

INTRODUCTION

Developmental Disabilities Literacy Promotion Guide for Pediatric Healthcare Providers

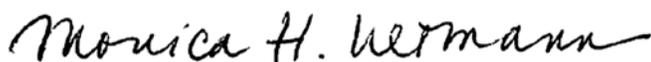
The Developmental Disabilities Literacy Promotion Guide was developed for pediatric primary care providers who care for infants and children with developmental challenges and provide support, advice, and helpful resources to their families. It was developed as part of Reach Out and Read's Special Initiatives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

The concept for this guide is based on the mandate of the American Academy of Pediatrics and Bright Futures to encourage pediatric 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 resource 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 disorder-specific section provides a brief description of the condition, advice for parents about reading with their child, and internet resources and books they can turn to for reliable information and support. Seven developmental disabilities are included: Speech and Language Problems; Autism Spectrum Disorder; Intellectual Disabilities (mental retardation); Inattention and Attention Deficit/Hyperactivity Disorder; Cerebral Palsy; and Vision and Hearing Impairments.

New information to share with parents concerning their complex children is always developing. 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 ideas or suggestions to share, please **email info@reachoutandread.org**.

Sincerely,



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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 attachment 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 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 difficult and slow because of:

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

UTILIZING BOOKS FOR DEVELOPMENTAL SURVEILLANCE

and 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 its inherent lack of standardization, books can serve as a unique way to observe the child’s developmental skills and his interaction with his parent or caretaker.

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

- Assess eye contact: normal, brief, sustained
- Assess attention to task as well as joint attention and focus
- Observe the child bringing items for shared enjoyment
- Assess language development:
 - Expressive: verbal (babbling, words, phrases, rhyming, spontaneous conversation), nonverbal (gestures, pointing)
 - Receptive: understanding directions, pointing to pictures
 - Pragmatics: the social context of language
 - Atypical Language: echolalia (immediate and delayed)
- Observe fine motor skills: holding the book, turning pages, pointing, tactile abilities, and preferences
- Observe the presence of turn-taking between the adult and child

Pediatric Healthcare Providers are in a unique position to play an influential role in the lives of infants and children with developmental disabilities in their care. Viewed as knowledgeable and experienced, providers can help parents understand their child’s developmental challenges, recognize their child’s individual strengths, and identify crucial community resources.

When providing families with anticipatory guidance concerning literacy activities:

- Encourage families to balance the demands of educational goals, therapies, and medical needs of the child with time for activities of mutual pleasure—shared reading, story-telling, and playing games.
- Encourage communication, modeling of reading and writing, and literacy-rich home environments.
- Acknowledge what parents and caretakers are already doing to promote early literacy in their children.
- For infants and children identified with developmental concerns at less than 3 years of age, direct parents to early intervention programs and disability-specific resources where they can learn how to engage their child in language, literacy, and play activities at home.
- Encourage adaptive approaches and tools to meet a child’s specific needs (e.g., story boxes, tactile experience books for children with visual impairments, specially-designed stories for children with autism, etc.).

GUIDANCE TO FAMILIES: a menu of activities to encourage literacy

DEVELOPMENTAL DIFFERENCES	speech and language problems	autism spectrum disorder (ASD)	intellectual disabilities
	Books that rhyme and/or repeat are particularly important.	Have conversations to build oral language and reciprocity. Explore books about feelings.	Frequency of reading, rhyming, and word play will be very important.
cerebral palsy (CP)	low vision or blindness	hearing loss or deafness	attention deficit hyperactivity disorder (ADHD)
Make sure books are accessible. Lap reading may be difficult.	Explore word window margins that track the line of print; create sufficient lighting. Tactile books are fun.	Signing and speaking the story may help the child understand books with and without words. Children can tap out rhythm in music books.	Reduce background noise and other distractions. Explore books that increase self-awareness.

Infants and Toddlers

Respond to your baby’s babbles and coos—have back and forth conversations.

Play touching and singing games with your baby’s body parts.

Music builds memory and language skills—singing lullabies can calm.

Replace television and technology time with name games, reading, and outdoor activities.

Play peek-a-boo, patty-cake, and puppet games.

Point to and name objects around your baby.

Explore infant/toddler programs at your library.

Cuddle your baby often. Smile and make eye contact.

Use books to help with transitions.

Read daily to your toddler, re-reading his/her favorite books for at least 5–10 minutes.

Make sure the people who take care of your baby make reading and conversations important.

Make it easy for your toddler to reach his/her own books.

Reinforce the sounds of your home language with stories, songs, and poems.

Preschool and School-age

Allow your child to build a personal library of books.

Have your child apply for his own public library card.

Talk about colors, numbers, letter names, and sounds on street signs, cereal boxes, T-shirts, and other things around your child.

Use the library for free audio books for long trips.

Word play and rhyming are powerful ways to prepare your child to learn to read.

Increase daily reading to 30 minutes.

Once your child is reading, take turns reading to one another.

Build your child’s listening skills by reading books with fewer pictures such as ***Charlotte’s Web*** or ***The Trumpet of the Swan***.

Keep reading with, and to, your child even once he masters reading.

Bring books in the car, on the bus, to the doctor’s office, and anywhere your child is required to wait.

Make sure your child sees and hears you reading.

Daily reading routines and reading practice are essential.

Write simple notes to your child using letters and pictures. Have him write back to you.

Word play and rhyming are powerful ways to prepare your child to learn to read.

Deepen your partnership with your child’s teacher by agreeing on frequent and specific modes of communication.