



ECI Library Matters

Down Syndrome Resources (updated)

This month, we are featuring library resources on Down syndrome. The library has many titles available on this and many other topics. For a complete selection of library materials, visit the online library catalog at www.texashealthlibrary.com.

If you would like to borrow library materials or receive copies of full-text articles, please contact the library at:

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Texas Department of State Health Services

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Social validity assessment in behavior interventions for young children: A systematic review. p. 156-169. Park, E.-Y., & Blair, K.-S. C.

Practitioner-implemented naturalistic developmental behavioral interventions: Systematic review of social validity practices. p. 170-182. D'Agostino, S. R., Douglas, S. N., & Dueñas, A. D.

Friendships and social acceptance of Portuguese children with disabilities: The role of classroom quality, individual skills, and dosage. p. 183-195. Ferreira, M., Aguiar, C., Correia, N., Fialho, M., & Pimentel, J. S.

Selected Journal Abstracts

Barton, E. E., Choi, G., & Mauldin, E. G. (2019). Teaching sequences of pretend play to children with disabilities. *Journal of Early Intervention, 41*(1), 13–29. Children with disabilities demonstrate fewer complex pretend play behaviors than children with typical development, which might limit their social participation in early childhood settings. A multiple-probe design was used to examine the relation between a single prompt procedure--constant time delay--and the acquisition, maintenance, and generalization of sequences of pretend play by children with disabilities, including children with Down syndrome. Results indicated systematic instruction was functionally related to increased levels of unprompted and different sequences of pretend play in all participants. However, individual adaptations were required for some of the participants. The findings replicate previous research on adult systematic instruction using response-prompting strategies to teach pretend play and extend the literature by measuring and reporting generalized sequences of pretend play. Overall, this study supports systematic, individualized instruction using response-prompting strategies to teach sequences of pretend play to children who do not display such behaviors.

Selected Journal Abstracts (continued)

Lorang, E., Sterling, A., & Schroeder, B. (2018). Maternal responsiveness to gestures in children with Down syndrome. *American Journal of Speech-Language Pathology, 27*(3), 1018–1029.

PURPOSE: This study compared gesture use in young children with Down syndrome (DS) and typical development (TD) as well as how mothers respond to child gestures based on child age and diagnosis.

METHOD: Twenty-two mother-child dyads with DS and 22 mother-child dyads with TD participated. The child participants were between 22 and 63 months and were matched on chronological age. We coded child gesture use and whether mothers recoded child gestures (i.e., provided a verbal translation) during naturalistic interactions.

RESULTS: The children with DS used more gestures than peers with TD. After controlling for expressive language ability, the two groups were not significantly different on child gesture use. Regardless of child diagnosis, mothers recoded approximately the same percentage of child gestures. There was a significant interaction between child diagnosis and child age when predicting the percentage of maternal gesture recodes; mothers of children with DS did not demonstrate differences in the percentage of maternal gesture recodes based on child age, but there was a negative relationship between the percentage of maternal gesture recodes and child age for the children with TD.

CONCLUSIONS: Young children with DS gesture more than chronological age-matched children with TD, therefore providing numerous opportunities for caregivers to recode child gestures and support language development. Early intervention should focus on increasing parent responsiveness to child gestures earlier in life in order to provide additional word-learning opportunities for children with DS.

Mason-Apps, E., Stojanovik, V., Houston-Price, C., & Buckley, S. (2018). Longitudinal predictors of early language in infants with Down syndrome: A preliminary study. *Research in Developmental Disabilities, 81*, 37–51.

PURPOSE: Children with Down syndrome (DS) typically have marked delays in language development relative to their general cognitive development, with particular difficulties in expressive compared to receptive language. Although early social communication skills, including gestures and joint attention, have been shown to be related to later language outcomes in DS, knowledge is limited as to whether these factors exclusively predict outcomes, or whether other factors (e.g. perceptual and non-verbal skills) are involved. This study addressed this question.

METHOD: Longitudinal data for a group of infants with DS (n = 14) and a group of typically-developing (TD) infants (n = 35) were collected on measures that have been shown to predict language in TD infants and/or those with developmental delays. These included: non-verbal mental ability,

Selected Journal Abstracts (continued)

speech segmentation skills, and early social communication skills (initiating and responding to joint attention, initiating behavioural requests).

RESULTS: Linear regression analyses showed that speech segmentation and initiating joint attention were the strongest predictors of later language in the TD group, whereas non-verbal mental ability and responding to joint attention were the strongest predictors of later language for infants with DS.

CONCLUSIONS: Speech segmentation ability may not determine language outcomes in DS, and language acquisition may be more constrained by social communication and general cognitive skills.

Pandolfi, V., Magyar, C. I., & Dill, C. A. (2018). Screening for autism spectrum disorder in children with Down syndrome: An evaluation of the pervasive developmental disorder in mental retardation scale. *Journal of Intellectual & Developmental Disability, 43*(1), 61-72.

Children with Down syndrome (DS) are at risk for autism spectrum disorder (ASD). They are often diagnosed later than other children in part due to difficulty differentiating ASD-related impairment from that associated with DS. The psychometric properties of the Pervasive Developmental Disorder in Mental Retardation Scale (PDD-MRS) were examined with the aim of informing ASD screening guidelines for children with DS.

METHOD: Analysis of archival data from children aged 3 to 15 years with DS (N = 386) evaluated the reliability and validity of the PDD-MRS.

RESULTS: Factor analyses yielded 2 factor-based scales: ASD and Emotional and Behavioural Problems. ASD reliably assessed ASD-specific symptoms, correlated with other ASD measures, and demonstrated good diagnostic accuracy. Emotional and Behavioural Problems assessed problems not diagnostic of ASD but may reflect part of the behavioural phenotype of DS and ASD.

CONCLUSION: The PDD-MRS appears to have utility in ASD screening for this population.

Ridding, A., & Williams, J. (2019). Being a dad to a child with Down's syndrome: Overcoming the challenges to adjustment. *Journal of Applied Research in Intellectual Disabilities: JARID, 32*(3), 678-690.

BACKGROUND: Historically, research exploring the impact of having a child with an Intellectual Disability (ID), has focused exclusively on mothers.

The present study aimed to investigate fathers' experiences of parenting a child with Down's syndrome (DS), their contributions, influences on family functioning and inclusion in their child's support provision.

METHOD: Semi-structured interviews were conducted with 15 fathers.

Interviews were analyzed using Grounded Theory (GT).

Selected Journal Abstracts (continued)

Schworer, E., Fidler, D. J., Lunkenheimer, E., & Daunhauer, L. A. (2019). Parenting behaviour and executive function in children with Down syndrome. *Journal of Intellectual Disability Research, 63*(4), 298–312.

BACKGROUND: Parenting behaviours influence many domains of child development, and recent work has demonstrated the specific effects of parenting on the development of executive function (EF) abilities. The relationship between parent-child interaction patterns and EF has been examined in typically developing (TD) children but has not yet been examined in dyads where the child has a diagnosis of Down syndrome (DS). **METHOD:** The current study examines the differences in patterns of parenting behaviours between DS dyads and dyads with TD children equated on nonverbal mental age. DS dyads (n = 42), child ages 59 to 118 months, and TD dyads (n = 28), child ages 30 to 49 months, participated in a modified version of the Parent-Child Challenge Task. Parent directive and teaching behaviours were coded, along with child compliance and noncompliance. Child participants also completed a laboratory measure of inhibition and working memory, and parents completed the Behaviour Rating Inventory of Executive Function-Preschool.

RESULTS: There was a greater frequency of parenting directives and child compliance in the DS dyads, and parents of children with DS were more likely to follow child compliance with directives than parents of TD children. In both groups, parenting directive behaviour was a significant predictor of child EF laboratory performance.

CONCLUSIONS: Results characterise the relationship between specific parenting behaviours and child EF in DS and TD dyads. The implications for parent training and intervention are discussed.

Sheehan, P., & Guerin, S. (2018). Exploring the range of emotional response experienced when parenting a child with an intellectual disability: The role of dual process. *British Journal of Learning Disabilities, 46*(2), 109–117.

This study aimed to explore the range of emotions experienced by parents in the early years of managing their child's disability, to assess the relevance of the Dual Process Model in understanding these emotions within an adjustment process and to identify the types of support and information perceived by parents as helpful during this time.

MATERIALS AND METHODS: Semi-structured interviews were conducted with parents of children (5-7 years) who had attended early intervention services. Eleven parents participated, six of children with Down syndrome and five of children with complex needs. Interviews were transcribed, and a thematic analysis undertaken.

Selected Journal Abstracts (continued)

RESULTS: Parents report experiencing a wide range of emotions, which were described as particularly intense in the early months following diagnosis. There was some ambivalence in relation to discussing emotions with professionals. The timing of the provision of information on emotions and the nature of the delivery of this information were considered crucial by parents in determining it as helpful or unhelpful to them. Reflecting the Dual Process Model, while a loss orientation was evident in descriptions of the early years, there was evidence of a restoration orientation.

CONCLUSIONS: Those delivering services must consider the delicate balance of maintaining awareness that intense emotions can be experienced during this adjustment process and being available when required, while respecting the privacy that many wish to preserve during the early years. One issue for professionals to address is how best to provide the necessary emotional support, mindfully and with respect for boundaries.

New Early Childhood Intervention Books

Caring for our children: National health and safety performance standards guidelines for early care and education programs, 4th ed. 2019. (LB 1139.23 C277 2019 ECI).

The fourth edition contains guidelines on the development and evaluation of the health and safety of children in early care and education settings. This guide features 10 chapters of more than 650 standards and dozens of appendixes with valuable supplemental information, forms, and tools.

Does time heal all? Exploring mental health in the first 3 years. 2018. (WS 350 K39 2018 ECI).

This book seeks to debunk the idea that all troubling behaviors arising in early childhood will simply pass with time, asserting instead that every effort should be made to diagnose and treat truly atypical issues early in life, while babies' brains are still flexible and malleable. This book weaves together complex case and treatment descriptions that focus specifically on the interplay between genetic, biological, psychological, and cultural variables present both in children and their environment.

Early childhood staff orientation guide. Sharon Bergen, 2016. (LB 1139.2 B495 2016).

This book explains best practices in the field of early childhood. It serves as an important first step into a new position and as a long-term resource for employees as they grow in the profession.

New Early Childhood Intervention Books (continued)

Effective early intervention: The developmental systems approach.

Michael J. Guralnick, 2019. (LC 4019.3 G978e 2019 ECI).

This book analyzes research and developments in early intervention through the lens of the Developmental Systems Approach (DSA). Starting with a clear explanation of the foundations of early intervention, the book then applies the DSA to four vulnerable populations: children at risk due to biological factors, specifically preterm birth, children at environmental risk, children with developmental delays, and children with autism spectrum disorder.

Finding your way with your baby: The emotional life of parents and babies.

Dilys Daws, 2015. (WS 105.5 E5 D272 2015 ECI).

This book explores the emotional experience of the baby in the first year, and that of the mother, father, and other significant adults. It does so in a way that is deeply informed by psychoanalytic understandings, infant observation, developmental science, and decades of clinical experience.

Practical solutions to practically every problem: The survival guide for early childhood professionals.

Steffen Saifer, 2017. (LB 1140.2 ST817 2017 ECI).

This book provides solutions to every possible problem faced by early childhood teachers before teachers encounter them. It focuses on issues faced by educators, including teaching twenty-first century life skills, technology, and cultural responsiveness. Educators will save time and energy with over eight hundred solutions to two hundred problems, including: daily dilemmas and classroom issues, partnering with families to raise happy children, dealing with problematic behaviors from co-workers, and learning to take care of yourself to prevent burn-out.

Prevent-teach-reinforce for families: A model of individualized positive behavior support for home and community.

Glen Dunlap, 2017. (LB 1139 P944 2017 ECI).

This guide explains how to implement positive behavior support to address behavioral difficulties, and how to engage families as true partners in the process.

Twelve essential topics in early childhood: A year of professional development in staff meetings.

Nancy P. Alexander, 2018. (LB 1775.6 AL374 2018 ECI).

This book is a tool for program administrators to prepare professional development experiences for their staff during staff meetings. These professional development experiences can also be modified to be part of an ongoing college class or child development credential.

New Down Syndrome Book

Off to a good start: A behaviorally based model for teaching children with Down syndrome. Book 1, foundations for learning. Emily A. Jones, 2019. (WS 107 J76 2019 ECI).

This book is a starting point for parents and professionals with little or no knowledge of Applied Behavior Analysis (ABA). It gives an overview of ABA and how to apply its principles and strategies to teach skills, and it provides background information on the characteristic learning profile of children with Down syndrome and how strengths (such as visual learning abilities and the desire to interact with others) can be used to overcome weaknesses. It also covers the importance of inclusion and high expectations and of generalizing skills learned in one setting to another.

Selected Down Syndrome Books

Babies with Down syndrome: A new parents' guide. Karen Stray-Gundersen, 2008. (WS 107.1 B114 2008 ECI).

Building a joyful life with your child who has special needs. Nancy J. Whiteman and Linda Roan-Yager, 2007. (271.3 W594b 2007 ECI).

Count us in: Growing up with Down syndrome. Jason Kingsley and Mitchell Levitz, 2007. (226.11 K55 2007 RHB).

The Down syndrome nutrition handbook: A guide to promoting healthy lifestyles. Joan E.G. Medlen, 2006. (226.11 M491 2006 ECI).

Down syndrome parenting 101: Must-have advice for making your life easier. Natalie Hale, 2011. (WS 107.1 H163d 2011 ECI).

Early communication skills for children with Down syndrome: A guide for parents and professionals, 3rd ed. Libby Kumin, 2012. (WS 107.1 K96 2012 ECI).

Expecting Adam: A true story of birth, rebirth, and everyday magic. Martha Beck, 2000. (226.11 B393e 2000 ECI).

Fine motor skills in children with Down syndrome: A guide for parents and professionals, 3rd ed. Maryanne Bruni, 2016. (WS 107 B896f 2015 ECI).

Selected Down Syndrome Books (continued)

Gifts: Mothers reflect on how children with Down syndrome enrich their lives. 2007. (WS 107.1 G458 2007 ECI).

Gifts 2: How people with Down syndrome enrich the world. 2009. (WS 107.1 G458 2009 ECI).

Gross motor skills for children with Down syndrome: A guide for parents and professionals, 2nd ed. Patricia C. Winders, 2014. (WS 107 W763 2014 ECI).

Not always happy: An unusual parenting journey. Kari Wagner-Peck, 2017. (WS 107.1 W133 2017 ECI).

The parent's guide to Down syndrome. Jen Jacob, 2016. (WS 107 J15p 2016 ECI).

Reflections from a different journey: What adults with disabilities wish all parents knew. Stanley D. Klein, 2004. (263.1 R332 2004 ECI).

The shape of the eye: Down syndrome, family, and the stories we inherit. George Estreich, 2011. (226.11 E82 2011 ECI).

Speech and language development and intervention in Down syndrome and Fragile X syndrome. Joanne Erwick Roberts, Robin S. Chapman, and Steven F. Warren, 2008. (219.4 R645s 2008 ECI).

When Down syndrome and autism intersect: A guide to DS-ASD for parents and professionals. Margaret Froehlke and Robin Zaborek, 2013. (WS 107 W556 2013 ECI).

The year my son and I were born: A story of Down syndrome, motherhood, and self-discovery. Kathryn L. Soper, 2009. (WS 107.1 S712y 2009 ECI).

Selected Down Syndrome Children's Books

47 strings: Tessa's special code. Becky Carey, 2012. (WS 107 C273 2012 ECI).

Animal fun for everyone. Marjorie W. Pitzer, 2013. (WS 107 P681a 2013 ECI).

The best worst brother. Stephanie Stuve-Bodeen, 2005. (805.1 S937b 2005 ECI).

Down syndrome. Marlene Targ Brill, 2007. (WS 107 B857 2007).

I can, can you? Marjorie W. Pitzer, 2004. (WS 107 P681ic 2004 ECI).

I like berries, do you? Marjorie W. Pitzer, 2013. (WS 107 P681i 2013 ECI).

My friend Isabelle. Eliza Woloson, 2003. (WS 107 W867 2003 ECI).

Russ and the almost perfect day. Janet E. Rickert, 2000. (WS 107 R539p 2000 ECI).

Russ and the firehouse. Janet E. Rickert, 2000. (WS 107 R539f 2000 ECI).

We'll paint the octopus red. Stephanie Stuve-Bodeen, 1998. (805.1 S937w 1998 ECI).

Selected Down Syndrome eBooks

Children with disabilities, 7th ed. Gaetano R. Lotrecchiano, Nancy J. Roizen, and Mark L. Batshaw, 2012.

This seventh edition of a trusted resource for professionals, families, and students presents extensive coverage of crucial developmental, clinical, educational, family, and intervention issues related to all aspects of children with disabilities. It includes a chapter on children with Down syndrome.

Life with a superhero: Raising Michael who has Down syndrome.

Kathryn U. Hulings, 2013.

Over twenty years ago, Kathryn Hulings adopted an infant with Down syndrome. She recounts the challenges and joys of parenting her son Michael.

New Early Childhood Intervention DVDs

Being with infants. 108 min. 2018.

This program gives caregivers and parents direct access to a comprehensive care approach from renowned child specialist Beverly Kovach, certified Montessori trainer and consultant for Magda Gerber's Resources for Infant Educators (RIE). It includes proper bottle feeding, lap feeding, diapering, sleep, play, and much more.

Daily schedules and caregiving. 92 min. 2016.

Eating, napping, playing, exploring objects and people, all infants and toddlers do these things but have varying personal routines from day to day. When caregivers provide consistent but flexible daily schedules and caregiving support, they let children know their needs are met, freeing the children to investigate their world. This program begins with an overview of an infant-toddler daily schedule that includes arrivals and departures, group times, feedings and mealtimes, personal care times, and choice time. It offers strategies for creating a daily schedule that is stable yet flexible enough to meet young children's needs. It also shows caregivers supporting children throughout the daily schedule in a series of un-narrated scenes.

Early intervention for social emotional development. 39 min. 2017. DD0827.

You can make long-lasting and positive changes at an early age to improve behaviors, mental health, and emotional well-being. Karen Hyché OTD, OTR/L, teaches strategies for successful social-emotional development for children birth to 5 years. Social-emotional health is influenced by our physical and sensory system as well as our environment. Hyché presents strategies for infants and young children who have sensory processing disorders, autism spectrum disorder, development delays, behavior issues or speech and language delays to improve social-emotional development. You will develop special techniques for infants and toddlers that have difficulty transitioning, poor sleep habits and poor eating habits. Discover treatment strategies that will work in the home, daycare, school and clinic, including sensory diets, personal stories, sensory motor strategies, environmental strategies, and video modeling.

Infant toddler learning environment. 43 min. 2017. DD0825.

Infants and toddlers are born explorers and the environments in which they are cared for become their laboratory. Watch how to create a supportive infant-toddler learning environment that invites children to explore their surroundings and supports their sensory-motor way of learning. This DVD contains Spanish language subtitles.

Teach me to see. 68 min. 2011. DD0828.

This program is suitable for parents, teachers, and occupational and physical therapists. It will help practitioners understand the activities that are functional and promote the optimal use of vision and other senses.

New Down Syndrome DVD

Just like you: Down syndrome. 14 min. 2012. (DD0826).

This DVD explores the life, hopes, challenges, and dreams of three kids living with Down syndrome. Elyssa, Rachel, and Sam share personal stories to help viewers better understand their condition and why they wish to be treated just like everyone else. They each have their own talents, characteristics, strengths, and challenges. Down syndrome is just one part of who they are.

Selected Down Syndrome DVDs

Boy in the world. 44 min. 2007. (DD0465).

Crossing Tahoe: A swimmer's dream. 44 min. 2008. (DD0224).

Development in practice: Activities for babies with Down syndrome. 77 min. 2007. (DD0716).

Development in practice: Speech and language activities for preschool children with Down syndrome. 76 min. 2007. (DD0717).

Discovery: Pathways to better speech for children with Down syndrome. 81 min. 2005. (DD0081).

Down syndrome: The first 18 months. 108 min. 2003. (DD0079).

Emma's gifts. 46 min. 2004. (DD0463).

Infants with disabilities. 25 min. 2008. (DD0563).

Kids with Down syndrome: Staying healthy and making friends. 120 min. 2008. (DD0483).

Mariah's story: A study in age 3 transition. 33 min. 1997. (DD0695).

Raising a child with Down syndrome. 27 min. 2006. (DD0142).

Teachings of Jon. 56 min. 2006. (DD0277).

Welcome to Holland: Resiliency in families raising children with special needs. 48 min. 2010. (DD0464).

Selected Down Syndrome Websites

The National Down Syndrome Society's mission is to be the national advocate for the value, acceptance and inclusion of people with Down syndrome. This website is immense and attempts to be the comprehensive information source on Down syndrome. See <http://www.ndss.org>.

The National Institutes of Health provides a Down syndrome registry. It is a centralized, secure national resource for storing and sharing health information about Down syndrome: <https://dsconnect.nih.gov/>.

"Learning about Down syndrome," from the National Human Genome Research Institute, is located at <http://www.genome.gov/19517824>.

More links to information and resources about Down syndrome are available at MedlinePlus, a website provided by the National Library of Medicine. See <http://www.nlm.nih.gov/medlineplus/downsyndrome.html>.

Your Child: Development and Behavior Resources from the University of Michigan Health System includes information and lots of links at <http://www.med.umich.edu/yourchild/topics/downsyn.htm>.

Local Texas Associations:

Down Syndrome Association of Brazos Valley: <http://dsabv.org/>

Down Syndrome Association of Central Texas: <http://dsact.org>

Down Syndrome Association of South Texas: <http://www.dsastx.org/>

Down Syndrome Guild of Dallas: <http://www.downsyndromedallas.org/>

Down Syndrome Partnership of North Texas: <http://www.dspnt.org/>

East Texas Down Syndrome Group: <http://www.etsdg.org/>

Panhandle Down Syndrome Guild: <http://www.panhandledsg.org/>

Texas Parent to Parent: This website was created by parents for families of children with all different kinds of disabilities, chronic illnesses, and other special needs throughout Texas. See <http://www.txp2p.org/>.