ECI Library Matters

Down Syndrome Resources (updated)

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

Library materials may be borrowed upon request. Electronic library materials may be accessed on any device with internet access. Please email any ECI library requests or questions to avlibrary@dshs.texas.gov.

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Selected Journal Abstracts

Observations of feeding practices of US parents of young children with Down syndrome. Surette, V. A., Smith-Simpson, S., Fries, L. R., Forde, C. G., & Ross, C. F. (2023). *Maternal & Child Nutrition, 19*(4). https://doi.org/10.1111/mcn.13548

Parental behaviors influence food acceptance in young children, but few studies have measured these behaviors using observational methods, especially among children with Down syndrome (CWDS). The overall goal of this study was to understand parent feeding practices used during snack time with young CWDS (N = 111, aged 11–58 months). A coding scheme was developed to focus on feeding practices used by parents of CWDS from a structured home-use test involving tasting variously textured snack products. Behavioral coding was used to categorize parental feeding practices and quantify their frequencies (N = 212 video feeding sessions). A feeding prompt was coded as successful if the child ate the target food product or completed the prompt within 20 s of the prompt being given without a refusal behavior. CWDS more frequently consumed the test foods and completed tasks in response to Autonomy-Supportive Prompts to Eat (49.3%), than to Coercive-Controlling Prompts to Eat (24.2%). By exploring the parent-CWDS relationship during feeding, we can identify potentially desirable parent practices to encourage successful feeding for CWDS. Future research should build upon the knowledge gained from this study to confirm longitudinal associations of parent practices with child behaviors during feeding.

Prenatal experiences and desires with early intervention for families of children with Down syndrome. Keilty, B., Jackson, M. A., & Smith, J. (2024). *Topics in Early Childhood Special Education*. https://doi.org/10.1177/02711214241237420

Part C early intervention (EI) starts no earlier than birth, even with a prenatal diagnosis resulting in automatic eligibility. Despite other early home visiting programs beginning prenatally and the increasing likelihood of uncovering certain diagnoses prenatally, pregnant families cannot access EI. This study sought to understand families' perspectives on their desire for prenatal EI and how EI could support them. Seventeen primarily White non-Hispanic mothers with a prenatal diagnosis of Down syndrome shared their prenatal experiences through retrospective, qualitative interviews. Three themes emerged: (1) prenatal period as a time to connect to EI, (2) different families, different prenatal desires, and (3) postnatal EI experiences, prenatal EI hopes. Families saw benefits to starting prenatally

to enroll in and understand EI and prepare for their baby's arrival through individualized outcomes. Families appreciated their postnatal EI and envisioned similar supports prenatally. Participants' shared experiences are discussed in relation to pre- and postnatal EI.

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Infant Mental Health Journal. Volume 45, Issue 4; July 2024

Issue Information. p. 355-356.

Parental sensitivity and family conversation: A naturalistic longitudinal study with both mothers and fathers across three time-points in early infancy. p. 357-368. Fink, E., Foley, S., Browne, W., & Hughes, C.

Spillover effects on the relationship with the partner of a mentalization-based intervention for pregnant women. p. 369-381. Berthelot, N., Larouche, K., Garon-Bissonnette, J., Deschênes, K., Drouin-Maziade, C., & Lemieux, R.

The effect of the separation of mother-preterm newborn infants hospitalized during the COVID-19 pandemic on maternal depression and stress levels, infant development, and bonding quality on Chilean dyads. p. 382-396. Ramírez, F. V., Huber, M. O., Ferrés, M. I. H., Montecino, M. S. C., Bravo, A. G., & Nudman, M. M.

Infants of mothers with early remitted clinical depression and mothers with no postpartum depression: Adaptive functioning in the second year of life. p. 397-410. Bornstein, M. H., Manian, N., & Henry, L. M.

"You go in heavy and you come out light": An interpretative phenomenological analysis of reflective practice experiences in an Irish infant mental health setting. p. 411-437. Tobin, M., O'Sullivan, N., & Rogers, E.

Evaluating the use of the AMBIANCE-Brief measure in clinical settings: Assessing acceptability, feasibility, and utility of the AMBIANCE-Brief. p. 438-448. Eirich, R., Pador, P., Watt, J., Racine, N., Lyons-Ruth, K., & Madigan, S.

Initial validation of the Health Environment Rating Scale-Early Childhood Consultation-Classroom (HERS-ECC-C). p. 449-463. Futterer, J., Mullins, C., Bulotsky-Shearer, R. J., Guzmán, E., Hildago, T., Kolomeyer, E., Howe, E., Horen, N., Sanders, L. M., & Natale, R.

Parental reflective functioning on the parent development interview: A narrative review of measurement, association, and future directions. p. 464-480. Slade, A. & Sleed, M.

Infants and Young Children. Volume 37, Issue 3; July/September 2024

From the editor p. 155-156.

Developmental monitoring in special supplemental nutrition programs for Women, Infants, and Children (WIC) increases referrals to social supports. p. 157-171. Barlow, K., Ghiringhelli, K., Sullivan, K., & Daly, A.

Child maltreatment-focused intervention research: A systematic literature review. p. 172-192. Banerjee, R., Movahedazarhouligh, S., & Ghosh, E.

Parent perspectives of early childhood special education transition: A systematic review. p. 193-215. Gaspar, C. R. & Jahromi, L. B.

Supporting families of children living in multiple households: A survey of early interventionists. p. 216-232. Puhlman, J. & Puhlman, D.

A content analysis of public-facing Part C early intervention websites of US States and territories. p. 233-251. Weaver, P., Rapport, M. J., Catalino, T., & Barreca, J.

Reconceptualizing family-centered partnerships in parent-implemented interventions. p. 256-269. Harbin, S. G., Choi, G., & Fettig, A.

New Books

Occupational therapy activities for kids: 100 fun games and exercises to build skills. Heather Ajzenman, 2020. CPE=2 (WS 368 A312 2020 ECI)

This book uses simple, fun activities to help kids learn the skills they need for daily life, from eating meals and writing the alphabet to socializing with friends and family. This family-friendly guide offers concise information on how occupational therapy works and shows how to apply it in a way that benefits your child.

New eBook

Multimodal AAC for individuals with Down syndrome. 2021.

This volume examines the role of multimodal augmentative and alternative communication (AAC) in supporting speech, language, and communication of individuals with Down syndrome, across the lifespan.

Selected Audiovisuals

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

Down syndrome: An updated look. Streaming. 58 min. 2015.

Down syndrome - second opinion. DVD or <u>Streaming</u>. 26 min. 2016. (DD0833)

Down syndrome for new parents: What to know during the first year. Streaming. 6 minutes. 2022.

Infant toddler learning environment. DVD or <u>Streaming</u>. 43 min. 2017. (DD0825)

Continuing Professional Education (CPE) Resources

Caring for your baby and young child: Birth to age 5, 7th ed. Tanya Altmann, 2019. CPE=23.25 (WS 105.5 C3 S545 2019 ECI)

Extreme caregiving: The moral work of raising children with special needs. Lisa Freitag, 2018. CPE=6 (WS 107.5 F866 2018 ECI)

Interaction: Enhancing children's access to responsive interactions. CPE=3 (LC 4019.3 I61 2018 ECI)

No small matter. DVD. 74 min. 2020. CPE=1.25 (DD0854)

Off to a good start: A behaviorally based model for teaching children with Down syndrome. Book 1, Foundations for learning. Emily A. Jones, 2019. CPE=4.5 (WS 107.1 J76 2019 ECI)

Off to a good start: A behaviorally based model for teaching children with Down syndrome. Book 2, Teaching programs. Kathleen M. Feeley. 2019. CPE=8 (WS 107.1 F295 2019 ECI)

The parent's guide to Down syndrome. Jen Jacob, 2016. CPE=4 (WS 107 J15p 2016 ECI)

Understanding fatherhood. DVD. 40 min. 2019. CPE=0.75 (DD0834)

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)

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

Selected eBooks

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.

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

Selected Websites

NEW! Centers for Disease Control and Prevention (CDC): <u>Down</u>

<u>Syndrome</u> provides facts about Down syndrome.

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

- B.U.D.S. Lubbock Better Understanding of Down Syndrome: budslubbock.org
- Down By the Border An Association Helping Children with Special Needs: downbytheborder.org
- Down Syndrome Association of Brazos Valley: <u>dsabv.orq</u>
- Down Syndrome Association of Central Texas: <u>dsact.orq</u>
- Down Syndrome Association of El Paso: <u>dsaep.orq</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 Partnership of North Texas: dspnt.org
- East Texas Down Syndrome Group: etdsg.org
- Galveston-Houston Families Exploring Down Syndrome: gclfeds.wildapricot.org
- Heart of Texas Down Syndrome Network: <u>hotdsn.org</u>
- Panhandle Down Syndrome Guild pdsg.org
- Red River Valley Down Syndrome Society: parisreach.org
- Rio Grande Valley Down Syndrome Association: rgvdsa.org

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 aims to be the national advocate for the value, acceptance, and inclusion of people with Down syndrome. The society's website is immense and attempts to be the comprehensive information source on Down syndrome. For more information, go to ndss.org.

NEW! National Institutes of Health: The Down Syndrome Consortium

The National Institutes of Health (NIH) joined governmental and private organizations interested in Down syndrome (DS), health care provider associations, and self-advocates to form the DS Consortium in 2011. Led by the *Eunice Kennedy Shriver* National Institute of Child Health and Human Development (NICHD), The Down Syndrome Consortium encourages research on the health of people with DSand the exchange of DS information among Consortium members and members of the DS community. For more information, go to downsyndrome.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 dshs.texas.gov/texas-birth-defects-epidemiology-surveillance/down-syndrome

Useful Library Information

HHSC ECI Website
ECI Library Matters

<u>Library Website</u> <u>Library Catalog</u>

Texas Department of State Health Services ECI Library Services

Email: avlibrary@dshs.texas.gov

Phone: 512-776-7260 **Toll-free:** 1-888-963-7111 ext. 7260 **Fax:** 512-776-7474 **Hours:** Mon.-Fri., 7:30 a.m.-5 p.m.

Address: 1100 W. 49th St. Moreton Building, 6th floor, Room M-652, Austin,

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