



DEVELOPMENTAL DISABILITIES

Literacy Promotion Guide

for Pediatric Healthcare Providers



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Project Team

REACH OUT AND READ DEVELOPMENTAL BEHAVIORAL PEDIATRIC CONSULTANT

Monica H. Ultmann, MD

Director, Center for Children with Special Needs and Division of Developmental Behavioral Pediatrics, Floating Hospital for Children at Tufts Medical Center

Clinical Professor of Pediatrics, Tufts University School of Medicine

REACH OUT AND READ NATIONAL CENTER

Alison Corning Clarke, MA, MSW, Programs Project Manager

Abigail Holstein, Marketing Manager

Diane Malcolmson, MBA, MIA, Chief Development Officer

Nikki Shearman, PhD, Chief of Network Strategy and Evaluation

ADVISORY BOARD

Marilyn Augustyn, MD, Director, Department of Developmental and Behavioral Pediatrics, Boston Medical Center, Boston, MA; Associate Professor of Pediatrics, Boston University School of Medicine

Kathleen Braden, MD, Emeritus Clinical Professor of Pediatrics, UMass Medical School, Worcester, MA

Pamela High, MD, Director, Division of Developmental-Behavioral Pediatrics at Rhode Island Hospital/The Warren Alpert Medical School of Brown University

Ella Kingsley, MA, Retired Teacher; parenting grandparent of a child with intellectual disability

Robert Needlman, MD, FAAP, Professor of Pediatrics, Case Western Reserve University School of Medicine; Pediatrician, MetroHealth Medical Center, Cleveland, OH; Co-Founder of Reach Out and Read

Christine Reilly, MEd, Teacher of Visual Impairment; parent of child with Cortical Visual Impairment

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Introduction

The Developmental Disabilities Literacy Promotion Guide For Pediatric Healthcare Providers



Dr. Monica H. Ultmann

Reading to her granddaughter

The Developmental Disabilities Literacy Promotion Guide was developed for primary care providers who treat infants and children with developmental challenges and provide support, advice, and helpful resources to their families. It was developed in collaboration with the professionals of the Reach Out and Read National Center and is part of their Special Initiatives program. The guide is designed to be used as a point of reference for healthcare providers already trained in the Reach Out and Read model of early literacy promotion and parent engagement, although new providers and trainees are also welcome to use the material.

The concept for this guide is based on the mandates of the many professional organizations that encourage healthcare practitioners to screen for and identify, at earlier ages, infants and children at risk for developmental disabilities, and to create medical homes for their ongoing primary care. The content provided within this guide supports the efforts of primary care providers who care for this complex group of children, as they provide anticipatory guidance and resources to parents and caretakers.

Each delay/disorder-specific handout for families, included in the material in separate tear-off sheets, provides advice for parents/caretakers about the importance of reading with their child, suggested books by age group, and internet resources and books they can turn to for reliable information and support. Eight developmental disabilities are included: Speech and Language Delay; Autism Spectrum Disorder; Motor Delay; Developmental Delay; Hearing Loss; Vision Loss; Short Attention Span, High Activity Level, or Attention Deficit Hyperactivity Disorder; and Learning Style Differences.

New information to share with parents is always emerging. We hope that you find this guide informative and helpful during your busy clinical day, as you introduce literacy promotion to some of the thousands of children with developmental disabilities (and their families) that Reach Out and Read serves. If you have questions and ideas or suggestions to share, please email info@reachoutandread.org.

Sincerely,

Monica H. Ultmann, M.D.

Reach Out and Read Developmental Behavioral Pediatric Consultant

Director, Center for Children with Special Needs
Floating Hospital for Children at Tufts Medical Center

Clinical Professor of Pediatrics
Tufts University School of Medicine

Emergent Literacy

Concept, Challenges, and Implications for Infants and Children with Developmental Disabilities

Emergent literacy refers to the steps infants and children progress through as they master the complex requisites for reading and writing. In addition to being a cognitive process, literacy acquisition involves a fine-tuned balance of linguistic, psychological, and social factors depending heavily on the attachments formed with important people in a child's immediate environment.

Acquiring language and literacy skills involves integrating literacy practices and routines into the everyday lives of families by:

- Early verbal and nonverbal interactions
- Opportunities to physically explore
- Daily exposure to reading aloud and/or oral stories
- Engaging toddlers in “playtalk” or imaginative, rich conversations that help to build oral language
- Word games (rhyming, singing, poetry)
- Scribbling and drawing
- Conversations about books and stories

For infants and children with suspected or diagnosed developmental disabilities, the process of acquiring early language and literacy skills may be slower and more difficult because of:

- Atypical social/emotional development
- Attachment and parent/child interactions
- Limited sensory and/or cognitive skills
- Physical constraints
- Attentional challenges
- Motor planning/mobility
- Misunderstanding a child's abilities



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Using Books During the Check-Up

Utilizing Books for Developmental Surveillance

Touchpoints for Anticipatory Guidance in Typically Functioning Infants and Children and those with Developmental Concerns

Giving a book to a child during a routine health maintenance visit allows the healthcare provider a unique opportunity to relate to the child and the family. When a child picks up a book, opens it, and begins to interact with its content, the healthcare provider can view the child through a different lens. Though not considered a screening tool because of the inherent lack of standardization, introducing books can serve as a unique way to observe the child's developmental skills and interaction with his or her parent or caretaker.

The following can be observed during an examination, dependent on the age and developmental level of the child:

- **Eye contact: normal, brief, sustained**
- **Attention to task as well as joint attention and focus**
- **The child bringing items for shared enjoyment, and the presence of turn-taking between the child and the adult**
- **How the parent and child interact surrounding book reading: body language, emotional signals, and efforts to engage the child**
- **Language development:**
 - Expressive: verbal (babbling, words, phrases, rhyming, spontaneous conversation), nonverbal (gestures, pointing)
 - Receptive: understanding directions, pointing to pictures
 - Pragmatic: the social context of language
 - Phonemic/Phonological awareness: ability to identify and mentally manipulate the sounds (phonemes), sound sequences, and sound structures in a syllable or word

- **Atypical Language:** echolalia (immediate and delayed)
- **Fine motor skills:**
 - Holding the book
 - Turning pages
 - Pointing
 - Tactile abilities
 - Preferences

When providing families with anticipatory guidance concerning literacy activities:

- Encourage families to balance the demands of the educational goals, therapies, and medical needs of the child with time for activities of mutual pleasure—shared reading, story-telling, playing games, and time enjoying the outside (hide and seek, going to the park).
- Encourage communication, modeling reading and writing, and building literacy-rich home environments.
- Acknowledge what parents and caretakers are already doing to promote early literacy in their children.
- Encourage adaptive approaches and tools to meet a child's specific needs (e.g., story boxes, tactile experience books for children with vision loss, social stories for children with autism, etc.)
- Acknowledge that the child may be difficult to engage or inattentive/hyperactive and provide positive feedback to caregivers about their daily work with the child and further suggestions for interventions.

When providing families with anticipatory guidance concerning support services for their infant or child:

- For infants and toddlers identified with developmental concerns prior to three years of age, direct parents to early intervention programs for evaluation. Suggest disability-specific resources to them through which they can learn how to engage their child in language, literacy, and play activities at home.
- For children approaching their third birthday, inquire whether their parents/caretakers and/or the Early Intervention team have contacted the special education department of their public school system and whether the child is being evaluated for preschool services.
- For children who are turning five years of age, inquire whether their parents/caretakers have met with their child's preschool team concerning preparation for their child's transition to kindergarten. If the child is not attending school, they should be encouraged to register and contact the special education department of their public school system to seek an evaluation for their child to qualify for services.



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Resources for Primary Care Providers

Healthcare Delivery and General Information on Literacy

BOOKS

Identifying and Addressing Developmental-Behavioral Problems: A Practical Guide for Medical and Non-Medical Professionals, Trainees, Researchers and Advocates

by Frances Page Glascoe, Ph.D., Kevin P. Marks, MD, Jennifer K. Poon, MD, and Michelle M. Macias, MD (2013)

AAP Developmental and Behavioral Pediatrics, Second Edition

Editor: Robert G. Voigt, MD, FAAP; Associate Editors: Michelle M. Macias, MD, FAAP, Scott M. Myers, MD, FAAP, and Carl Tapia, MD, MPH, FAAP (2018)

Guide to Learning Disabilities for Primary Care: How to Screen, Identify, Manage, and Advocate for Children with Learning Disabilities

by Larry B. Silver, MD, FAACAP and Dana L. Silver, MD, FAAP (2010)

Encounters with Children: Pediatric Behavior and Development, Fourth Edition

by Suzanne D. Dixon and Martin T. Stein (2005)

Children with Disabilities, Seventh Edition

Edited by Mark Batshaw MD, Nancy Roizen MD, Gaetano Lotrecchiano, Ed.D., Ph.D. (2012)

WEB RESOURCES

Find all web resources at reachoutandread.org/ddresources

READING TO CHILDREN

AAP Books Build Connections Toolkit
www.aap.org/en-us/literacy/Pages/default.aspx

Reach Out and Read Literacy Resources
www.reachoutandread.org/resource-center/

GENERAL INFORMATION AND HEALTH SUPERVISION GUIDELINES ON DEVELOPMENTAL DISABILITIES (LIMITED LIST)

American Academy of Child and Adolescent Psychiatry (AACAP)
www.aacap.org

American Academy of Family Physicians (AAFP)
www.aafp.org

American Academy of Pediatrics (AAP)
www.aap.org

American Academy of Physician Assistants (AAPA)
www.aapa.org

Center for Disease Control: Developmental Disabilities
www.cdc.gov/ncbddd/developmentaldisabilities/index.html

National Association of Pediatric Nurse Practitioners (NAPNAP)
www.napnap.org



Suggested Activities

to Encourage Literacy for All Children

FOR INFANTS OR TODDLERS

- Cuddle your baby often. Smile and make eye contact.
- Respond to her babbles and coos—have back and forth conversations.
- Play touching and singing games with his nose, toes and tummy.
- Play peek-a-boo, patty-cake, and puppet games.
- Sing lullabies to calm her. Music builds memory and language skills.
- Point to and name objects around him.
- Clap along to the rhythm of the words in rhyming books
- Read to your toddler every day for at least 5-10 minutes.
- Include books in daily routines such as naptime and bedtime.
- Re-read her favorite stories.
- Make it easy for your toddler to reach his/her own books.
- Tell stories and sing songs and rhymes in your home language.
- Replace television and technology time with the Name Game, reading, and outdoor activities.
- Encourage the people who care for him to read and talk with him.
- Explore infant/toddler programs at your library.

FOR PRESCHOOL OR SCHOOL-AGE CHILDREN

- Increase daily reading to 20-30 minutes.
- Build his listening and comprehension skills by reading books with more words and fewer pictures such as *Frog and Toad* or longer picture books.
- Help her to build a personal library of books.
- Bring books in the car, on the bus, to the doctor's office, and anywhere else he is required to wait.
- Use the library for free audio books for long trips.
- Have her apply for her own public library card.
- Talk about colors, numbers, letter names, and sounds on street signs, cereal boxes, T-shirts, and other things around him.
- Point to pictures and talk about them.
- Play rhyming games and word games like the Name Game.
- Even if she is starting to read, keep reading with, and to, her.
- Take turns reading to each other.
- Early reading and writing skills develop at the same time, so help him use crayons, markers, and paint to draw pictures



Activities to Encourage Language and Literacy Development

	HOW TO READ WITH YOUR INFANT OR TODDLER	WHAT TO READ WITH YOUR INFANT OR TODDLER
Speech and Language Delay	<ul style="list-style-type: none"> ■ Use books that rhyme and/or repeat. ■ Talk about the story to aid comprehension. 	<p><i>Brown Bear, Brown Bear, What Do You See?</i> by Bill Martin, Jr.</p> <p><i>Each Peach Pear Plum</i> by Allan and Janet Ahlberg</p> <p><i>Sign and Sing-Along Series</i> by Annie Kubler</p>
Developmental Delay	<ul style="list-style-type: none"> ■ Reading, rhyming, and word play are important. ■ Read books about everyday activities and objects. 	<p><i>I Can, Can You?</i> by Marjorie W. Pitzer</p> <p><i>Kids Like Me</i> by Laura Ronay (and other titles)</p> <p><i>Families</i> by Rena D. Grossman (and other titles)</p>
Motor Delay	<ul style="list-style-type: none"> ■ Find a way to position the child next to you. ■ Use books with thick, sturdy pages. 	<p>Stroller Strap Books such as <i>Ears, Nose & Toes</i></p> <p>E-Z Page Turners such as <i>Trucks</i> and <i>Opposites</i></p>
Vision Loss	<ul style="list-style-type: none"> ■ Sit close together with light on the page. ■ Use scratch and sniff books and those with textures, mirrors, shiny or raised objects, and black and white pictures, or audio books. ■ Introduce Braille books early. 	<p><i>Pat the Bunny</i> by Dorothy Kunhardt (and other Touch and Feel books)</p> <p><i>DK Braille: Animals</i> (and other titles)</p> <p><i>How Do Dinosaurs Eat Cookies?</i> by Jane Yolen</p> <p><i>Black & White</i> by Tana Hoban</p>
Hearing Loss	<ul style="list-style-type: none"> ■ Make sure she can see the reader's face AND the book. ■ Turning pages, touching pictures, and lifting flaps will help prepare him for sign language ■ Use simple signs while speaking the story. 	<p><i>Sign and Sing Along Series</i> by Annie Kubler</p> <p><i>Baby Signs</i> by Joy Allen</p> <p><i>Meal Time</i> by Anthony Lewis (and other titles)</p> <p><i>My First Book of Sign Language</i> by Joan Holub</p>
Autism Spectrum Disorder	<ul style="list-style-type: none"> ■ Books with faces can help her recognize emotions. ■ Reading and conversations build oral language, joint attention, and reciprocity. 	<p><i>Global Babies</i> by Mara Ajmera</p> <p><i>Smile!</i> by Roberta Grobel Intrater</p> <p><i>Feelings</i> by Susan Canizares</p>
Short Attention Span, High Activity Level, or ADHD	<ul style="list-style-type: none"> ■ Read to your toddler every day for at least 5–10 minutes. ■ Turn off all media to read without distraction. ■ Keep reading even if he wanders off; he may still be listening. 	<p><i>The Itsy Bitsy Spider</i> by Rosemary Wells</p> <p><i>If You're Happy and You Know It</i> by Annie Kubler</p> <p><i>Ring Around a Rosie</i> by Annie Kubler</p> <p><i>Row, Row, Row Your Boat</i> by Annie Kubler</p>
Learning Style Differences	<ul style="list-style-type: none"> ■ No guidance is included here because Learning Style Differences are not diagnosed before preschool. 	

HOW TO READ WITH YOUR PRESCHOOL OR SCHOOL-AGE CHILD

WHAT TO READ WITH YOUR PRESCHOOL OR SCHOOL-AGE CHILD

Speech and Language Delay	<ul style="list-style-type: none"> Practice letter sounds: "What sound does 'ball' start with?" Find words that start with the same sound, or rhyming words. 	<p><i>Hippos Go Berserk!</i> by Sandra Boynton</p> <p><i>Mr. Brown Can Moo! Can You?</i> by Dr. Seuss</p> <p><i>Does a Chimp Wear Clothes?</i> by Fred Ehrlich</p>
Developmental Delay	<ul style="list-style-type: none"> Read books about everyday activities, such as going to bed. Talk about the pictures and name objects as you read. 	<p><i>At the Seashore</i> by Ruth Koeppel</p> <p><i>The Little Engine That Could</i> by Watty Piper</p> <p><i>Sounds on the Go!</i> by Gail Donovan</p>
Motor Delay	<ul style="list-style-type: none"> Ask his occupational and/or physical therapist about special tools to help prop up the book. Find books that have buttons that make sounds. 	<p><i>Susan Laughs</i> by Jeanne Willis</p> <p><i>Hello, Goodbye Dog</i> by Maria Gianferrari</p>
Vision Loss	<ul style="list-style-type: none"> Find large print books about things she likes. Find audio books that he can start with a button. Continue with word/letter sound games. Present real objects from the book for children to touch and explore and talk about their features. 	<p><i>Mr. Brown Can Moo! Can You?</i> by Dr. Seuss (use with plastic or stuffed animals)</p> <p>Books with wheels or parts that move</p> <p><i>The Black Book of Colors</i> by Menena Cottin and Rosana Faria</p>
Hearing Loss	<ul style="list-style-type: none"> Use stuffed animals to act out the story. Read the same story again and again. This will help your child catch words he may have missed. 	<p><i>Sign Language, My First 100 Words</i> by Michiyo Nelson</p> <p><i>One Trick for One Treat</i> by Dawn Babb Prochovnic</p> <p><i>Splish, Splat!</i> by Alexis Domney</p>
Autism Spectrum Disorder	<ul style="list-style-type: none"> Explore books about feelings. Read books on her special interests. Find audio books that operate with a button. 	<p><i>My Many Colored Days</i> by Dr. Seuss</p> <p><i>Llama, Llama Mad at Mama</i> by Anna Dewdney</p>
Short Attention Span, High Activity Level, or ADHD	<ul style="list-style-type: none"> Explore books that increase self-awareness. Break up short periods of reading with play time. 	<p><i>The Adventures of Taxi Dog</i> by Debra Barracca</p> <p><i>Tyrannosaurus Wrecks!</i> by Sudipta Bardhan-Quallen</p> <p><i>The Day the Teacher Went Bananas</i> by James Howe</p>
Learning Style Differences	<ul style="list-style-type: none"> Read often and point and sound out letters. Choose books with simple rhymes and story lines your child will understand. Ask your child questions about the book to help comprehension. 	<p><i>LMNO Peas</i> by Keith Baker</p> <p><i>Is Your Mama a Llama</i> by Debbie Guarino</p> <p><i>BINGO</i> by Rosemary Wells</p>

Reach Out and Read National Center

89 South Street, Suite 201
Boston, MA 02111
www.reachoutandread.org
info@reachoutandread.org
Phone: 617.455.0600
Social: @reachoutandread



Founded in 1989 at Boston City Hospital (now Boston Medical Center), Reach Out and Read is a national nonprofit organization that gives young children a foundation for success by incorporating books into pediatric care and encouraging families to read aloud together. Reach Out and Read currently serves 4.7 million children and their families, reaching 1 out of every 4 low-income children in the US. The Reach Out and Read network brings together 32,000 medical providers at over 6,000 program sites in all 50 states and Washington, D.C. The Reach Out and Read model is endorsed by the American Academy of Pediatrics. Reach Out and Read is a registered 501c3.



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