

Literacy Development Milestones in Children with Down Syndrome

¹Jennifer Harris, MSE; ¹Rebecca Bernstein, BA; ¹Kristine Wolter-Warmerdam, PhD ABD, MA; ¹Francis Hickey, MD

¹The Sie Center for Down Syndrome, Children's Hospital Colorado, Aurora CO



Background

- Children and young adults with Down syndrome (DS) have different literacy patterns compared to their neurotypical peers
- Currently no validated development schedule for literacy skills in the DS population
- Professionals are limited in ability to identify development and assess for interventions of youth with DS

Objectives

- Evaluate the literacy development of children with DS using a large cohort of school-age children
- Identify potential factors, other than age, that may impact literacy achievement
- Establish baseline data for a future reliability and validity assessment of the clinic Literacy Development Parent Questionnaire (LDPQ)

Methods

- Caregivers of patients ages 3-18 years seen by the education specialist at a pediatric DS clinic received the standard of care clinic LDPQ
 - Focus on literacy skills of alphabetic principle, phonological awareness, and phonics
 - 7 literacy levels assessed
- Retrospective review of 294 LDPQ surveys were analyzed from 271 unique patients
 - Mean age=9.3 years, SD=4.0
 - Primary language, English (n=236) and Spanish (n=35)

Results

LDPQ: Literacy Levels

- Overall, 7 literacy levels were classified
- Examples of specific skills per level are outlined below

Literacy Level Skills

Foundational Reader-1

Pats book/pictures
 Looks at pictures
 Turns page board book
 Matches objects

Early Emergent Reader-2

Will join in ABC song
 Will sit/listen to short story
 Knows name in print
 Matches letters of name

Emergent Reader-3

Points out/name's letters outside of name
 Knows 17-26 letters by name
 Can spot like/unlike letter sounds
 Can clap words into syllables
 Can point out/read 5-20 sight words

Developing Reader-4

Can match upper to lowercase letters
 Knows 17-26 letters by sound
 Can name/point to 20+ sight words
 Can answer WHAT and WHO in text

Early Fluent Reader-5

Names/sorts by last sound
 Sounds out words with 2/3 sounds
 Answers questions from text
 Names/points to 50-100 sight words

Emergent Fluent Reader-6

Knows common letter combinations
 Names/points to 100+ sight words
 Sounds out words with silent "e"
 Self-corrects simple errors
 Makes basic predictions

Fluent Reader-7

Reads words with vowel + r
 Substitutes one phoneme for another
 Reads to gather information
 Comes up with alternative solution
 Sounds out new, complex words

Literacy Level Identification

- Individual literacy level scores were calculated for each patient
 - Each skill: Yes=2 points; Sometimes=1 point; Not yet=0 points
 - Children were identified as within the literacy level if achieved $\geq 70\%$ of total possible score
- Ages were categorized based on similar literacy patterns
 - 3-4 years (n=35); 5 years (n=32); 6 years (n=31); 7 years (n=32); 8 years (n=30); 9-10 years (n=41); 11-12 years (n=27); 13-14 years (n=35) | 15-18 years (n=31)

Factors Impacting Literacy

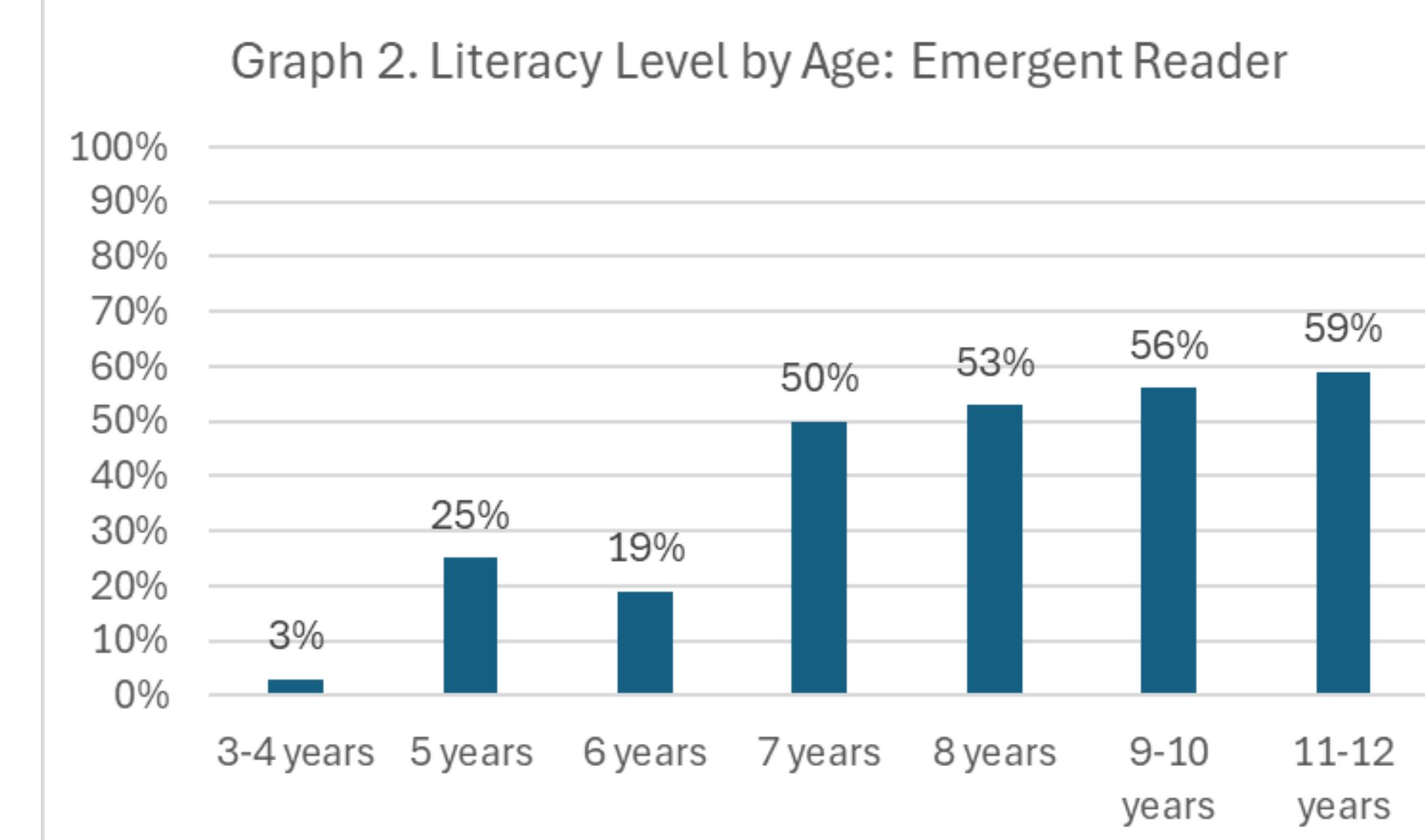
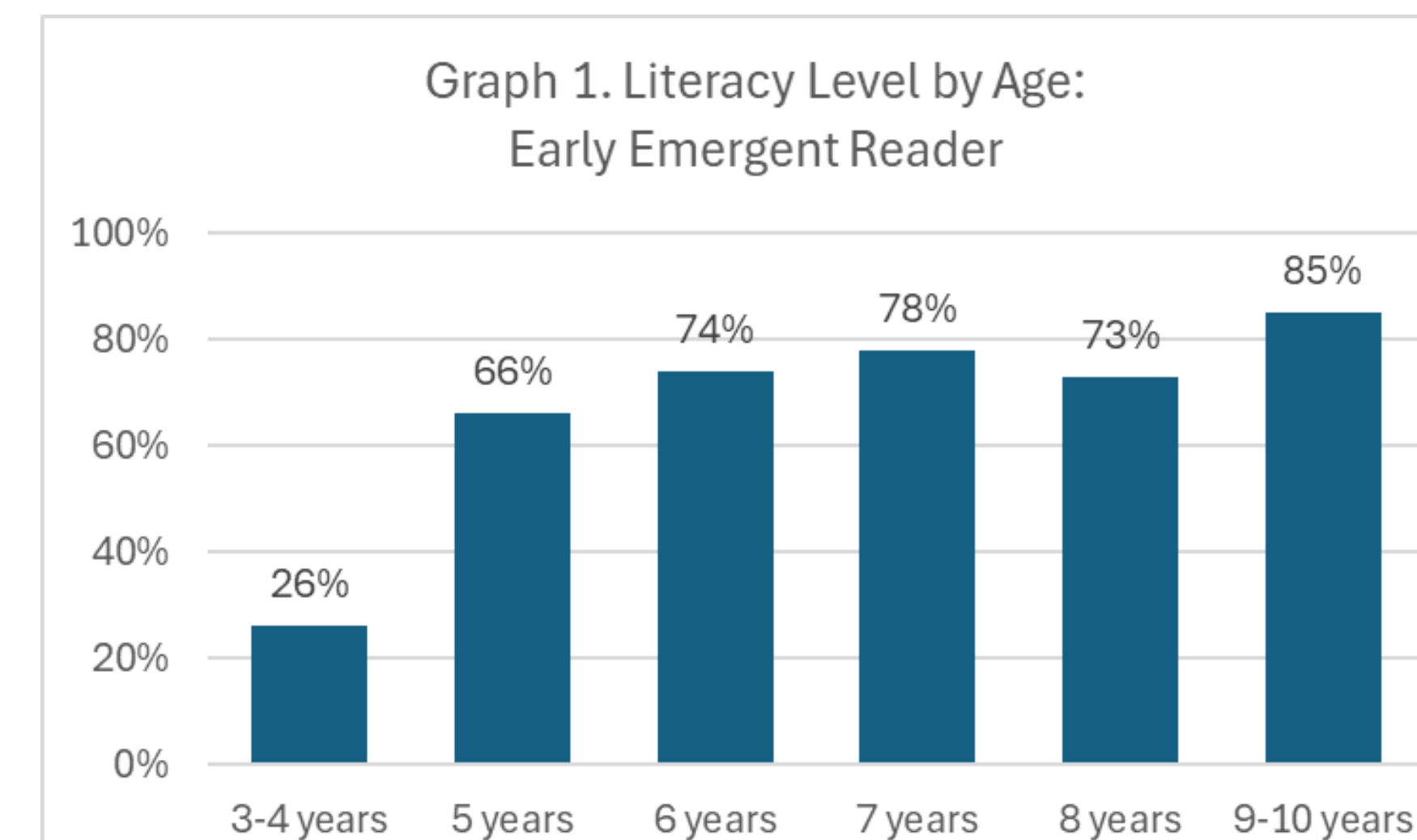
- Binomial logistic regressions were run to determine impact of primary language in the home, expressive language delay [identified by Augmentative and Alternative Communication (AAC) referral], gender, average minutes per week child is read to, and age on literacy achievement for each level (Table 1)

Table 1. Logistic regressions predicting likelihood of literacy achievement based on age, gender, primary language, average number of minutes the child is read to, and expressive language delay

Literacy Level	Model	Significant Factors
Foundational Reader	$\chi^2(5) = 20.384, p < 0.001$	Reading per week: $p=0.006$; Primary language: $p=0.025$
Early Emergent Reader	$\chi^2(5) = 47.925, p < 0.001$	Age: $p<0.001$; Gender: $p=0.010$; Reading per week: $p<0.001$; Primary language: $p=0.006$
Emergent Reader	$\chi^2(5) = 55.794, p < 0.001$	Age: $p<0.001$; Primary language: $p<0.001$; AAC: $p=0.050$
Developing Reader	$\chi^2(5) = 45.450, p < 0.001$	Age: $p<0.001$; Primary language: $p=0.050$
Early Fluent Reader	$\chi^2(5) = 32.098, p < 0.001$	Age: $p<0.001$; Primary language: $p=0.032$
Emergent Fluent Reader	$\chi^2(5) = 35.539, p < 0.001$	Age: $p<0.001$; Reading per week: $p=0.045$
Fluent Reader	$\chi^2(5) = 23.337, p < 0.001$	Age: $p<0.001$; Reading per week: $p=0.026$

Literacy Level Findings by Age

- Literacy reader level
 - Foundational – Present in children with DS 3+ years
 - Early Emergent – Emerges at 5 years of age (Graph 1)
 - Emergent – Emerges at 7 years of age (Graph 2)
 - Developing – Gradually begins at 8 years of age
 - Early Fluent – Varies starting at 8 years
 - Emergent Fluent – Varies starting at 11-12 years
 - Fluent – Gradually begins at 11-12 years



Conclusions

- Individuals with DS follow a unique timeline in development of literacy skills
- Factors such as gender, expressive language, primary language, and time spent being read to impact literacy outcomes at different ages and stages of development
- Preliminary data offers a promising foundation for developing clear trajectories, timelines, and strategies to support literacy development

Implications

- Literacy development of school-age children with DS should be assessed based on performance relative to other children with DS
- Early identification of advanced, age appropriate or delayed development, as well as potential risk factors, are important for professionals for determining targeted interventions and support
- Future research is crucial to better develop a literacy development schedule in DS

Disclosures

The authors declare that they have no conflict of interest with respect to the research, authorship, and/or publication of this article. The authors received no financial support for the research, authorship, and/or publication of this article.

References

- Abbeduto, L., McDuffie, A., Thurman, A. J., & Kover, S. T. (2016)
- Bird, J., Bishop, D. V., & Freeman, N. H. (1995)
- Bochner, S., Outhred, L., & Pieterse, M. (2001)
- Boudreau, D. (2002)
- Centers for Disease Control and Prevention. (2020, October 23)
- Cupples, L., & Iacono, T. (2000)
- Mackrides, P. S., & SUSAN J RYHERD, E. (2011)
- Nash, H., & Heath, J. (2011)
- Ricci, L. (2011)
- Roch, M., & Jarrold, C. (2008)
- van Bysterveldt, A., & Gillon, G. (2014)