

ECI Library Matters

Down Syndrome and Other Medical Diagnoses Resources

This issue features updated library resources on Down syndrome and other medical diagnoses. Journal article abstracts are also included. For a listing of library titles, visit 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 ECI library requests or questions to avlibrary@dshs.texas.gov.

In This Issue

- [Selected Journal Abstracts](#)
- [Selected Journal Table of Contents](#)
 - [Infant Mental Health Journal](#)
Volume 46, Issue 4; July 2025
 - [Journal of Early Intervention](#)
Volume 3, Issue 4; September 2025
- [New Audiovisual](#)
- [New Books](#)
- [New eBooks](#)
- [Selected Audiovisuals](#)
- [Continuing Professional Education Resources](#)
- [Selected Children's Books](#)
- [Selected eBooks](#)
- [Selected Websites](#)
- [Useful Library Information](#)

Selected Journal Abstracts

Complex medical needs and homelessness: A case study of the natural environment.

Williams, C. S., Sawyer, G. E., & Ostrosky, M. M. (2025). *Topics in Early Childhood Special Education*, 45(1), 7-20.

<https://doi.org/10.1177/02711214251316522>

Infants and toddlers with complex medical needs are likely to receive early intervention (EI) services, which take place in children's natural environments (NEs). Little is known about the NE of children with complex medical needs or how their EI services are implemented in consideration of their intersectional identities. In this case study, we explored the NE of one child with complex medical needs who was experiencing homelessness and how his EI services were embedded in his NE. We used multiple qualitative methods, including observations, interviews, document review, auto-photography, and photo-elicitation. Using thematic analysis, we developed five themes from the data: (a) description of the child's NE, (b) the family's planning and intentionality, (c) positivity and acceptance, (d) family expertise versus provider expertise, and (e) a continuum of practices. Implications relate to practices that align with a family's unique circumstances and the need for research that addresses a family's intersectional experiences navigating disability.

Development, education, and services in children with Down syndrome: A cohort analysis from a clinical database.

Soccorso, C., Hojlo, M., Pawlowski, K., Lombardo, A., Davidson, E., Sargado, S., DePillis, R., & Baumer, N. *Frontiers in Psychology*, 15. <https://doi.org/10.3389/fpsyg.2024.1348404>

Background: Prior research has characterized neurodevelopmental phenotypes for Down syndrome (DS), but there is variability in age of milestone attainment and limited identification of early predictors of developmental trajectories. Additionally, less is known about receipt of education and services in relation to development.

Objective: This study describes the delivery of education and therapies in the setting of general developmental and behavioral needs in a large clinical cohort of children with DS seen in a specialized Down Syndrome Program (DSP).

Method: The clinically collected data included 814 patients with DS who were seen at a specialty DSP at a large, tertiary pediatric care center from March 2018 to January 2023. Data were collected through caregiver-and clinician-reported history at clinical visits to the program. Descriptive frequencies were utilized to describe participant demographics, skills and behaviors, and receipt of services, across age groups in childhood.

Results: Delays were present across all developmental domains; in particular, delays in language, communication, and academic skills, and behavioral challenges were commonly reported. Almost all children received Early Intervention (EI)

services, and many young children received non-public therapies after completing EI. Older participants demonstrated more impairments than younger age groups, yet received services at lower rates, particularly behavioral and speech language interventions.

Conclusion: A snapshot of developmental skill attainment in individuals with DS is provided. Therapies to support the levels of need were reported at much lower frequencies than the level of need reported to target aspects of development and behavior. Several gaps in therapies and educational services were identified. There is an important need for tailoring supports, based on developmental level, to meet individual needs. These findings may help to inform policy change related to developmental and education services for individuals with DS.

Selected Journal Table of Contents

Infant Mental Health Journal. Volume 46, Issue 4; July 2025

Issue Information. p. 359-360.

A decolonial perspective on Indigenous infant and early childhood mental health: Reclaiming Indigenous ways for the next seven generations.

p. 361-375. Richardson, M., Waubanascum, C., Waters, S.F. & Sarche, M.

Perinatal discrimination and maternal depressive symptoms associated with infant development in African American families. p. 376-390. Harden, B. J., Martoccio, T. L., Morrison, C. M. & Brown, S.

Holding up the mirror. p. 391-405. Batz, R., Walter, M. C., Burnham, M. M. & Fiore, L. B.

A systematic review and meta-analysis of parental mentalization in fathers and mothers. p. 406-423. Trepiak, P., Deneault, A. A. & Bureau, J. F.

Parent and child gender effects in the relationship between attachment and both internalizing and externalizing problems of children between 2 and 5 years old: A dyadic perspective. p. 424-444. Matetovici, M., Spruit, A., Colonesi, C., Garnier-Villarreal, M. & Noom, M.

Validating the parental reflective functioning questionnaire - infant version using a Rasch model. p. 424-444. Stuart, A. C., Egmoose, I., Wendelboe, K. I., Smith-Nielsen, J. & Vaever, M. S.

Baby steps of parenting: Turkish adaptation of Infancy Parenting Styles Questionnaire and mother- and infant-related characteristics affecting parenting in infancy. p. 459-477. Bahtiyar-Saygan, B.

Bridging attachment theory and interpersonal acceptance-rejection theory in the strange situation procedure in a low-risk sample in Egypt. p. 478-485. Zaki, N. M. & Shehat, M. A.

Journal of Early Intervention. Volume 3, Issue 4; September 2025

A pilot study of the effectiveness and feasibility of an early intervention leadership program for families of children with disabilities. p. 251-264.
Burke, M., Li, C., Fulton, K. & Cheung, W. C.

Investigating caregivers' advocacy efforts in early intervention using auto-photography and photo-elicitation interviews. p. 265-285. Schraml-Block, K. M. & Ostrosky, M. M.

Experiences of service coordinators utilizing the getting ready approach for home visits. p. 286-308. Kuhn, M. & Higgins, J.

Positive experience, passive engagement: Parents' descriptions of their involvement in early intervention services. p. 309-329. Decker, K. B., Fry, M. M., Foster, T. D., Feigel, A. J. & Cook, G. A.

Speech-language outcomes in dual-language learners following early intervention: What about caregiver language? p. 330-346. Heymann, P., Gonzalez, M., Natale, R. A. & Bagner, D. M.

Examining the impact of COVID-19 on early intervention service provision for military families: A brief report. p. 347-360. Zellner, M. A., Grauzer, J., Kaat, A. J. & Roberts, M. Y.

Feasibility and acceptability of an adapted evidence-based team training approach from health care to the early intervention context: A brief report. p. 361. Albright, J., Rushworth, S., Kuriyan, A., Duresso, B., Testa, S. & Wolk, C. B.

New Audiovisual

Early interventions for pediatric occupational and physical therapy — A lecture. 358 min. 2015. [Streaming](#).

This video seminar offers strategies and guidelines for working with pediatric therapy patients. It discusses therapy for preemies after discharge, therapies that help toddlers who display atypical development, and interventions for head and trunk control and to facilitate transitional movements.

New Books

Children and youth with complex cerebral palsy: Care and management. 2019. **CPE=10.25** (WS 342 C536 2019 ECI)

This title is also available in eBook format.

This book explores management of the many medical comorbidities these children encounter, including orthopedic concerns, mobility and equipment needs, cognition and sensory impairment, difficult behaviors, seizures, respiratory complications and nutritional challenges, among many others. Summary points at the end of each chapter provide at-a-glance access to key recommendations. An appendix provides adaptable care tools to guide clinicians in evaluation, preventive care, and crisis management.

When Down syndrome and autism intersect: A guide to DS-ASD for parents and professionals, 2nd ed. 2024. **CPE=13.5** (WS 107 W556 2024 ECI)

A guide to supporting individuals with the complex dual diagnosis of both Down syndrome and autism spectrum disorder. Written by a team of parents and experts, it covers every aspect of caring for children and adults with DS-ASD and offers sound information and resources steeped in research and clinical findings.

New eBooks

Broccoli boot camp: Basic training for parents of selective eaters, 2nd ed. Keith E. Williams, 2024. **CPE=7**

This book presents commonsense behavioral interventions to successfully expand children's diet variety and preferences for healthy foods. Learn how to overcome a child's selective eating. It describes ways to increase compliance, factors to consider when choosing an intervention, and strategies to shape behavior. Five intervention plans are presented with step-by-step procedures, modifications, and tips on maximizing success.

Welcoming a newborn with Down syndrome: A new parent's guide, 2nd ed. 2025.

This free to download book offers support and accurate, reliable information to the new parents of a baby with Down syndrome. It covers topics like breastfeeding,

adjusting to a diagnosis, preparing siblings, understanding medical issues, preparing for the future, and, most importantly, it shares diverse stories about the daily lives of families whose children have Down syndrome at different ages.

Selected Audiovisuals

Down syndrome: An updated look. 58 min. 2015. [Streaming](#).

Down syndrome: second opinion. 26 min. 2016. DVD (DD0833) or [Streaming](#).

Down syndrome for new parents: What to know during the first year. 6 minutes. 2022. [Streaming](#).

Infant toddler learning environment. 43 min. 2017. DVD (DD0825) or [Streaming](#).

Continuing Professional Education Resources

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

Children with disabilities, 8th ed. Mark L. Batshaw, 2019. eBook. **CPE=15**

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

Genetic disorder sourcebook, 8th ed. James Chambers, 2023. eBook. **CPE=15**

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

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

Occupational therapy activities for kids: 100 fun games and exercises to build skills. Heather Ajzenman, 2020. Book. **CPE=2** (WS 368 A312 2020 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. Book. **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. Book. **CPE=8** (WS 107.1 F295 2019 ECI)

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

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

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.

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 Websites

[Centers for Disease Control and Prevention \(CDC\): Down Syndrome](#) provides facts about Down syndrome.

Texas has several local Down syndrome associations with websites. Please visit each website for more information.

- B.U.D.S. Lubbock - Better Understanding of Down Syndrome: budslubbock.org
- Down By the Border: downbytheborder.org
- Down Syndrome Association of Brazos Valley: dsabv.org
- Down Syndrome Association of Central Texas: dsact.org
- Down Syndrome Coalition for El Paso: dscep.org
- 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.net
- Galveston-Houston Families Exploring Down Syndrome: gclfeds.wildapricot.org
- Heart of Texas Down Syndrome Network: hotdsn.org
- Panhandle Down Syndrome Guild pdsg.org
- Rio Grande Valley Down Syndrome Association: rgvdsa.org

MedlinePlus Down Syndrome, an online medical resource provided by the National Library of Medicine, offers resources about Down syndrome.

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 a almost comprehensive information resource on Down syndrome.

National Institutes of Health: The Down Syndrome Consortium

The Down Syndrome Consortium encourages research on the health of people with DS and the exchange of DS information among Consortium members and members of the DS community.

National Human Genome Research Institute provides an online resource on Down syndrome.

Texas Department of State Health Services Down Syndrome provides online resources for new and expecting parents.

Useful Library Information

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Library Website
Library Catalog

Texas Department of State Health Services ECI Library Services

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