to students whose school performance is adversely affected by one of 13 conditions

- IDEA-recognized disabilities:
- Speech or language impairment
 - Autism
 - Deaf-blindness
 - Emotional disturbance
 - Hearing impairment
 - Intellectual disability
 - Multiple disabilities
 - Orthopedic impairment
 - Other health impairments
 - Specific learning disability
 - Traumatic brain injury
 - Visual impairment



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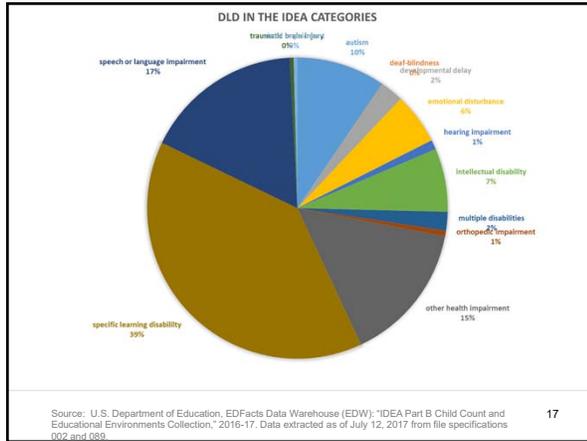
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Source: U.S. Department of Education, ED Facts Data Warehouse (EDW), "IDEA Part B Child Count and Educational Environments Collection," 2016-17. Data extracted as of July 12, 2017 from file specifications 002 and 089

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HOW PREVALENT IS DLD?



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Tomblin et al. (1997)

- U.S. population study
- Kindergartners
- Prevalence of SLI = 7.4%

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<p>Tomblin et al. (1997)</p> <ul style="list-style-type: none"> • U.S. population study • Kindergartners • Prevalence of SLI = 7.4% 	<p>Norbury et al. (2016)</p> <ul style="list-style-type: none"> • U.K. population study • First graders • Prevalence of DLD = 7.6%
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DLD is 5 times more prevalent than autism
(Centers for Disease Control and Prevention, 2015)

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PEOPLE WITH DLD ARE UNDERSERVED

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People with DLD are Underserved
(Norbury et al., 2016)

	w/o	w/ DLD
social emotional behavioral Dx	5%	10%
low academic achievement	30%	89%
statement of special need	.12%	3.5%
receiving speech-language Tx outside of school	10.5%	39%

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People with DLD are Underserved
(Norbury et al., 2016)

	w/o	w/ DLD
social emotional behavioral Dx	5%	10%
low academic achievement	30%	US Estimates: 25-33%
statement of special need	.12%	
receiving speech-language Tx outside of school	10.5%	<small>23</small>

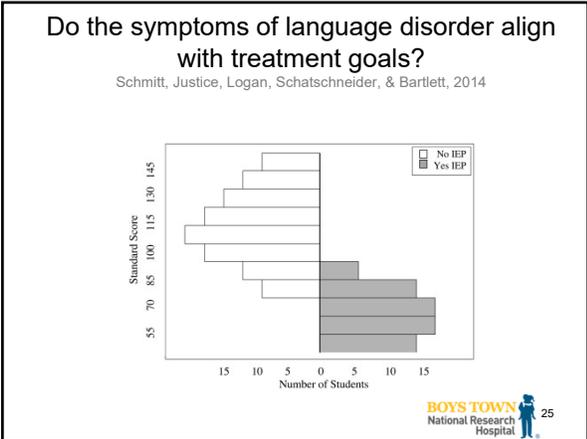
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Some are Particularly Likely to Go Without Service (Morgan et al., 2016)

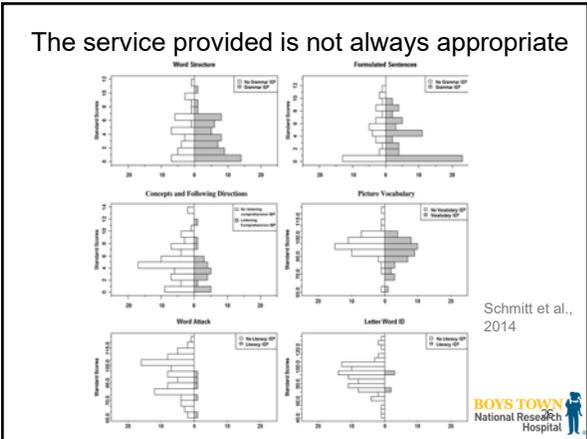
- At 48 months, girls are 65% less likely than boys to receive speech-language Tx
- At 24, 48, 60 months, African American children are about 50% less likely than White children to receive S-L Tx
- At 24 months, children who are not from wealthy families are about 50% less likely than wealthy children (highest SES quintile) to receive S-L Tx
- Family education level is a significant predictor of which children with DLD receive services (Wittke & Spaulding, 2018)

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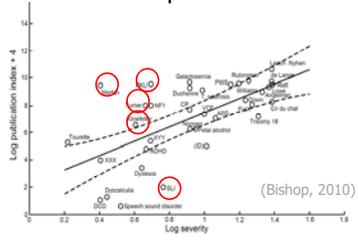
Which Neurodevelopmental Disorders Get Researched and Why? (Bishop, 2010)

- Identified publications (1985–2009) on 35 neurodevelopmental disorders
- Derived publication index reflecting N publications relative to prevalence.
- Considered publication index relative to severity. Less prevalent conditions tend to be more severe.

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DLD Has a Complicated Genetic Basis

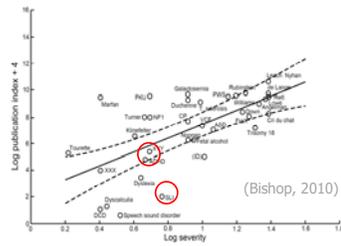


(Bishop, 2010)



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DLD is Not Treated With Drugs

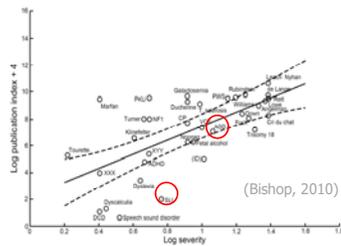


(Bishop, 2010)



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DLD Could Use a Good Awareness and Advocacy Campaign



(Bishop, 2010)



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DLD is Invisible
(to the eyes AND the ears)



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DLD Has No Consistent Name

- 33 different English terms have been used in the literature at least 600 times each (Bishop, 2014)
 - Specific language impairment
 - Primary language impairment
 - Receptive-expressive language disorder
 - Speech-language impairment
 - Language learning impairment
 - Language delay

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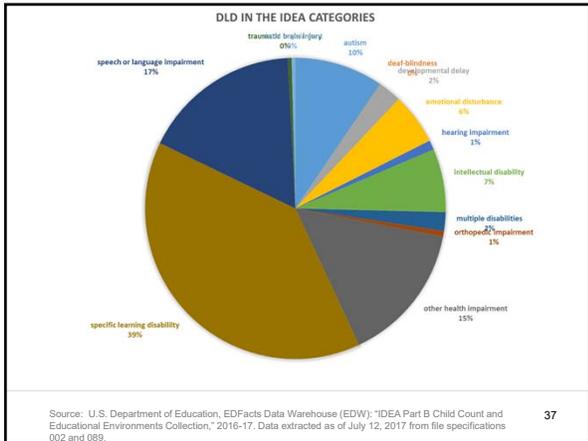
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DLD is a Societal Creation

- IDEA "...represents the intersection of political beliefs and scientific ideas about disability within the specific cultural context of America at a particular time in history." (Reid & Valle, 2004, p. 471)

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I believe that for many of these children, the "cause" of the language limitation is simply the product of the same types of variations in genetic and environmental factors that lead some children to be clumsy, others to be amusical, and still others to have little insight into their own feelings...

As with any subpar skill, special instruction may be appropriate, and seems especially so here, given the importance of verbal ability in our society.

-Leonard, 1991



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DLD is Misunderstood to be a 'Delay'

- The neurodevelopmental disorders are conditions with **onset** in the developmental period. - DSM-5
- Other neurodevelopmental disorders:
 - Intellectual Disabilities
 - Autism Spectrum Disorder
 - Attention-Deficit/Hyperactivity
- If you have DLD at age 5, **it is highly likely that you will have it forever** (Tomblin et al., 2003).

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The Functional Impact of DLD is not Appreciated

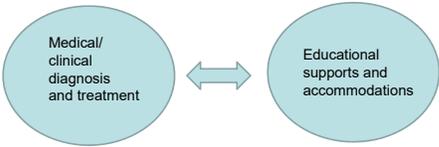
- Why does it matter if my child knows fewer words or makes more grammatical errors?
- Functional impact is part of the definition of DLD (Bishop et al., 2017)



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“Ownership” of diagnosis is not as firm

- Who diagnoses Autism?
- Who diagnoses ADHD?
- Who diagnoses Down Syndrome?
- Who diagnoses hearing loss?

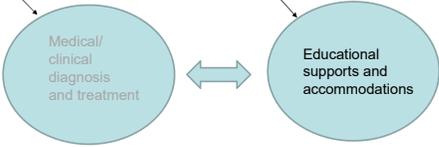



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“Ownership” of diagnosis is not as firm

- Who diagnoses DLD?
- Where?

<ul style="list-style-type: none"> • No universal screening • No clear medical referral route • Limited insurance coverage • Complicated (team) approach required to ensure accurate differential diagnosis 	<ul style="list-style-type: none"> • Culture tends to be “anti-label” • Emphasis on educational qualification, not diagnosis • Complicated team approach required to ensure accurate differential diagnosis
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Why does this matter as long as the child qualifies for the service he/she needs?

A diagnostic label is a verbal shorthand that allows for clear communication between professionals.

A label promotes awareness -> policy -> funding-> research -> practice

Information is powerful. It allows parents (and children) information, connection with others, agency, and comfort.

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Why does this matter as long as the child qualifies for the service he/she needs?

"parents who felt that they understood the child better as a result of the clinical evaluation reported a decline in adjustment problems, specifically conduct and depression. Behaviors that were previously viewed as troublesome may no longer be perceived as such, or at least may be attributed to factors that are outside the child's control."

"...the goal of evaluation should not be simply to document skill levels and deficits as measured by tests, but to reframe the parent's understanding of the child in a way that is more adaptive."

-Sorensen et al., 2003, p. 20

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WHAT ARE THE CONSEQUENCES OF IGNORING DLD?


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DLD is associated with depressed academic outcomes

(Young et al., 2002)

Achievement Scores	No DLD (n = 175)	w/ DLD (n = 74)
Spelling	106 (11)	93 (15)
Reading comprehension	110 (15)	90 (14)
Word ID	112 (16)	94 (14)
Word attack	110 (14)	100 (16)
Calculation	107 (17)	89 (15)



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DLD imposes risks for learning disabilities

(Young et al., 2002)

Prevalence of LD (<25th percentile)	No DLD (n = 176)	w/DLD (n = 74)	Relative Risk
Reading	6%	37%	6
Spelling	7%	40%	6
Math	12%	54%	4
Reading + Spelling	5%	32%	7
Reading + Math	3%	34%	11
Spelling + Math	5%	32%	7
Reading + Spelling+ Math	3%	30%	12



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DLD is associated with depressed academic outcomes at age 18

(Young et al., 2002)

Achievement Scores	No DLD (n = 175)	w/ DLD (n = 74)
Spelling	106 (11)	93 (15)
Reading comprehension	110 (15)	90 (14)
Word ID	112 (16)	94 (14)
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Those who had articulation disorder at kindergarten were included
(n = 35 in No DLD; n = 25 in w/DLD)

Outcomes did not vary with artic status.
Exception, lower word ID



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“Mia continues to require support services to access the curriculum at school.”

-Mia's mom

Homework: 4-5 hours per night in middle school, 3-4 hours per night in high school.

- Tutors
- Friends
- Study groups
- Family
- Me



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Adults with DLD are twice as likely to experience unemployment for more than 12 mos than other adults. (Law et al., 2009)



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In a sample of 88 preschoolers with DLD, 54% presented w/ s-e-b problems

(Maggio et al., 2014)

- Internalizing (emotional) 85%
 - Emotionally reactive
 - Anxious/depressed
 - Somatic complaints
 - Withdrawn
- Externalizing (behavioral) 57%
 - Attention problems
 - Aggressive behavior



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DLD imposes risks

School children w/ DLD are 3x more likely to be bullied (Conti-Ramsden & Botting, 2004)

Girls w/ DLD are 3x more likely to experience sexual abuse (Brownlie et al., 2017)

People w/ DLD are 6x more likely to experience anxiety (Conti-Ramsden & Botting, 2008)

People w/ DLD are 3x more likely to experience depression (Conti-Ramsden & Botting, 2008)




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DLD imposes risks

Teen boys w/DLD are 4x more likely to engage in delinquent behavior (Brownlie et al., 2004)

Adults with DLD are significantly less likely than others to understand their Miranda Rights (Rost & McGregor, 2012)

Among 52 young adult offenders, 44% had DLD (Hopkins et al., 2018)




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We Are Failing to Provide Adequate Clinical Services to People With DLD

- Allowed (mandated) to treat in U.S. public schools
- Common
- Persistent
- Yields a functional impact



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HOW YOU CAN HELP



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IDENTIFICATION



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NSLHA Language verification guidelines for school-age students

- Meets verification criteria
- Documentation of adverse effect on educational performance
- Determination that a need for sp/lang services is evident




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Meets verification criteria

❖ **Results of standardized and criterion-referenced assessments of language**

- Assessment yields standard score points of 84 or below
- ✓ Receptive language standard score:
- ✓ Expressive language standard score:
- ✓ TOTAL language standard score:

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❖ **Results of criterion-based speech-language sampling based on formal testing responses, language samples, and/or story retells**

Student demonstrates difficulty with:

- Sentence Length and Complexity (e.g., MLU, transitions, conjunctions, etc.)
- Semantics/Vocabulary
- Syntax/Grammatical Structures (e.g., verb tense, pronouns, word order, word endings, articles, auxiliary verbs)
- Word Finding/Word Retrieval
- Linguistic Non-fluencies (e.g., revisions, false-starts, repetitions, fillers)
- Pragmatics
- Retells less than 70% of a grade-level story retell
- Answers less than 70% of comprehension questions

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❖ **Consideration of the student's intellectual ability**

❖ **Educationally relevant medical information**

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My take

<p>What is great about the verification criteria</p> <ul style="list-style-type: none"> • Allows both norm-referenced and criterion-referenced measures (plural) • Includes a broad range of potential problem areas/allows for individual variation • Considers IQ and medical issues but does not ID on that basis 	<p>What you can do</p> <ul style="list-style-type: none"> • Select tools carefully • If a cut off of 84 is mandated, then you must select tests that are sensitive to DLD at that cutoff
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Documentation of adverse effect on educational performance

◆ **Information from the parent/teacher survey and/or direct observation of the student in the natural environment or classroom**

Rating Scale or Checklist, EXAMPLES:

- o CELF-5 Observational Rating Scale identifies 3 or more descriptors within 2-4 skill areas (listening, speaking, reading, writing) across multiple environments
- o Teacher Input – LANGUAGE Survey identifies 3 or more descriptors with 2-3 areas (communication, social-emotional, academics) in the general education classroom

NOTE: "Often" and "Always" constitute as areas of concern

SLP observational data from the natural environment or general education classroom

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◆ **Results of criterion-referenced assessments related to the general curriculum**

- Reading – Below Average ability as compared to same-age peers (e.g., DIBELS, MAP Growth, Lexile Level, Guided Reading Level), Below Standards on NSCAS
- Writing – Beginning or Developing rating on writing prompts, Below Standards on NSCAS
- Math – Beginning or Developing rating on formative assessment measures (e.g., Math District Interim Benchmarks), Below Standards on NSCAS

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My take

<p>What is great about the adverse effects criteria</p> <ul style="list-style-type: none"> • Considers impact in a variety of settings • Considers impact on math, not just reading and writing 	<p>What you can do</p> <ul style="list-style-type: none"> • Know that agreement between parent and teacher surveys is typically low • Teachers are often uncomfortable making referrals for language • Help teachers know what to look for
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DETERMINATION THAT A NEED FOR SPEECH/LANGUAGE SERVICES IS EVIDENT

❖ The student's response to short-term scientific, research-based intervention (Reference to Nebraska Multi-tiered system of support processes/procedures)

Intervention strategies implemented and outcome

Student has not made sufficient progress to meet age or state-approved grade-level standards and it would not be likely that without special education intervention the rate of progress would meet that of same-age peers.





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My take

<p>What you can do</p> <ul style="list-style-type: none"> • Know that children with DLD might qualify for services under speech-language OR specific learning disability 	<p>Section 2: State Definition • Specific Learning Disability – To qualify for special education services in the category of specific learning disability, the child must have 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 an imperfect ability to listen, think, speak, read, write, spell, or to do mathematical calculations. The category includes conditions such as perceptual disabilities, brain injury, minimal brain dysfunction, dyslexia, and developmental aphasia.</p>
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My take

What you can do

- Ensure speedy access to services A student may be referred for multidisciplinary team evaluation at any time within the MTSS Framework; in no way should an MTSS process delay the initial evaluation of a student that is suspected of having a disability.

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AWARENESS AND UNDERSTANDING

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You have access to two critical players in the life of a child with DLD

<p>Teachers and other school personnel</p> <ul style="list-style-type: none"> • What is language? • Why is spoken language critical to academic success? • What are the signs of a child who needs support with spoken language? • What does the term DLD mean? 	<p>Parents</p> <ul style="list-style-type: none"> • What is the difference between an eligibility determination and a diagnosis? • How can parents find information about their child's language problem? • Help parents avoid confusion: terminology, the fluidity of developmental diagnoses, expectations
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DLD Awareness and Advocacy Efforts

- CATALISE: A multinational and multidisciplinary Delphi consensus study: Identifying language impairments in children (Bishop et al., 2016)
- CATALISE: A multinational and multidisciplinary Delphi consensus study of problems with language development: Terminology (Bishop et al., 2017)



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DLD Awareness and Advocacy Efforts

- RADLD.org, @RADLD.page, #RADLD, #DLDeuandme
- International DLD Awareness Day 2018
 - Impressions on Facebook = 569,479
 - Impressions on Twitter = 258,700
- Upcoming issue of *Perspectives*
 - CATALISE process and findings
 - Terminology
 - Genetics
 - CATALISE recommendations as they play out in the U.S.



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October 18 is International DLD Awareness Day!



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What will you do?

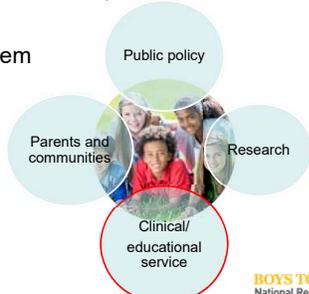
- Read the CATALISE papers in your journal group?
- Put a "what is language" poster in your school?
- Tell someone what DLD is?
- Plan an SLP-teacher workshop using materials provided at RADLD?



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More importantly...

- Work optimally within the system
- Change the system





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Thank you

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