

# 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](http://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](mailto:avlibrary@dshs.texas.gov).

## **In This Issue**

- **Selected Journal Abstracts**
- **Selected Journal Table of Contents**
  - **Infant Mental Health Journal**  
Volume 44, Issue 4; July 2023
  - **Infants and Young Children**  
Volume 36, Issue 3; July/September 2023
  - **Topics in Early Childhood Special Education**  
Volume 43, Issue 2; August 2023
- **New Audiovisuals**
- **New Books**
- **Selected Audiovisuals**
- **Selected Books**
- **Selected Children's Books**
- **Selected eBooks**
- **Selected Websites**
- **Useful Library Information**

## Selected Journal Abstracts

### **CDC's "Learn the Signs. Act Early." Developmental milestone resources to improve early identification of children with developmental delays, disorders, and disabilities.**

Abercrombie, J., Wiggins, L., & Green, K. K. (2022). *Zero to Three*, 43(1), 5-12.

Approximately 1 in 6 children in the US has a developmental delay, disorder, or disability (DD). Early identification of DDs can help families access services that empower children and families, and it can improve child outcomes. The "Learn the Signs. Act Early." (LTSAE) Program at the Centers for Disease Control and Prevention (CDC) encourages parents and providers to monitor every child's early development and act when there is a concern. In February 2022, LTSAE released revised materials that include updated developmental milestone checklists to better support ongoing conversations between families and professionals. This article describes the purpose of the checklists and how early childhood professionals can use these free resources to engage families in developmental monitoring.

### **Families' access to early intervention and supports for children with developmental disabilities.**

Sapiets, S. J., Hastings, R. P., Stanford, C., & Totsika, V. (2023). *Journal of Early Intervention*, 45(2), 103-121.

<https://doi.org/10.1177/10538151221083984>

Early intervention (EI) provision is critical for families who have children with developmental disabilities (DD), but existing evidence suggests accessing EI is not always straightforward. The purpose of this study was to provide a comprehensive description of access to various EI supports (e.g., professionals, services, interventions) for families of young children with suspected or diagnosed DD across the United Kingdom and to investigate perceived ease of access to support, unmet need for support, and barriers and facilitators of access to support. Overall, 673 parental caregivers of children aged 0 to 6 years with suspected or diagnosed DD (e.g., developmental delay, intellectual disability, autism) completed our survey anonymously. Across education, health, and social care, services accessed the most were pediatrics ( N = 569, 84.5%), speech and language ( N = 567, 84.2%), and general medical practice ( N = 530, 78.8%). However, only 18.9% ( N = 127) accessed packaged interventions. More than three-quarters ( N = 508, 75.5%) reported an unmet need for early support, indicating a mismatch between the availability and capacity of services and demand for support. Parents also reported common barriers (e.g., obstructive services and unhelpful professionals) and facilitators (e.g.,

supportive and competent professionals, enabling parent factors) of access. Implications for policy, practice, and research are discussed.

**A systematic review of speech, language and communication interventions for children with Down syndrome from 0 to 6 years.**

Seager, E., Sampson, S., Sin, J., Pagnamenta, E., & Stojanovik, V. (2022). *International Journal of Language and Communication Disorders*, 57(2), 441-463. <https://doi.org/10.1111/1460-6984.12699>

**Background:** Speech and language acquisition can be a challenge for young children with Down syndrome (DS), and while early intervention is important, we do not know what early interventions exist and how effective they may be.

**Aims:** To systematically review existing early speech, language and communication interventions for young children with DS from birth up to 6 years, and to investigate their effectiveness in improving speech, language and communication outcomes in children with DS. Other outcomes are changes in parental behaviour and their responsiveness.

**Methods & Procedures:** We conducted a systematic search of relevant electronic databases to identify early intervention studies targeting speech, language and communication outcomes in children with DS published up to May 2020. A total of 11 studies that met the inclusion criteria were synthesized and appraised for quality using the PEDro-P scale. There were a total of 242 children. We identified three types of intervention: communication training and responsive teaching, early stimulation programme, and dialectic-didactic approach.

**Main contribution:** The findings from nine out of the 11 studies reported positive outcomes for children's language and communication up to 18 months following the intervention. All nine studies reported interventions that were co-delivered by parents and clinicians. However, there was also a de-accelerated growth in requesting behaviours in the intervention group reported by one study as well as a case of no improvement for the intervention group. Three studies provided some evidence of improvements to parent outcomes, such as increased parental language input and increased responsiveness. However, there was a moderate to high risk of bias for all studies included.

**Conclusions:** The findings from this review suggest that interventions that have high dosage, focus on language and communication training within a naturalistic setting, and are co-delivered by parents and clinicians/researchers may have the potential to provide positive outcomes for children with DS between 0 and 6 years of age. Due to the limited number of studies, limited heterogeneous data and the moderate to high risk

of bias across studies, there is an urgent need for higher quality intervention studies in the field to build the evidence base.

To receive full-text articles of the abstracts listed here, please email [avlibrary@dshs.texas.gov](mailto:avlibrary@dshs.texas.gov).

## Selected Journal Table of Contents

**Infant Mental Health Journal.** Volume 44, Issue 4; July 2023.

Issue Information p. 449-450.

Promoting reflective practice in an infant and early childhood training program. p. 451-465. Lombardi, C., Bladen, A., Foley, M. T., Galante-DeAngelis, M., Larrabee, K., & Robinson, J.

Differences in infant negative affectivity during the COVID-19 pandemic. p. 466-479. Morris, A. R. & Saxbe, D. E.

Using the candidacy framework to conceptualize systems and gaps when developing Infant Mental Health (IMH) services: A qualitative study. p. 480-494. Phang, F. T. H., Weaver, A., Blane, D. N., Murphy, F., Dawson, A., Hall, S., De Natale, A., Minnis, H., & McFadyen, A.

An intensive longitudinal investigation of maternal and infant touching patterns across context and throughout the first 9-months of life. p. 495-512. Mercuri, M., Stack, D. M., De France, K., Jean, A. D. L., & Fogel, A.

Reflections on the infant mental health endorsement process in Virginia. p. 513-525. Dye, K., Spence, C., & Brock, J. R.

Facilitating caregiver-child interactions in home visiting: A qualitative observational study. p. 526-540. Huber, L. T., Molthen, F., Cook, G., & Hughes-Belding, K.

Will I love my second baby as much as my first? Prevalence and psychosocial correlates of maternal-fetal relationship anxiety for second-time mothers. p. 541-553. Volling, B. L., Tan, L., Rosenberg, L., & Bader, L. R.

'Nobody taught her how to be a mother': The lived experience of mothering without a mother. p. 554-571. Walsh, A., Tiernan, B., Thompson, B., McCormack, D., & Adair, P.

Mental health and sleep quality of low-income mothers of one-year-olds during the COVID-19 pandemic. p. 572-586. Premo, E. M., Magnuson, K. A., Lorenzo, N. E., Fox, N. A., & Noble, K. G.

Patient navigation models for mental health of parents expecting or caring for an infant or young child: A systematic review. p. 587-608. Harris, S. A., Harrison, M., Hazell-Raine, K., Wade, C., Eapen, V., & Kohlhoff, J.

**Infants and Young Children.** Volume 36, Issue 3; July/September 2023.

From the editor. p. 175-176.

Preschool and childcare expulsion: A review of the literature. p. 177-194. DuShane, D. & Yu, S.

Providing virtual support to children with mild developmental delays in response to the pandemic. p. 195-210. Gonzalez, M., Rama, C., Nawab, A., Robertson, E., Partridge, P. M., Ashkenazi, A., Mansoor, E., Van Weelden, J., Peña, K., & Natale, R.

Distance learning in an inclusive preschool focused on autism during the COVID-19 pandemic: A mixed-methods multiple case study of four children. p. 211-227. Siller, M., Murthy, H., & Fuhrmeister, S.

Exploring parents' perceptions of an early intervention for toddlers with autism. p. 228-246. Amsbary, J. & Able, H.

Evaluation strategies for Florida's Early Childhood Comprehensive Systems Impact Project. p. 247-266. Marshall, J., Hume, E., Prieto, C., Ade, C., Delva, J., Geffrard, C., Dias, E., & Elger, R. S.

**Topics in Early Childhood Special Education.** Volume 43, Issue 2; August 2023.

Future Topics. p. 87-88.

Using peer coaches as community-based competency drivers in Part C early intervention. p. 89-102. Romano, M., Schnurr, M., Barton, E. E., Woods, J., & Weigel, C.

Systematic modeling and prompting to teach math skills to preschoolers with disabilities. p. 103-115. Hardy, J. K. & Hemmeter, M. L.

Increasing the number sense understanding of preschool students with ASD. p. 116-128. Ingelin, B. L., Intepe-Tingir, S., & Hammons, N. C.

Examining early childhood teacher candidate's perceptions of diversity regarding material selection. p. 129-141. Sloan, S. O. & Coogle, C. G.

High-quality inclusion in preschool settings: A survey of early childhood personnel. p. 142-155. Steed, E. A., Rausch, A., Strain, P. S., Bold, E., & Leech, N.

Family ASL: An early start to equitable education for deaf children. p. 156-166. Lillo-Martin, D. C., Gale, E., & Pichler, D. C.

Conference calendar. p. 167

Author guidelines. p. 168

## **New Audiovisuals**

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

What will the first year of life be like for a baby with Down syndrome? What kind of support and care do they need? What is it like being a sibling of a child with Down syndrome? Brian Skotko, M.D., M.P.P., Medical Geneticist and Emma Campbell Endowed Chair on Down Syndrome at MassGeneral Hospital for Children, explains what parents can expect during the first year of raising a child with Down syndrome, including information on breastfeeding, necessary testing, and more.

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

This documentary that explores early childhood education and how our country is raising its youngest citizens. The program brings public attention to this vital question by sharing powerful stories and stunning truths about the human capacity for early intelligence and the potential for quality early care and education to benefit America's social and economic future.

## New Books

**Adapting early childhood curricula for children with disabilities and special needs.** Ruth E. Cook, 2020. (LB 1139 C771 2020 ECI)

This book uses a developmental focus, rather than a disability orientation, to discuss typical and atypical child development and curricular adaptations. The integrated, non-categorical approach assumes that children are more alike than different in their development. The inclusive focus assumes that attitudes, environments, and intervention strategies can be adapted so that all young children with disabilities or other special needs can be included.

**Assessment: Recommended practices for young children and families.** 2020. (LB 3051 A846 2020 ECI)

This book offers professionals and families multiple ways to implement the assessment practices across the settings in which children grow and learn.

## 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 [Streaming](#). 26 min. 2016. (DD0833)

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

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

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

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

**Rare.** DVD. 56 min. 2012. (DD0659)

**Understanding fatherhood.** DVD. 40 min. 2019. (DD0834)

## Selected Books

**Addressing challenging behaviors and mental health issues in early childhood.** Mojdeh Bayat. 2020. (LB 1139.25 B356 2020 ECI)

**Bringing your baby with Down syndrome home: A guide to the first month.** Jeannie Visootsak, 2014. (WS 107 V832 2014 ECI)

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

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

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

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

**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)

**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)

**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 107.1 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. (WS 107.1 F295 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)

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

**Raising exceptional children: A guide to understanding learning differences and empowering your child**. Marianne Young, 2020.  
(LC 4019.3 Y68 2020 ECI)

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

**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)

## 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

To read the eBooks listed here, please [email](#) the library for instructions and access information.

**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

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

- B.U.D.S. Lubbock - Better Understanding of Down Syndrome:  
[budslubbock.org](http://budslubbock.org)

- Down By the Border – An Association Helping Children with Special Needs: [downbytheborder.org](http://downbytheborder.org)
- Down Syndrome Association of Brazos Valley: [dsabv.org](http://dsabv.org)
- Down Syndrome Association of Central Texas: [dsact.org](http://dsact.org)
- Down Syndrome Association of El Paso: [dsaep.org](http://dsaep.org)
- Down Syndrome Association of Houston: [dsah.org](http://dsah.org)
- Down Syndrome Association of South Texas: [dsastx.org](http://dsastx.org)
- Down Syndrome Guild of Dallas: [downsyndromedallas.org](http://downsyndromedallas.org)
- Down Syndrome Partnership of North Texas: [dspnt.org](http://dspnt.org)
- East Texas Down Syndrome Group: [etdsg.org](http://etdsg.org)
- Galveston-Houston Families Exploring Down Syndrome: [ghfeds.wildapricot.org](http://ghfeds.wildapricot.org)
- Heart of Texas Down Syndrome Network: [hotdsn.org](http://hotdsn.org)
- Panhandle Down Syndrome Guild [pdsg.org](http://pdsg.org)
- Red River Valley Down Syndrome Society: [parisreach.org](http://parisreach.org)
- Rio Grande Valley Down Syndrome Association: [rgvdsa.org](http://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](http://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](http://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 the health of people with Down syndrome across their lifespans. For more information, go to [dsconnect.nih.gov/](http://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](http://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](https://dshs.texas.gov/texas-birth-defects-epidemiology-surveillance/down-syndrome).

## Useful Library Information

**HHSC ECI Website**  
**ECI Library Matters**

**Library Website**  
**Library Catalog**

### **Texas Department of State Health Services ECI Library Services**

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