Building Resilience through Literacy Promotion

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Disclosure

- I declare that neither I, nor my immediate family, have a financial interest or other relationship with any manufacturer(s) of a commercial product(s) or service(s) which may be discussed at the conference.
Objectives

- Emphasize the benefits of Literacy Promotion in building Resilience, particularly in Children with Developmental Disabilities and their families

- Exemplify how Reach Out and Read provides a practical approach for identifying developmental disabilities, as well as, a framework for building Resilience
Resilience → Psychological Resilience

- The ability of a substance or object to spring back into shape
- The capacity to recover quickly from difficulties
- The capacity to adapt successfully in the face of threats or disaster
- The capacity to withstand stress or catastrophe
- The capacity to adapt and overcome risk and adversity
How do we build RESILIENCE in Children?
The 7 Cs Framework for Building Resilience

- Competence
- Confidence
- Connection
- Character
- Contribution
- Coping
- Control
Protective Factors

- Good Cognitive Function
- Positive Relationships
How can Providers promote **RESILIENCE** in Children with Disabilities & their families?

- Acknowledge and explain any disabilities that are detected, offer family an opportunity to ask questions
  
  ° **Understanding helps the patient/family to build a strong foundation**

- Provide advice/tips for how to promote development
  
  ° **Having family actively engaged & involved in patient’s care strengthens their foundation**

- Provide resources, i.e. reading materials, organizations, support groups
  
  ° **Having these resources available and support systems in place aide in adaptability if adverse situations arise**

- Discuss the potentials for progress/prognosis
  
  ° **Realistic expectations aide in adaptability if adverse situations arise**
How can Providers promote RESILIENCE in Children with Disabilities & their families?

To assist in this, ROR developed a Developmental Disabilities Literacy Promotion Guide for Pediatric Health Care Providers (summary chart available on-line).

ROR is currently in collaboration with Autism Speaks for a grant-funded pilot program.
Reach Out and Read

- Nonprofit organization
- Trains and supports medical providers who give books to children and advice to parents about the importance of reading aloud at well-child exams.
- Builds on the unique relationship between parents and medical providers.
- Goal is to develop essential early literacy skills in young children via the existing healthcare infrastructure.
- Each year, Reach Out and Read serves 4 million children across all 50 states, focusing on those in low-income families.
- During the preschool years, children served by Reach Out and Read score three to six months ahead of their non-Reach Out and Read peers on vocabulary tests, preparing them to start school on target.
Emergent Literacy

- Steps infants and children progress through as they master the complex requisites for reading and writing

- Integral factors:
  - Cognitive
  - Linguistic
  - Physical
  - Psychological
  - Social/attachment
Potential Challenges with Emergent Literacy in Developmentally Disabled Children

- 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
Identifying Specific Challenges

- Utilizing the ROR method and observing a child’s interaction with a book and his/her parent can assist in identifying a child’s specific disabilities
  - Is this child able to make eye contact?
  - Is this child able to maintain his/her age-appropriate attention level?
  - Is this child able to age-appropriately maneuver the book (i.e. hold the book, turn pages in the book, etc.)?
  - Is this child interacting with their parent/caretaker appropriately?
  - Is this child expressing age-appropriate speech development (expressive, receptive, pragmatic)?
  - Is this child expressing any atypical language behavior (i.e. echolalia)?
- Identifying specific disabilities, provides an opportunity to engage family members and increase their understanding of the child’s needs
Speech & Language Problems

Challenges
- Difficulty sharing their thoughts with words or gestures
- Difficulty saying words clearly
- Difficulty understanding spoken or written language

Tips
- Repetitive, rhyming books
- Have child name/repeat objects in book
- Practice phonetics with child while reading
  - Rhyming words
  - Similar sounds

Resources
- The Parent's Guide to Speech and Language Problems by Debbie Feit and Heidi Feldman
- American Speech-Language-Hearing Association—(800) 638-8255 or www.asha.org
- Speechville Express—www.speechville.com
Intellectual Disabilities

Challenges
- Slower progression of development
- May not engage well
- May have physical limitations as well

Tips
- Respond to gurgles and other sounds as this is infant’s form of speech
- Focus on books that teach everyday things: colors, shapes, etc.
- Read aloud, and encourage child to point out objects in book

Resources
- Children with Mental Retardation: A Parents’ Guide edited by Romayne Smith
- American Association on Intellectual and Developmental Disabilities—(800) 424-3688 or www.aaidd.org
- National Down Syndrome Society—(800) 221-4602 or www.ndss.org
Cerebral Palsy (CP)

Challenges
- Potential physical limitations
- Potential speech limitations
- Potential cognitive delays

Tips
- Have child name/repeat names of objects in book
- Arrange seating to be as close to child as possible if lap reading is not feasible
- Work with child’s therapists to identify special assistive tools (i.e.: to prop up book for child)

Resources
- Cerebral Palsy: A Complete Guide for Caregiving by F. Miller and S.J. Bachrach
- Children with Cerebral Palsy: A Parent’s Guide edited by Elaine Geralis
- United Cerebral Palsy Association—(800) 872-5827 or www.ucp.org
- Siblings Support—www.siblingsupport.org
Low Vision or Blindness

Challenges
- Visual Limitations

Tips
- Choose books that provide tactile stimulation (texture/pop-ups)
- Listen to audio books together
- Large-print books or Braille books for older children

Resources
- Look at It This Way: Toys and Activities for Children with Visual Impairment by Roma Lear
- National Association for Parents of Children with Visual Impairments—(800) 562-6265 or www.spedex.com/napvi
Hearing Loss or Deafness

Challenges

- Hearing Limitations
- Speech Limitations

Tips

- Repeating the same story will provide a better opportunity for child to catch the words
- Assure child can see your face and the pictures
- Choose books that provide tactile stimulation (texture/pop-ups)
- Begin sign language in addition to reading

Resources

- Language and Literacy Development in Children Who Are Deaf by Barbara Schirmer
- Literacy and Your Deaf Child: What Every Parent Should Know by David Stewart and Bryan Clarke
- Literacy Learning for Children Who Are Deaf or Hard of Hearing by Lyn Robertson and Carol Flexer
- American Society for Deaf Children—(866) 895-4206 or www.deafchildren.org
- American Speech-Language-Hearing Association—(800) 638-8255 or www.asha.org
ADHD

Challenges

- Short Attention Span
- Easily distracted
- Hyperactivity

Tips

- Short periods of reading built into daily routine, maybe as quiet time before nap or bedtime
- Find quiet spot, away from other distractions
- Choose interactive books when possible
- Encouraged child to read-along

Resources

- Parenting Children with ADHD: 10 Lessons that Medicine Cannot Teach by Vincent J. Monastra, PhD.
- The ADD & ADHD Answer Book: Professional Answers to 275 of the Top Questions Parents Ask by Susan Ashley
- CHADD National Resource Center—(800) 233-4050 or www.help4adhd.org
- Children and Adults with Attention Deficit/Hyperactivity Disorder (CHADD)—(800) 233-4050 or www.chadd.org
Autism Spectrum Disorder

Challenges
- Difficulty making eye contact
- Difficulty sharing their thoughts
- Short attention span
- Difficulty engaging

Tips
- Read for short periods of time
- Build reading into daily routine
- Using books that have photos of people’s faces may help child to recognize emotions
- Use this time as an opportunity to engage child
- Coordinate with behavioral or occupational therapists to see how reading can help enhance their therapeutic modalities

Resources
- A Practical Guide to Autism: What Every Parent, Family Member, and Teacher Needs to Know by Fred Volkmar and Lisa Wiesner
- Autism Society of America—(800) 328-8476 or www.autism-society.org
Anticipatory Guidance

- Encourage balance of demands of education, therapy, medical needs with activities of mutual pleasure. Link reading to cuddle & play time!
- Encourage literacy-rich home environment
- Positively reinforce parents current activities
- Referral to Early Intervention when applicable
- Encourage adaptive approaches and tools to meet child’s specific needs
- National Dissemination Center for Children with Disabilities—(800) 695-0285 or www.nichcy.org
### SUGGESTED BOOKS: INFANT AND TODDLER

#### some suggested books for your infant and toddler

<table>
<thead>
<tr>
<th>speech and language problems</th>
<th>autism spectrum disorder (ASD)</th>
<th>intellectual disabilities</th>
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<tr>
<td><em>Mother Goose Rhymes</em> or <em>Dr. Seuss books</em> with rhyme stories</td>
<td><em>Bablies</em> by Susan Santanas</td>
<td><em>I Can, Can You</em> by Marjorie M. Pitzer</td>
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<tr>
<td><em>Each Peach Pear Plum</em> by Allan and Janet Ahlberg</td>
<td><em>Global Babies</em> by Mara Almara</td>
<td>Books by Laura Remig such as:</td>
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<td><em>Chicken Little Boom Boom</em> by Bill Martin, Jr.</td>
<td><em>Smile</em> by Roberta Grobel Intrater</td>
<td><em>Kiddi's ABC</em> or <em>Kiddi Like Me: Learn Colors</em></td>
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<td><em>Lots of Feeling</em> by Shelly Rubner</td>
<td>Books by Nadia Crane, such as:</td>
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<td><em>Books by Susan Santanas</em> such as <em>Bablies on the Move</em></td>
<td><em>Families</em> or <em>Bathing the Rainbow</em></td>
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<td><em>Dr. Seuss's ABC</em></td>
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<td><em>Feelings</em> by Susan Santanas</td>
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<td><em>This Feelings Book</em> by Todd Parr</td>
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<td>* hugs and Kiss* by Roberta Grobel Intrater</td>
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<td><em>Books by Eric Carle</em> such as:</td>
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<td>Fisha Fixerman's Stroller Story Books. The straps make the books easy to handle and the sturdy pages stay open and are easy to turn.</td>
<td><em>My Very First Book of Colors</em></td>
<td><em>My Very First Book of Numbers</em></td>
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<tr>
<td><em>I Love My Family</em></td>
<td><em>My Very First Book of Shapes</em>, or <em>Eric Carle's ABC</em></td>
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<td>E-Z Page Turners is a series of books made for Thornton Kids. These books are specially designed to help little ones turn the pages. You can buy them online or ask your child's occupational therapist for help finding this brand.</td>
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<td>Titles include <em>Trucks, Opposites, and Mommies and Babies</em></td>
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<td>Look for books that have soft or textured shapes. Find books that have pop-out pieces and textures your child can feel and name.</td>
<td>Choose board books with simple signs. Some titles include:</td>
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<td><em>Pat the Bunny</em> and other Touch and Feel books by Dorothy Kunhardt</td>
<td><em>Baby Signs</em> by Joy Allen</td>
<td><em>Goodnight Moon</em> by Margaret Wise Brown</td>
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<tr>
<td><em>Three Little Ducks</em> and other Noah Along books with toys to handle</td>
<td><em>My First Book of Sign Language</em> by Joan Holub</td>
<td>Books by Rosemary Wells such as <em>Boy, Binky Spider</em> or <em>Twinkle, Twinkle Little Star</em></td>
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<tr>
<td><em>Where Is Baby's Belly Button</em> by Karen Katz</td>
<td><em>Books by Anne Kubiak</em> such as <em>My First Signs</em></td>
<td>Books by Annie Kubler such as:</td>
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<td><em>Are You Ticklish</em> by Melanie Mitchell</td>
<td><em>and Sign and Sing Along</em></td>
<td><em>If You're Happy and You Know It</em>, <em>Ring Around the Rosie</em>, or <em>Row, Row, Row Your Boat</em></td>
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<td><em>Whose Book Is Bumpy</em> or <em>High Tide</em> by Kate Davis</td>
<td><em>Books by Anthony Lewis</em> such as <em>One Day, Two Bad Animals</em></td>
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**Suggested Books: School-Aged Child**

### Speech and Language Problems
- Books that encourage interaction or role-playing.
- **Does a Chimp Wear Clothes?** by Prad Ebril, M.D.
- **Hippo Goes Beserk!** by Sandra Boynton
- **Mr. Brown Can Moo! Can You?** by Dr. Seuss

### Autism Spectrum Disorder (ASD)
- Books by Simplify Taback such as *There Was an Old Lady Who Swallowed a Fly* and *This Is the House that Jack Built*
- **Lyle Lyle Crocodile** by Bernard Waber

### Intellectual Disabilities
- **At the Seashore** by Ruth Kowap
- **Poke-A-Dot Old MacDonald's Farm** by Travis King
- **Sounds on the Go** by Gail Downen

### Cerebral Palsy (CP)
- **Harold and the Purple Crayon** by Crockett Johnson
- **We Are Going on a Bear Hunt** by Helen Oxenbury
- **The Napping House** by Audrey Wood

### Low Vision or Blindness
- **The Wheels on the Bus Go Round and Round and other books with wheels that move**
- **Children's Book of Nursery Rhymes** and other children's poetry books
- **Mr. Brown Can Moo, Can You?** by Dr. Seuss (use with plastic or stuffed animals)

### Hearing Loss or Deafness
- **Each Peach Pear Plum** by Allen and Janet Ahlberg
- **Jabberwocky** by Lewis Carroll
- **Sheep in a Jeep** by Nancy Shaw

### Attention Deficit Hyperactivity Disorder (ADHD)
- **Adventures of Taxi Dog** by Debra Barnoski
- **Maybe A Bear Ate It** by Robie Harris
- **The Day the Teacher Went Bananas** by James Howe
ROR & Autism Speaks Grant

- Provides developmentally-appropriate books to children with ASD during their well-child checkups
- Provides age-appropriate books about autism to siblings of children with ASD
- Provides parents/caregivers of children with ASD with an ASD-specific handout on encouraging literacy
ROR & Autism Speaks Grant

- Provide pediatric care providers information on effectively using the ROR model to better support children with ASD

- Providers at each site given copies of the ROR Developmental Disabilities Literacy Promotion Guide
ROR & Autism Speaks Grant

- Rush Pediatrics Primary Care Center
- UIHHS Department of Pediatrics
- UIHHS Developmental Disabilities Family Clinic
- UIHHS Mile Square Health Center
References


- Building Resilience in Children and Teens. Kenneth R Ginsburg, MD, MS Ed, FAAFP with Martha M Jablow. AAP

- Developmental Disabilities Literacy Promotion Guide for Pediatric Health Care Providers. Reach Out and Read.
Contact Information

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