

ECI Library Matters

Down syndrome resources (updated)

This issue features updated library resources on Down syndrome. Abstracts of articles on this topic are also included. For a complete listing of library titles, go to the library's online catalog at **texashealthlibrary.com**.

Important News: The DSHS Library is now able to ship library materials again. However, due to the COVID-19 pandemic, the DSHS Library remains closed to visitors. Library staff continue to work remotely from home. Electronic library resources are available on any computer or mobile device with internet access. Please email any requests or questions to avlibrary@dshs.texas.gov.

In This Issue

- Selected Journal Abstracts
- Selected Journal Table of Contents:
 - <u>Infant Mental Health Journal</u>. Volume 41, Issue 5; September/October 2020.
 - Infants and Young Children. Volume 33, Issue 4; October/December 2020.
 - Zero to Three. Volume 40, Issue 6; May 2020.
- New Books
- Selected Audiovisuals
- Selected Books
- Selected eBooks
- Selected Websites

Texas Department of State Health Services

USEFUL INFORMATION

<u>Texas Health and Human</u> <u>Services</u>

HHS Office of Ombudsman: 1-877-787-8999

ECI Website

ECI Library Matters

CONTACT INFORMATION

Texas Department of State Health Services <u>Audiovisual Library</u>

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Selected Journal Abstracts

Correlates of early cognition in infants with Down syndrome.

Fidler, D. J., Schworer, E., Will, E. A., Patel, L., & Daunhauer, L. A. (2019). *Journal of Intellectual Disability Research.* 63(3), 205-214. Background: While delays in cognitive development are detectable during early development in Down syndrome, the neuropsychological and biomedical underpinnings of cognitive skill acquisition in this population remain poorly understood.

Method: To explore this issue, 38 infants with Down syndrome [mean chronological age = 9.65 months; SD = 3.64] completed the Bayley Scales of Infant Development-III and a set of laboratory tasks that measured sustained attention (duration of visual attention during a 1-min object exploration task), attention shifting (mean latency to shift attention on an alternating object presentation task) and visual short-term memory (dishabituation to a novel object on a change preference task).

Results: Latency to shift attention was negatively associated with Bayley Cognitive Scale raw scores, even when controlling for the effects of chronological age, $r(33) = _.41$, P = .02. In addition, prematurity status was associated with latency to shift attention. Conclusions: Early attention shifting may be an important factor that facilitates overall cognitive skill acquisition in infants with Down syndrome, and premature birth may be a risk factor for difficulties on this dimension.

Feeding and swallowing difficulties in children with Down

syndrome. Anil, M. A., Shabnam, S., & Narayanan, S. (2019).

Journal of Intellectual Disability Research. 63(8), 992-1014.

Background: The anatomical and physiological characteristics such as neuromotor coordination impairments and craniofacial and structural abnormalities frequently interfere with the acquisition of effective oral-motor skills which can in turn result in the development of potential feeding problems and swallowing dysfunction. The present study was undertaken with the aim of assessing the feeding and swallowing problems, if any, in children with Down syndrome in the age range of 2–7 years.

Methods: A questionnaire was formulated and administered on 17 children with Down syndrome (10 females and 7 males) and 47 typically developing children (20 females and 27 males).

Results: The present study revealed that feeding difficulties were predominantly present in children with Down syndrome. These difficulties were found in all the three phases of swallow and were greatest for solids followed by liquids. They also had issues with physical, functional and emotional aspects of feeding. Further, the children with Down syndrome exhibited poor sensorimotor abilities which could have lead to the difficulties in feeding.

Conclusions: The study highlights the importance of including feeding assessment in the evaluation protocol of infants and children with Down syndrome.

Implementation of developmental screening by childcare providers.

Shahidullah, J. D., Forman, S. G., Norton, A. M., Harris, J. F., & Palejwala, M. A. (2020). *Infant and Young Children.* 33(1), 21-34.

Early identification of young children at developmental risk is important for linkage to needed services. Yet, despite guidelines for developmental screening, many pediatricians do not systematically use screening tools. Because many young children spend time in childcare settings, conducting screening in these settings may improve rates of early identification. Surveys were sent to 356 childcare providers who attended brief developmental screening training to determine practices and perceptions related to implementation of screening in the childcare setting. A 51.7% useable response rate was obtained. A majority of respondents strongly agreed that developmental screening should be conducted in childcare centers, that it is important for staff to discuss developmental concerns with parents and to link children with concerns to resources, and that their center director supported use of the screening tool. Several attitudes both about developmental screening and about organizational support had a positive and significant relationship with current use and intended future use of developmental screening tools. Findings suggest that even brief staff training may positively impact screening attitudes and practices, although follow-up technical assistance may result in fuller, more effective implementation.

Infant illness severity and family adjustment in the aftermath of NICU hospitalization. Grunberg, V. A., Geller, P. A., & Patterson, C. A. (2020). *Infant Mental Health Journal*. *41*(3), 340-355.

Up to 15% of parents have an infant who will spend time in a neonatal intensive care unit (NICU). After discharge, parents may care for a medically fragile infant and worry about their development. The current study examined how infant illness severity is associated with family adjustment. Participants included parents with infants who had been discharged from the NICU 6 months to 3 years prior to study participation (N = 199). Via a Qualtrics online survey, parents reported their infants' medical history, parenting stress, family burden, couple functioning, and access to resources. Multivariable regression analyses revealed that more severe infant medical issues during hospitalization (e.g., longer length of stay and more medical devices) were associated with greater family burden, but not stress or couple functioning. Infant health issues following hospitalization (i.e., medical diagnosis and more medical specialists) were associated with greater stress, poorer couple functioning, and greater family burden. Less time for parents was associated with increased stress and poorer couple functioning. Surprisingly, parents of infants who were rehospitalized reported less stress and better couple functioning, but greater family burden. Family focused interventions that incorporate psychoeducation about provider—patient communication, partner support, and self care may be effective to prevent negative psychosocial sequelae among families.

Maternal input and child language comprehension during book reading in children with Down syndrome. Barton-Hulsey, A., Lorang, E., Renfus, K., & Sterling, A. (2020). *American Journal of Speech-Language Pathology.* 29(3), 1475-1488.

Purpose: Communication interactions between parents and children during shared book reading impact a child's development of both language and literacy skills. This study examined maternal language input and child expressive communication during a shared book reading activity in children with Down syndrome (DS) and children with typical development (TD). Additionally, children's receptive language was examined to understand the relationship between maternal language input and child receptive language ability.

Method: Participants included 22 children with DS and 22 children with TD between 22 and 63 months of age and their mothers. Each mother-child dyad participated in a 7-min naturalistic shared book reading activity. Results: Compared to mothers of children with TD, mothers of children with DS used significantly more utterances with less grammatical complexity, but a similar range of vocabulary diversity. Mothers of children with DS used more questions, descriptions, gestures, and labels, whereas mothers of children with TD used nearly half of their utterances to read directly from books. Children with DS communicated at a similar frequency compared to their peers with TD; however, they produced significantly fewer spoken words.

Conclusions: This study reveals important differences between early shared book reading interactions and provides implications for future research targeting parent-coached intervention strategies that may enhance children's learning during shared book reading by providing access to expressive language and print instruction.

Rates of prelinguistic communication and early symbol use in young

children Down syndrome: Using a progress-monitoring tool to model growth. Romana, M., Kaiser, A., Lounds-Taylor, J., & Woods, J. (2020). American Journal of Speech-Language Pathology. 29(1), 49-62. Purpose: This study aims to provide descriptive data on rates of expressive communication skill use in young children with Down syndrome (DS) across early childhood. Children with DS are known to have delays in expressive communication, but there are little current data on rates of communication in early skills, such as gestures, vocalizations, words, and word combinations. In addition, few studies use measures that offer a composite or "across-skills" view of early development across time.

Method: This article used a longitudinal descriptive design to generate growth curves for expected rates of communication in young children with DS in 4 major skill elements as measured by the Individual Growth and Development Indicator-Early Communication Index. Using data from 19 children aged 11-42 months with DS, we used hierarchical linear modeling to generate growth curves for children with DS while comparing them to the benchmarked data available for children who are typically developing. Results: Results indicate relative strengths in gesture use, a longer period of vocalizations, and lower rates of growth in single and multiple word combinations across time. Children differed significantly from one another on all parameters.

Conclusion: These data indicate a need to develop and research interventions to support the transition from gestures to words and that support early word combinations in young children with DS.

Selected Journal Table of Contents

Infant Mental Health Journal. Volume 41, Issue 5; September/October 2020.

Studying the process of psychoanalytic parent-infant psychotherapy: Embodied and discursive aspects. p. 589-602. Avdi, E., Amiran. K., Baradon, T., Broughton, C., Sleed, M., Spencer, R., & Shai, D.

Evaluating the "possums" health professional training in parent-infant sleep. p. 603-613. Whittingham, K., Palmer, C., Douglas. P., Creedy, D. K., & Sheffield, J.

Mother's prenatal and postpartum depression symptom and infant's sleep problems at 6 months. p. 614-627. Dias, C., & Figueiredo, B.

The prenatal maternal representations of mothers at risk of recurrent care proceedings in the Family Drug and Alcohol court: A thematic analysis. p. 628-641. Meier, J., & Edginton, E.

Mothers' self-reported emotion dysregulation: A potentially valid method in the field of infant mental health. p. 642-650. Leerkes, E. M., Su, J., & Sommers, S. A.

Developmental and medical factors associated with parenting stress in mothers of toddlers born preterm in a neonatal follow-up clinic. p. 651-661. Dempsey, A. G., & Keller-Margulis, M. A.

Do postpartum anxiety and breastfeeding self-efficacy and bonding at early postpartum predict postpartum depression and the breastfeeding method? p. 662-676. Minamida, T, Iseki, A., Sakai, H., Imura, M., Okano, T., & Tanii, H.

Predictors and moderators of improved social-emotional functioning in mothers with substance use disorders and their young children enrolled in a relationship-based case management program. p. 677-696. Hilderbrandt, U. C., Graham, J., & Grant, T. M.

Efficacy of interventions to improve psychological adjustment for parents of infants with or at risk of neurodevelopmental disability: A systematic review. p. 697-722. Dickinson, C., Whittingham, K., Sheffield, J., Wotherspoon, J., & Boyd, R. N.

The contributions of child-mother attachment, maternal parenting stress, and military status to the prediction of child behavior problems. p. 732-737. Tupper, R., Bureau, J. F., Deneault, A. A. Dixon-Luinenburg, T., & St-Laurent, D.

Selected Journal Table of Contents (continued)

Infants and Young Children. Volume 33, Issue 4; October/December 2020.

Developing a screening tool for young children using an ecological framework. p. 237-258. DeCandia, C. J., Volk, K. T., Unck, G. J., & Donegan, L.

Evaluation of a brief teacher coaching program for delivering an early intervention program to preschoolers with Autism Spectrum Disorder. p. 259-282. Tupou, J., Waddington, H., & Sigafoos, J.

Using environmental modification and teacher mediation to increase literacy behaviors in preschool settings. p. 283-299. Deris, A. R., DiCarlo, C. F., Wagner, D., & Oborn, K.

Challenges and successes in addressing food selectivity in children with developmental disabilities during preschool mealtimes. p. 300-312. Gast, A., Shepley, C., & Lane, J. D.

Supporting early communication skills of children with developmental disorders in South Africa: Caregiver and clinician perspectives about mobile health applications. p. 313-331. Bornman, J., Romski, M., King, M., Madima, V., & Sevcik, R.

A review of siblings' needs and interventions supporting their adaptation in the neonatal intensive care unit. p. 332-351. Savanh, P., Aita, M., & Heon, M.

To request full-text copies of journal articles listed in the Journal Table of Contents, please contact the library staff by email: avlibrary@dshs.texas.gov.

Selected Journal Table of Contents (continued)

Zero to Three Journal. Volume 40, Issue 6; July 2020.

Relationships and interdisciplinary collaboration: Integrating infant and early childhood mental health in the pediatric oncology setting. p. 5-11. Harman, J. L., Willard, V. W., & Jurbergs, N.

Helping young fathers across the transition to parenthood: A rock or a rolling stone? p. 12-20. Florsheim, P., Moore, D., Burrow-Sanchez, J.

Chance elevator encounters and tenacious champions: Collaborative referrals between child welfare and early intervention. p. 21-32.

Bernstein, H. K., Hartman, L., Hebbeler, K., Kaufman, J. L., Magaw, D., Shaw, E. F., Schmidt, L. K., & Spiker, D.

Getting kicked out of the "bubble": Rupture and repair in the consultative relationship. p. 33-38. Bennett, A., & Hack, J.

Adolescent parents and neurodevelopmental maturation: Changing the medical home model for teen parents and their children. p. 39-42. Hasbrouck, S., Smith, H., & Ashby, B.

The warmest handoff: Using child-parent psychotherapy to ease placement transitions. p. 43-49. Jessing, B., & Cole-Mossman, J.

PERSPECTIVES: Loving my baby through withdrawal: Infusing principles of infant and early childhood mental health in the treatment of Neonatal Abstinence Syndrome. p. 50. Harman, J. L.

To request full-text copies of journal articles listed in the Journal Table of Contents, please contact the library staff by email: avlibrary@dshs.texas.gov.

Down Syndrome: New Books

Addressing challenging behaviors and mental health issues in early childhood. Mojdeh Bayat. 2020. (LB 1139.25).

This essential volume provides research-based strategies to help educators address challenging behaviors in early childhood and elementary years. Drawing on research and approaches from the fields of neuroscience, child development, child psychiatry, counselling and applied behavior analysis, this text offers teachers simple strategies to manage behaviors and promote mental health and resilience in young children.

Off to a good start: A behaviorally based model for teaching children with Down syndrome, Book 2, Teaching programs. Kathleen M. Feeley. 2019.

This book is a starting point for parents and professionals with little or no knowledge of Applied Behavioral Analysis (ABA). Book 2: Teaching Programs shows readers how to teach hundreds of essential skills using proven discrete-trial methods with prompts and reinforcement rather than the more informal ways that people typically teach children with Down syndrome. Note: The library also owns **Off to a good start:**A behaviorally based model for teaching children with Down syndrome, Book 1, Foundations for learning.

Down Syndrome Resources: Selected Audiovisuals

Being with infants. 108 min. 2018. Streaming.

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

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

Daily schedules and caregiving. 92 min. 2016. Streaming.

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

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

Down Syndrome: Selected Audiovisuals (continued)

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

Down syndrome: The first 18 months, 2nd ed. 108 min. 2010. DVD. (DD0561).

Early intervention for social emotional development. 39 min. 2017. DVD. (DD0827).

ECI teleconference: Down syndrome - what's there to know. 110 min. 2005. DVD. (DD0182).

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

Expecting Adam: A true story of birth, rebirth and everyday magic. 780 min. 2011. Audiobook on CD. (CA0040).

Infant toddler learning environment. 43 min. 2017. DVD. (DD0825).

Infants with disabilities. 25 min. 2008. Streaming or DVD. (DD0563).

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

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

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

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

Teach me to see. 68 min. 2011. DVD. (DD0828).

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

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

Down Syndrome: Selected 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).

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

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

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

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

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).

Effective early intervention: The developmental systems approach. Michael J. Guralnick, 2019. (LC 4019.3 G978e 2019 ECI).

Expecting Adam: A true story of birth, rebirth, and everyday magic. Martha Beck, 2000. (226.11 B393e 2000 ECI). This title is also available on audiobook. (CA0040).

Finding your way with your baby: The emotional life of parents and babies. Dilys Daws, 2015. (WS 105.5 E5 D272 2015 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).

Down Syndrome: Selected 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).

Neurocognitive rehabilitation of Down syndrome: The early years. 2011. (WS 107.5 R3 2011).

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

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).

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

Practical solutions to practically every problem: The survival guide for early childhood professionals. Steffen Saifer, 2017. (LB 1140.2 ST817 2017 ECI).

Prevent-teach-reinforce for families: A model of individualized positive behavior support for home and community. Glen Dunlap, 2017. (LB 1139 P944 2017 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).

Down Syndrome: Selected Books (continued)

Twelve essential topics in early childhood: A year of professional development in staff meetings. Nancy P. Alexander, 2018. (LB 1775.6 AL374 2018 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).

Down Syndrome: Selected 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).

Down Syndrome Resources: Selected eBooks

Library ebook titles are available to Texas ECI state and program staff. They may be accessed on a computer or mobile device with an internet connection. To receive access information, email the library at avlibrary@dshs.texas.gov. Visit the online library catalog to see all library titles at texasheathlibrary.com.

Children with disabilities, 7th ed. Gaetano R. Lotrecchiano, Nancy J. Roizen, and Mark L. Batshaw, 2013.

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.

Genetic disorder sourcebook. Sandra J. Judd, 2013.

This book provides basic consumer health information about heritable disorders, including disorders resulting from abnormalities in specific genes, such as hemophilia, sickle cell disease, and cystic fibrosis, and chromosomal disorders, such as Down syndrome or fragile X 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.

Down Syndrome: Selected Websites

Local Down Syndrome Associations: Texas has sixteen local Down syndrome associations. Please visit individual association websites for more information.

- BUDS Better Understanding of Down Syndrome: <u>budslubbock.org</u>
- Down By the Border: <u>downbytheborder.org</u>
- Down Syndrome Association of Brazos Valley: dsabv.org
- Down Syndrome Association of Central Texas: dsact.org
- Down Syndrome Association of El Paso: <u>dsaep.org</u>
- Down Syndrome Association of Houston: dsah.org
- Down Syndrome Association of South Texas: dsastx.org
- Down Syndrome Guild of Dallas: downsyndromedallas.org
- **Down Syndrome League of Victoria:** DownSyndromeLeagueVictoria
- Down Syndrome Partnership of North Texas: dspnt.org
- East Texas Down Syndrome Group: etdsq.org
- Galveston-Houston Families Exploring Down Syndrome: ghfeds.org
- Heart of Texas Down Syndrome Network: hotdsn.org
- Panhandle Down Syndrome Guild: pdsg.org
- Red River Valley Down Syndrome Society: parisreach.org
- Rio Grande Valley Down Syndrome Association: rqvdsa.orq

Down Syndrome: Selected Websites (continued)

MedlinePlus, an online medical resource provided by the National Library of Medicine, offers resources about Down syndrome. For more information, go to medlineplus.gov/downsyndrome.html.

National Down Syndrome Society 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. For more information, go to ndss.org.

National Institutes of Health provides DS-Connect®, a powerful resource where people with Down syndrome and their families can connect with researchers and health care providers, express interest in participating in certain clinical studies on Down syndrome, including studies of new medications and other treatments, and take confidential health-related surveys aimed at better understanding of the health of people with Down Syndrome across their lifespans. For more information, go to dsconnect.nih.gov/.

National Human Genome Research Institute provides an online resource on Down syndrome. For more information, go to genome.gov/Genetic-Disorders/Down-Syndrome.

Texas Department of State Health Services Down Syndrome provides online resources for new and expecting parents. For more information, go to ds.texas.gov/birthdefects/downsyndrome/.

Your Child: Development and Behavior Resources is an online resource from the University of Michigan Health System. For more information, go to med.umich.edu/yourchild/topics/downsyn.htm.