


Reading Development in Individuals with Down Syndrome

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1


Introduction

- PhD
 - University of Alabama, 2013
 - Developmental Science & Cognitive Psychology
 - Focus on Intellectual & Developmental Disabilities
 - Minor in Quantitative Studies
- Postdoctoral Fellowship
 - LifeSpan Institute, University of Kansas, 2013-2015
 - Grant Supported: T32
 - Focus on Single-Subject Design + Reading Interventions
- Assistant Professor
 - University of Mississippi, 2015-2019
 - University of Nebraska-Lincoln, 2019-present




2

My Research



- Learning, language, and literacy in intellectual and developmental disabilities
- Down syndrome cognitive and linguistic phenotype



3



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4

Overview

- Reading development
 - Definitions, stages of reading development
- What is known about reading in Down syndrome
 - Intervention work and recommendations
- Ways to get involved
- Q&A

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5

Disclosures & Caveats


- I am both a researcher and a parent...
- As a researcher I want you to know...
 - There's not enough research on this topic
 - I did more research, converging evidence to trust the patterns of findings and to understand the nuanced differences.
 - Hopefully in 5-10 years, I can come back with new and updated information
 - Research is probabilistic – every finding doesn't apply to every individual, but it is meant to explain the most possible cases
 - Just like with all individuals, there is a lot of variability across individuals with Down syndrome
- As a parent I know...
 - You want suggestions and recommendations, so I am going to use what we do know to offer that
- As a researcher, educator, and parent, I want to say...
 - Your child's reading skills in no way reflect their worth

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6

Question?

What is your goal for your child's (or students' or clients') reading?



7

Reading Development




8

Importance of Reading

- Avenue to independence and social engagement
 - *Acquiring literacy skills contributes to quality of life and full participation in society.* (Copeland & Keefer, 2014)
 - Academics, employment, independent living, social engagement, civic engagement, improved health outcomes
- "Rich get richer"
 - Become better readers, cognitive benefits
 - Struggle in school, constrained opportunities, less independence and even satisfaction as adults

(Adams, 1990; Stanovich, 1986)




9

Ultimate Goal of Reading?

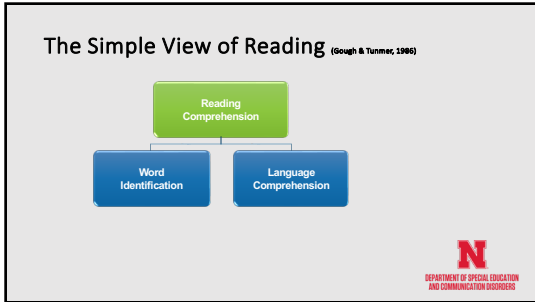
Reading comprehension is the goal

- Understanding what you read
- Allows one to use reading as a tool (for learning, communicating, work, enjoyment)
- Many different subskills must be learned and coordinated for someone to become a proficient reader

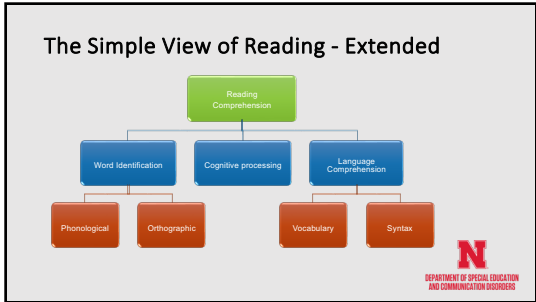
(Catts & Kamhi, 1999)



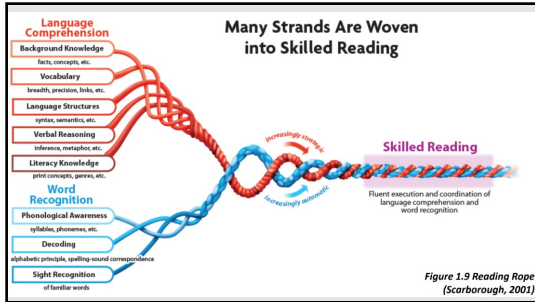
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11



12



13

Some definitions

- **Reading comprehension** – extracting meaning from print; understanding printed text
- **Reading fluency** – accuracy + speed + prosody; efficient reading allows readers to extract meaning from print (comprehend)
- **Word identification** – reading individual words, context free
- **Phonological decoding** – sounding out new/unfamiliar words
 - Phonics
- **Orthographic processing** – visual aspect of reading, recognizing what words look like, spellings
 - *thomer vs. thmoer*

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14

Some definitions


- **Phonological awareness** – identifying and manipulating oral language across multiple levels (sentences, phrases, words, individual phonemes)
 - **Phonemic awareness** – at the level of the phoneme
- **Letter identification** – identification of single printed letters and/or corresponding spoken sounds
- **Language comprehension** – understanding the meaning behind language
- **Vocabulary** – understanding/producing words to represent something
- **Syntax** – arrangement of words and phrases to create sentences

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15

How do these skills develop?

- Several broad theories of reading development
 - Pre-reading — Learning to Read — Reading to Learn
 - Fluent, not discrete "stages"




16

Chall's Stages of Reading Development <small>(Chall, 1967)</small>		
Prereading		
Stage 0	Birth-formal schooling	Language, speech sounds, phonological awareness
Learning to Read		
Stage 1	6-7 years	Grapheme-phoneme correspondences, alphabetic principle, decoding
Stage 2	7-8 years	Consolidation phase to improve decoding and orthographic processing, fluency
Reading to Learn		
Stage 3	9-13 years	Early comprehension, one view-point
Stage 4	14-18 years	Analyzing information from multiple perspectives; begin using reading as a tool to learn new information
Stage 5	18+ years	Construction and reconstruction; using reading to construct and refine views


17

How are these skills supported?




- Prereading
 - Home literacy and language environments
 - Exposure and nature of literacy-related activities in the home (e.g., access to books, quantity and quality of parent-child shared book reading)
 - Promotes language, phonological awareness, word identification
 - Helps children learn conventions of print, such as differences between letters and words, and increases children's interest and attention to print
 - Parents can "scaffold" language development

(Loveall & Burton-Husley, 2021)




18

How are these skills supported? 

- Learning to Read
 - Explicit instruction in alphabetic principle, phonics, and phonology-based interventions to help children "break the letter-to-sound barrier"
- Reading to Learn
 - Support reading comprehension and development of more complex writing skills
 - Build background knowledge and vocabulary
 - Learn about different kinds of texts (e.g., fiction vs. expository) and writing for different purposes (e.g., persuasive)
 - Strategies for evaluating text, drawing inferences, and making informed decisions

(Loveall & Burton-Husley, 2021)




19

How should these skills be taught?


The Big 5 in Reading

- Phonemic Awareness
- Phonics
- Fluency
- Vocabulary
- Reading Comprehension


(National Reading Panel, 2000)



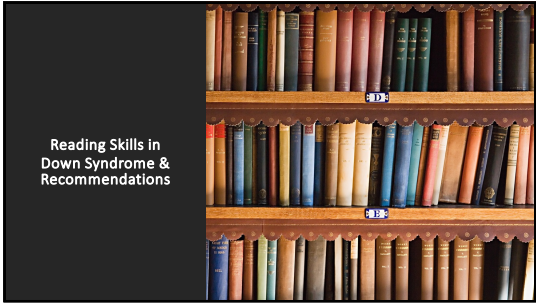
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Question 

Where is your child at in their reading development?
 What skills are they good at?
 What skills do they need more work on?



21




Reading Skills in Down Syndrome & Recommendations

22

What do we know about reading development in individuals with Down syndrome?

- Very little longitudinal data
 - Most studies have examined specific reading skills in individuals with Down syndrome compared to groups with typical development or other intellectual and developmental disabilities/differences
- Wide age ranges in these studies, so this overview focus on the skills developed at each stage rather than chronological ages of participants
- When assessing reading and providing instruction/intervention, educators and clinicians should also focus on the individual's skills rather than their chronological age
 - Don't think they have to wait to get started
 - Don't think they have to keep pace with peers
 - Don't limit them


(Loveall & Barton-Hulsey, 2021)



23

Additional Considerations


- Many things can impact reading development
 - Phenotypic (aka common Down syndrome characteristics) Considerations
 - Executive function – working memory
 - Attention
 - Individual differences
 - Speech/language
 - Motivation
 - Environmental factors
 - Exposure to language, print
 - Instructional techniques
- Historically, reading instruction for students with intellectual disabilities, including Down syndrome, has been slow
 - Couldn't read
 - Decoding too hard → only teach "functional" sight words
- Today, we know that students with Down syndrome can learn to read
 - Includes moving beyond sight words
 - How to decode
 - Reading comprehension



24

Speech & Language in Down Syndrome


- Within speech, babbling may be delayed (Kent & Vorperian, 2013)
 - Matters because caregivers respond to babbling, provides speech input, promotes speech and language development
- First words will likely be delayed (Stoel-Gammon, 2001)
- Vocabulary is a relative strength, but grammar and syntax will likely be difficulties later (Abbeduto et al., 2007)
- Receptive language (comprehension/understanding) is usually stronger than expressive language (producing language) (Abbeduto et al., 2007)



25

Prereading


- Home literacy environments seem rich (including interactive reading with parents), not clear how this compares to other children
 - And initial evidence suggests it predicts child's word learning/vocabulary (Dulin, Lowell, Mattie, 2023; Jeremic et al., accepted)
- Phonological awareness seems to be an area of difficulty (Lowell & Barton-Hulsey, 2021)
 - In the 1990's a study suggested that children with Down syndrome could learn to read without any phonological awareness skills
 - This, paired with noted strengths in visual processing, led some to believe that children with Down syndrome would benefit more from a more visual approach to reading
 - However, recent and converging evidence suggests that children with Down syndrome can develop phonological awareness skills and that they positively relate to reading outcomes



26

How to Support Prereading


- Request SLP or someone knowledgeable about early language development on your child's early intervention team
- Foster rich language environments
 - Talk to your child a lot!
 - Respond to babbling
 - Isolate vocabulary words
 - Teaching vocabulary can improve language but also phonological decoding skills (Hess et al., 2012)
 - Adjust your language to meet their child's developmental needs (e.g., simplify syntax)
 - No evidence that sign language or AAC harm speech development in Down syndrome
- Foster rich home literacy environments
 - Have books accessible
 - Participate in shared book reading and make it interactive (have your child sit in your lap facing you to engage with you more during reading, let them turn the pages, don't rush, be expressive)
 - Don't think you have to stop reading with your child when they reach a certain age
 - Model reading
 - Use whatever is interesting to your child



27

How to Support Preading

- Promote phonological awareness
 - ABCs, letter sounds
 - Rhyming games
 - Combining words
- During shared book reading teach letters and letter sounds
- (Print referencing) An intervention by Van Bysterveldt et al. (2006) had parents of four-year-old children with Down syndrome:
 - State the letter name while pointing to the letter in a book
 - Describe the sound it makes
 - Bring their child's attention visually as well as orally to the target letter and corresponding phoneme in initial position in a word, while pointing to the word
 - This is the letter "S". It makes the "ssss" sound. "SSSS" is the first sound in the word "Spot" (point to Spot).
 - Balance number of letters you do this with to maintain the child's interest in the story.




28

Learning to Read

- Word identification is an area of strength
 - Once thought to be "an island of ability"
- Phonological decoding (sounding out) is often an area of difficulty
 - Phonological skills predict word identification (awareness, decoding, memory)
- Much less research on orthographic processing, but may be a relative strength
 - Specifically for real words (salad vs. sallad)
 - More difficult for new or unknown letter patterns (thomer vs. thmoer)


(Loveall & Burton-Hulsey, 2021)



29

Learning to Read


- Word identification is an area of strength
- Frequently hypothesized to link to phenotypic strengths in visual skills
- However, may also be tied to instructional practices
- Historically, whole word approaches have been used
- Only more recently that phonics approaches have been used



30

How to Support Learning to Read

- Whole words vs. phonics
 - **Whole word approach** – “look and say”, teach the entire word and then have students practice them by reading appropriate stories and other passages
 - Stresses meaning of words and believes that students will learn the “code” incidentally
 - Drilling students with letters and sounds hurts their motivation to read
 - Benefit is that students can learn a large number of individual words
 - Drawback is that students don’t learn letter-sound correspondences that are needed to decode new words
 - **Phonics** – “language code”, teach relationships between graphemes/letters and phonemes/sounds
 - Produces better readers → word recognition, vocabulary, comprehension
 - Within the last 20 years, more research on Down syndrome has begun to focus on decoding




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31

How to Support Learning to Read

- Shift from just teaching whole words to phonics has resulted in research that considers both
 - Phenotypic strengths (visual skills)
 - Individual differences (stronger language skills lead to better readers)
- Many researchers have recommended a combined approach that capitalizes on visual strengths but still teaches phonics
- Lemons et al. (2017) adapted a reading program targeting letter-sound knowledge, phonological awareness, and phonological decoding for 6-8-year-old children with Down syndrome



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32


How to Support Learning to Read

What we know about Down syndrome


- Instructional materials developed to support strengths in visual processing by using highly imageable words paired with pictures during decoding
- Target letters were printed and enlarged so they could be physically manipulated during activities
- Intervention modified its language/instructions to reduce cognitive load
- Participants could respond nonverbally by pointing to target words
- Teachers were taught to redirect students back to the lesson if they attempted to socially engage in off-topic conversation

Individual Differences

- Order of instruction was customized based on each child’s speech production ability, with easiest sounds targeted first

Results 

- A majority of participants learned directly taught letter-sound relations, but they learned at different rates.
- Considering phenotypic strengths and weaknesses while still focusing on phonological processing skills was beneficial




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33

Reading to Learn

- Reading comprehension in Down syndrome has received little attention in research
- Likely an area of difficulty though, even relative to word identification levels
- Appears that language comprehension is particularly important to reading comprehension in Down syndrome
 - Learning Lab: tested 21 adolescents and adults with Down syndrome
 - Mean age = 25
 - Mean IQ = 48
 - Specifically recruited as "readers"
 - Tested Simple View
 - Listening comprehension was only significant predictor of reading comprehension
 - But all participants had strong word identification and decoding skills
 - Now need to test younger readers




(Loweall & Burton-Hujsy, 2021; Loweall et al., 2023)



34

Supporting Reading to Learn

- No intervention studies specific to Down syndrome
- Turn to research on typical development and with intellectual disabilities
- Strategies to support reading comprehension:
 - Develop strong foundation in decoding and language
 - Vocabulary doubly beneficial
 - Strategy Instruction
 - Reciprocal Teaching
 - Graphic Organizers




35

Supporting Reading to Learn

- **Strategies** – cognitive processes that people use to help them understand what they read
 - Find the main idea
 - Prediction
 - Generating questions
 - Summarizing
 - Clarifying
 - Identifying key characters
- **Reciprocal teaching** – approach in which student and teacher or peers take turns reading portions of a text and using strategies to deepen their understanding


(Copeland & Keefe, 2016)



36

Supporting Reading to Learn

- **Repeated reading** – strategy in which a student repeatedly reads a passage
 - Passage should be at the student’s instructional level (but still age-appropriate), and motivating to them
 - Includes modeling and feedback
 - Need corrective feedback, particularly when making word reading errors
 - Can have student read passage a set number of times or until they reach a predetermined CWPM (correct words per minute)
 - Can include paired reading




37

Supporting Reading to Learn

Reread-Adapt and Answer-Comprehension (RAAC) by Therrien et al. (2006)

1. Students read generic questions related to the text prior to reading the actual text
2. Students read and then re-read a text at their instructional level to a tutor who corrects any decoding/word reading errors
3. Once the student reaches a set performance criterion, they move on to a more difficult passage
4. Student is asked to answer comprehension questions (both factual and inferential)



38


Supporting Reading to Learn

Adaptations for students with ID (Ihu, Therrien et al. 2012)

- Before reading a passage, students were asked to read generic questions related to components of narrative passages
- Read passage three consecutive times
 - Timed
 - Tutor used an error correction procedure until all missed words were read correctly
 - Tutor provided feedback on fluency, accuracy, and prosody
- Student asked comprehension questions
 - Generic comprehension questions
 - Four passage-specific factual questions
 - Four passage-specific inferential questions

Question Generation Prompts

How did the main character feel?
 Who is the main character?
 Where and when did the story take place?
 What did the main character do?
 How did the main character feel?



39

Supporting Reading to Learn

Error Correction Procedure

- Occurred after each passage reading
- Tutor points to the word that was read incorrectly and said, "This word is _____. What word?"
- After modeling all the incorrectly read words in the passage, the tutor pointed to each word and asked the student to read them independently, "What is this word?"
- This error correction procedure was repeated until the student read all words correctly without additional help

Feedback on fluency, accuracy, and prosody provided after this error-correction procedure


Level 4	<input type="checkbox"/> I read most of the story to help you understand it better.
	<input type="checkbox"/> I repeated or modeled with a few words.
	<input type="checkbox"/> I reread and explained words or phrases.
	<input type="checkbox"/> I read with expression.
Level 3	<input type="checkbox"/> I read most of the story to 5 to 10 word phrases.
	<input type="checkbox"/> I repeated or modeled with a few words.
	<input type="checkbox"/> I reread and explained words or phrases.
	<input type="checkbox"/> I read most of the story with fluency.
Level 2	<input type="checkbox"/> I read most of the story in short word phrases.
	<input type="checkbox"/> I repeated or modeled one easy word.
	<input type="checkbox"/> I did not emphasize important words or phrases.
Level 1	<input type="checkbox"/> I did not read with expression.
	<input type="checkbox"/> I read most of the story word by word.
	<input type="checkbox"/> I repeated or modeled one easy word.
	<input type="checkbox"/> I did not emphasize important words or phrases.
	<input type="checkbox"/> I did not read with expression.

40

Supporting Reading to Learn

Comprehension

- After student read passage three times, tutor asked student to answer comprehension questions
- If the student did not know or answered incorrectly, the tutor provided prompts
 - Read the passage again to find the answer, "Can you find the answer in the passage?"
 - If this did not result in the correct answer, the tutor asked the student to read the sentence where the correct answer could be found or inferred, "Can you find the answer in this sentence?"
 - If this did not result in a correct answer, the tutor provided the correct answer and explained the reason
- At the end of the session, they asked the 8 passage-specific questions




41


Supporting Reading to Learn

What can parents do?


- Find things that are interesting to read for their child
- Read with them
- Identify words they don't know and talk about them (how to pronounce them, what they mean)
- Ask questions before, during, and after reading to support comprehension
- Don't limit yourselves/them to "books"
 - Social media
 - Text messaging
 - Apps/games that promote reading/writing/spelling
 - Magazines



42

Question 


What has been the most challenging or frustrating things about teaching your child (student/client) to read?



43

Tips for Families (Lemons et al., 2016)

- Review data from the school to understand your child's current strengths and areas of need.
- As students get older, consider postsecondary needs and target independence, employment, and social aspects (friends, leisure).
- Work with school personnel to plan specific goals, services to meet these goals, data that will be shared to monitor progress, and the location of services that will ensure goals can be appropriately targeted.
- If you don't understand, ask questions.
- Request guidance from teachers on how you can support instruction at home.
 - Don't overdo it.
 - Keep reading fun.
 - Spend more time on increased access to literature.
 - For more basic skills, your role should be more practice than primary instruction.




44

Other Tips

- Many of the research-based strategies used for typical development also work for students with ID
 - But they likely will need instruction to be broken down, sustained, and intensive instruction
- Start teaching reading comprehension strategies early and incorporate into comprehensive instruction
 - Even when students are still learning to read at the word level
 - Making and checking predictions, sequencing, story grammar, making inferences
- Use instructional materials that are based on students' interests whenever possible to promote engagement and support comprehension
- Offer supports for working memory, executive function, and other cognitive skills

(Allor et al., 2010; 2014; Copeland & Keefe, 2016)



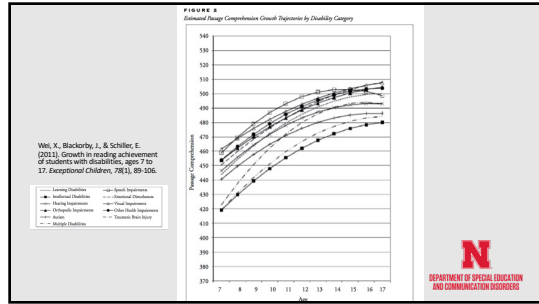
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Question?

What is a “win” you’ve had when it comes your child’s reading?



46

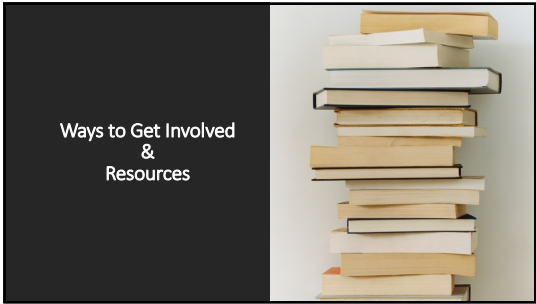


47

“We have found no way of predicting a child’s potential for reading or readiness to read. In our view, both concepts are meaningless... The only way to find out how far they may progress is to continue to teach them.”

Sue Buckley & Gillian Bird

48



49

Current Research Studies

Reading Comprehension in Down Syndrome

- NIH Funded study
- Ages 10-18 years
- In-person, but we can travel to you or reimburse you for traveling to us!

```

graph TD
    RC[Reading Comprehension] --> WI[Word Identification]
    RC --> CP[Cognitive processing]
    RC --> LC[Language Comprehension]
    WI --> P[Phonological]
    WI --> O[Orthographic]
    LC --> V[Vocabulary]
    LC --> S[Syntax]
  
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
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Upcoming Research Studies


- Adaptive Behaviors in Down Syndrome
 - Caregivers of individuals birth to 22 years
 - Remote
- Babble Boot Camp
 - Direct intervention to promote early speech/language development (18RB to 1 year)
 - Remote
- Early Intervention
 - Understand family experiences with early intervention in Nebraska (birth to 5 years on an IFSB or ISF)
 - Remote

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51

Resources 

- Reading and Language Intervention for Children with Down Syndrome (RLI)
• <https://www.dsvhsystem.com/focus/innovations/rli/introduction/>
- What Works Clearinghouse
• <https://ies.ed.gov/ncee/wwc/>
- AAC & Reading Overview
• <https://leader.cubs.asu.edu/doi/10.1044/leader.FB1.08122003.6>
- Learning Lab for Intellectual & Developmental Disabilities
• <https://cebs.unl.edu/learninlab/>
- Susan Loveall
• Loveall1@unl.edu



52

Questions



53


Thank you so much!



54

10 Research-Based Tips for Enhancing Literacy Instruction for Students with Intellectual Disability (Lemons et al., 2016)


- 4. Provide instruction with sufficient intensity to accomplish goals
 - 4. Difficulties with inclusion vs. pullout instruction
 - 5. Likely need multiple years of intervention
- 5. Seek out professional development opportunities
- 6. Remember that language abilities are the underlying foundation for reading skills
 - 4. Make connections with language, collaborate with SLPs



58

10 Research-Based Tips for Enhancing Literacy Instruction for Students with Intellectual Disability (Lemons et al., 2016)

- 7. Scaffold working memory
 - 7. Use visuals to support
- 8. Target specific parts of a scope and sequence to focus instruction
 - 7. For example, identify limited number of new words or sounds to be taught at a time
- 9. Use data to guide instruction and adaptation
- 10. Involve service providers and family members



59
