

ECI LIBRARY MATTERS

October 2015



DARS Inquiries: 1-800-628-5115
DARS Website:
www.dars.state.tx.us

ECI Library Matters is available electronically at:
<http://www.dars.state.tx.us/ecis/resources/librarymatters/>

Contact Information

Texas Dept. of State Health Services Audiovisual Library
(512) 776-7260
Toll-free: 1-888-963-7111 ext. 7260
Fax: (512) 776-7474
E-mail: avlibrary@dshs.state.tx.us

Hours: Monday-Friday, 7:30-5:00

Physical Location:
1100 W. 49th St.
Moreton Bldg. Room 652
Austin, TX 78756

Mailing Address:
1100 W. 49th St.
P.O. Box 149347, MC 1975
Austin, TX 78714-9347

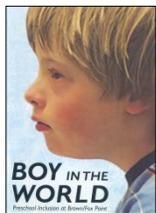
Library Web site:
<http://www.dshs.state.tx.us/avlib/>

Library Catalog:
<http://www.texashealthlibrary.com>

Down Syndrome Resources (updated)

This month we are featuring books, videos, children's books, websites, and journal articles about Down syndrome.

Down Syndrome – DVDs



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

This documentary follows four-year-old Ronen, a young boy with Down syndrome. It demonstrates that inclusive preschool classrooms benefit both children with special needs and their typical peers. It also examines the nuts and bolts of successful inclusion as well as the challenges of educational practices that help all children to learn and to find their place in the world.

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

Karen Gaffney, who has Down syndrome, becomes one of the few ultra-swimmers to cross the nine-mile width of Lake Tahoe. Karen talks about the challenges she has faced as a person with Down syndrome and the encouragement she has received from family and friends.

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

This DVD provides an overview of language development in youngsters with Down syndrome from ages 2 and up. It shows the techniques developed by experts such as Dr. Libby Kumin and Professor Sue Buckley. By integrating spoken language, sensory input, text and reading, and sign language, children with Down syndrome can improve their understanding of the world around them long before they can speak clearly. That knowledge pays off when they do start to speak, because they have a head start on language while their talking skills are catching up. Knowing letter sounds and sight words helps children fine-tune pronunciation and lays the ground work for true reading.

Down syndrome: the first 18 months. 108 min. 2010. (DD0561).

The new edition of this DVD is organized around four chapters: the newborn, health concerns, therapies, and new expectations. It presents interviews throughout with nine international medical experts on Down syndrome and several parents of children with Down syndrome discussing their children.

Down Syndrome – DVDs (continued)

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

Presenter Chris Simon, a parent of a child with Down syndrome, gives an overview of Down syndrome. She defines Down syndrome, reviews the common physical features, and its developmental aspects while providing facts about the condition. Typical parent reactions are explained so that caregivers can respond in ways that are helpful to the new parents and child. This program offers details about current interventions, controversial therapies, and research.



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

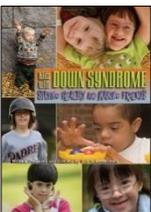
This documentary film follows the journey of Emma who was born with Down syndrome and her twin sister, Abigale who is a typically developing child. Viewers see the strategies used to include Emma in an inclusive school environment and witness the process of the Individual Education Plan meeting. Bonus features consist of an 8 minute version of the film, a clip of Emma's speech evaluation, and a presentation from the Stanford University Medical School Center for Research and Treatment of Down syndrome.

Imagine the possibilities. 14 min. 2003. (DD0263).

This documentary tells the story of Karen Gaffney, a woman with Down syndrome, and her participation in a relay swim across the English Channel.

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

This program was filmed in Ireland. It depicts the difficulties and uncertainties of a couple whose first child was born with Down syndrome. Now expecting their second baby, the family undergoes increased stress as their 10 month old son awaits heart surgery. Viewers learn about the parents' initial reaction to his condition, their quick acceptance of it, and the ways in which they began to deal with his health issues. A public health nurse helps the family build their knowledge and coping skills. This program is also available online.



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

Parents and professionals provide guidance to families with children who have Down syndrome. Along with the joys of childhood come the everyday challenges of parenthood, such as toilet training and behavior issues, and the demands of caring for a child with special needs, including IEP preparation and working with health care professionals. Children with Down syndrome may also have medical concerns that require close attention, such as sleep apnea and issues related to hearing, nutrition, and exercise.

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

This DVD profiles a little girl with Down syndrome, her family, and their transition journey from infant-toddler intervention to special education services at the nearby Head Start. Viewers also meet the service providers who assisted this family during their transition.

Opening the doors of tomorrow. 24 min. 2001. (DD0265).

This program focuses on the keys to successful inclusion from a student's point of view. A classroom of education students ask Karen Gaffney about inclusive classroom settings and what worked for her. Karen delivers a polished presentation full of important information for both families and educators.

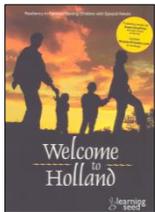
Raising a child with Down syndrome. 27 min. 2006. (DD0142).

Children with Down syndrome and their families share their experiences. Doctors explain what Down syndrome is and give advice.

Down Syndrome – DVDs (continued)

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

A documentary film maker chronicles the life of her 40 year old brother Jon, a man with Down syndrome. The filmmaker follows Jon through his daily routines and interviews his parents and siblings about their experience of having a family member with Down syndrome.



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

This program follows the journey of three families who have children with special needs. It highlights the theories of Dr. Thomas Knestrict. Two families have a member with Down syndrome. One family has a child with 22Q13 Deletion (Phelan-McDermid) syndrome. Viewers learn how these three families have successfully met the challenges of raising a child with special needs.

These resilient families understand the importance of structure and predictability in the home and have learned the value of rules, rituals, and routines. These families experience the stress and joys of raising a child with special needs, and not only survive, but thrive.

Down Syndrome – Books

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

This book provides information on prenatal testing, early intervention, legal medical issues, and resources. Written for parents by parents, doctors, nurses, educators, and lawyers, it covers everything parents need to know about raising their child with Down syndrome. Also available in Spanish: *Bebés con síndrome de down: guía para padres.* (226.11 S913b 1998 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).

This book was written by a mother whose child has Down syndrome and another mother of a child with special needs. However, it goes beyond simply describing their journey. It gives detailed information about how to maintain a balanced and even joyful life in spite of all the challenges of having a child with special needs. Exercises are included to help readers put the information into practice.

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. This title is available through Ebsco eBooks. Contact the library at (512) 776-7559 for more information.

Children with disabilities: a longitudinal study of child development and parent well-being. Penny Hauser-Cram, 2001. (200.8 H376 2001).

Researchers present the findings of a longitudinal investigation of child development and family well-being during the first decade of life for children with Down syndrome and other developmental delays.

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

Two boys with Down syndrome discuss their life experiences growing up with Down syndrome and share their innermost thoughts, feelings, hopes and dreams, and their lifelong friendship.

Down Syndrome – Books (continued)

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

This book presents information on nutrition and healthy living for children with Down syndrome. It encourages parents to start teaching healthy habits early in their child's life but also stresses that it is never too late to begin healthy habits.

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

This book offers advice on everything from celebrating children's unique personalities and seeing them for who they are to insisting they finish their chores. The author leads readers through every stage of growing up and lends support to parents, encouraging them rather than making them feel inadequate in the journey before them.

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).

This book focuses on speech and language development from birth through the stage of making 3-word phrases. It contains the information parents need to help each child meet his or her communication potential. Challenges such as hearing loss, difficulty with oral-motor movements, and a slower pace of development are discussed. Real-life examples are given throughout the book. The CD-ROM contains forms for recording early milestones, forms for developing plans, forms for evaluations, and forms for treatment planning. An earlier edition is also available in Spanish: *Cómo favorecer las habilidades comunicativas de los niños con síndrome de down*. (226.11 K96c 1994 ECI).

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

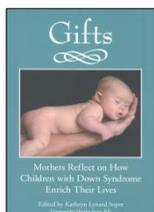
This book tells the story of a mother expecting a baby with Down syndrome. She learns that having her baby with special needs teaches her very important lessons she never learned at Harvard and that there are many experiences that cannot be explained solely by science. This title is also available as a book on compact disc as CA0040.

Fine motor skills in children with Down syndrome: a guide for parents and professionals. Maryanne Bruni, 2006. (226.11 B896f 2006 ECI).

This book explains the best practices and procedures for helping children master the finger and hand skills needed for home and school activities. It is written by an occupational therapist who has worked extensively with children with Down syndrome.

Genetics and mental retardation syndromes: a new look at behavior and interventions. Elizabeth M. Dykens, Robert M. Hodapp, and Brenda M. Finucane, 2000. (WS 107 D996g 2000 RHB).

This book presents a comprehensive guide to the genetic and behavior characteristics of nine specific genetic mental retardation syndromes explaining how they affect individuals' behavior.



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

In this candid and poignant collection of personal stories, sixty-three mothers describe the gifts of respect, strength, delight, perspective, and love, which their child with Down syndrome has brought into their lives. The contributors to this collection have diverse personalities and perspectives, and draw from a wide spectrum of ethnicity, world views, and religious beliefs. Their diverse experiences point to a common truth: the life of a child with Down syndrome is something

to celebrate.

Down Syndrome – Books (continued)

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

Edited by Kathryn Lynard Soper, this follow-up to the bestselling first volume, Gifts 2 presents a broader perspective on Down syndrome and life by including passionate stories by siblings, grandparents, cousins, aunts, and uncles, as well as mothers of older children. Friends, teachers, medical professionals, and coaches also share the joys of knowing and caring for someone with Down syndrome.

NEW! 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).

In this book the author explains the many physiological reasons that children with Down syndrome experience delays in their gross motor development and presents a physical therapy treatment plan from birth to age 6.

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. This title is available through Ebsco eBooks. Contact the library at (512) 776-7559 for more information.

A parent's guide to Down syndrome: toward a brighter future. Siegfried M. Pueschel, 2001. (WS 107.1 P977p 2001 ECI).

This guide for new parents of a child diagnosed with Down syndrome identifies what parents should expect as their child grows and what they can hope for in terms of health, schooling, and the child's life in the community.

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

This book contains an essay written by an adult with Down syndrome. He was asked to write about something he wished his own parents had read or been told while he was growing up.

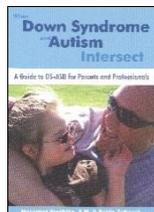


The shape of the eye: Down syndrome, family, and the stories we inherit. George Estreich, 2011. (226.11 E82 2011 ECI).

Writer George Estreich describes how raising a child with Down syndrome impacted everything else in his life, including his approach to writing and the way he now perceives other events in his own life and in the lives of his family members.

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).

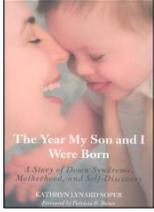
This book clarifies the distinct speech and language issues associated with Down syndrome and Fragile X syndrome. It helps readers conduct individualized assessment and intervention. It helps readers understand the behaviors, characteristics, and genetics associated with both syndromes. It will also help professionals apply the techniques where appropriate with individuals with other disabilities such as autism.



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

This book offers a thorough examination of the unique profile of a Down Syndrome-Autism Spectrum Disorder (DS-ASD) diagnosis and best practices for screening, treatment, and caretaking through the lifespan. This resource will greatly benefit families whose child is already diagnosed, and also those who suspect something more than Down syndrome. Professionals will find information on how to distinguish DS-ASD from a diagnosis of just Down syndrome, and guidance on providing services for children and adults.

Down Syndrome – Books (continued)



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).

Soper takes us along on her personal journey through Thomas's tumultuous first year, as she strives to balance the loss of the child she thought she would have with loyalty for the baby she actually holds in her arms. Can she love Thomas for himself? Can she protect him from the world's insensitivity and from her own doubts? Ultimately, Soper escaped her downward spiral of despair and emerged with newfound peace. Antidepressant therapy restored her equilibrium, and interactions with friends and family brought needed perspective. But the most profound change came through her growing relationship with Thomas. His radiant presence shone through her outer layers of self, where fear and guilt festered, and reached the center of her very being where love, acceptance, and gratitude blossomed in abundance.

Down Syndrome – Children's Books

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

The book describes some of the challenges baby Tessa's Down syndrome diagnosis might bring while never losing focus on the message that a family's love is the same for everyone.

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

Come along with these babies and toddlers with Down syndrome as they enjoy the company of their favorite animals. This board book is filled with colorful photographs.

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

Older sister Emma tries to be patient while teaching three-year-old Isaac, who has Down syndrome, how to communicate using sign language. The book includes questions and answers about sign language.

Big brother Dustin. Alden R. Carter, 1997. (805.1 C323 1997 ECI).

A boy with Down syndrome helps his parents and grandparents get ready for the birth of his baby sister and chooses the perfect name for her.

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

Come along with these babies and toddlers with Down syndrome as they discover their world and enjoy new experiences. This board book is filled with colorful photographs.

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

Pitzer photographs young children with Down syndrome enjoying a wide selection of healthful foods, from fruits and veggies to meats and snacks.

My friend Isabelle. Eliza Woloson, 2003. (PZ W866m 2003 ECI).

A young boy named Charlie describes the activities he shares with his friend Isabelle, a girl with Down syndrome.

My sister Annie. Bill Dodds, 1993. (805.2 D661 1993 ECI).

This book presents the story of growing up, trying to be accepted, and having a sister with Down syndrome, which at times makes life a challenge for Charlie.

Russ and the almost perfect day. Janet E. Rickert, 2000. (PZ R539r 2000 ECI).

Russ, a student with Down syndrome, is having a perfect day until he realizes that the five-dollar bill he has found probably belongs to a classmate.

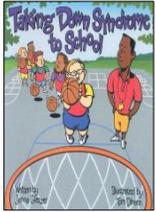
Down Syndrome – Children’s Books (continued)

Russ and the apple tree surprise. Janet E. Rickert, 1999. (PZ R539 1999 ECI).

After Russ, a five-year-old with Down syndrome, picks a basket of apples and helps his mother and grandmother bake a pie, his grandfather invites him into the backyard for a surprise.

Russ and the firehouse. Janet E. Rickert, 2000. (PZ R539rf 2000 ECI).

Russ, a five-year-old with Down syndrome, visits his uncle’s firehouse and gets to help with the daily chores.



Taking Down syndrome to school. Jenna Glatzer, 2002. (PZ G549t 2002 ECI).

A young boy describes what it is like to have Down syndrome, what special help he needs to do well in school, and how to be his friend.

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

This is a children’s story about a six-year-old girl, Emma, who is anxiously waiting for the birth of her new sibling. She anticipates all of the things they will do together. When her little brother Isaac is born with Down syndrome, Emma senses her father’s concern and she wonders if her brother will be able to do all of the things she has planned. Emma and her father realize Isaac is the baby they have been dreaming of, and with her help and patience there probably isn’t anything Isaac can’t do.

Down Syndrome – Selected 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 has launched a Down syndrome registry. 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>.

An article regarding the prevalence of Down syndrome, summarized by the Centers for Disease Control and Prevention, may be found at <http://www.cdc.gov/ncbddd/birthdefects/features/key-findings-down-syndrome-prevalence.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://www.downsyndromeofbcs.com/>
- Down Syndrome Association of Central Texas: <http://dsact.org/>
- Down Syndrome Association of Houston: <http://dsah.org/>
- Down Syndrome Association of South Texas: <http://www.dsasa.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/>.

Information for teachers of students with Down syndrome may be found at Down Syndrome in the Classroom: http://www.teach-nology.com/teachers/special_ed/disabilities/down/.

Down Syndrome – Selected Journal Articles

If you would like to receive copies of articles, please contact the library staff at (512) 776-7260, toll-free: 1-888-963-7111 ext. 7260, fax: (512) 776-7474, e-mail: avlibrary@dshs.state.tx.us.

Cardiac problems in Down syndrome. Marder L, Tulloh R, Pascall E. *Paediatr & Child Health*. 2015;25(1):23-29.

Down syndrome is associated with increased risk of a range of medical problems. One of the major causes of morbidity and mortality is congenital heart disease. Pulmonary arterial hypertension, which occurs more frequently in this population can affect those with or without congenital heart disease. Typical signs and symptoms of these problems may not be present, and screening in the newborn period together with prompt diagnostic assessment and treatment is important to reduce the long term impact of these conditions. Even with early treatment, many children with Down syndrome will have ongoing complications and pulmonary arterial hypertension. Close surveillance and active management throughout childhood and into adulthood is needed in order to optimise quality of life long term.

Children with Down syndrome are high-risk for severe Respiratory Syncytial Virus disease. Stagliano DR, Nylund CM, Eide MB, Eberly MD. *J Pediatr*. 2015;166(3):703-9.e2.

Objective: To assess Down syndrome as an independent risk factor for respiratory syncytial virus (RSV) hospitalization in children younger than 3 years of age and to evaluate illness severity. Study design: A retrospective cohort study of children enrolled in the military health system database was conducted. The effect of Down syndrome on RSV hospitalization was assessed by Cox proportional hazards model, while we controlled for risk factors. Disease severity was assessed by length of hospital stay, need for respiratory support, and age at hospitalization. Results: The study included 633 200 children and 3 209 378 person-years. Children with Down syndrome had a hospitalization rate of 9.6% vs 2.8% in children without Down syndrome. Down syndrome had a greater adjusted hazard ratio (HR) for RSV hospitalization than most risk factors, 3.46 (95% CI 2.75-4.37). A sensitivity analysis demonstrated HR 3.21 (95% CI 2.51-4.10) for patients with Down syndrome ages 0-23 months and HR 5.07 (95% CI 2.21-11.59) ages 24-36 months. The median (IQR) length of stay of children with and without Down syndrome was 4 days (2-7) and 2 days (1-4) ($P < .001$). Patients with Down syndrome had a greater risk of requiring respiratory support (relative risk 5.5; 95% CI, 2.5-12.3). The median (IQR) ages at admission for children with and without Down syndrome were 9.8 months (5.5-17.7) and 3.5 months (1.7-8.7) ($P < .001$). Conclusions: Down syndrome is independently associated with an increased risk for RSV hospitalization. Children with Down syndrome are older at time of RSV hospitalization and have more severe RSV illness than children without Down syndrome. This increased risk for hospitalization continues beyond 24 months.

Down syndrome and fathering: an exploration of ambiguous loss. Bentley G, Zvonkovic A, McCarty M, Springer N. *Fathering*. 2015;13(1):1-17.

Fathers of children with Down syndrome (DS) described their attitudes and coping behaviors, responses were evaluated in the context of Ambiguous Loss theory, using a person-oriented, mixed-methods approach. In general, the fathers expressed the ambiguity of loving the child they had while mourning a life they may have anticipated. Three clusters of fathers (Mastering, Connecting, and Thriving) were identified and described. Mastering cluster fathers used action-oriented coping strategies to manage their life. Connecting cluster fathers engaged in outreach activities related to DS. Thriving cluster fathers embraced their life and reframed their experiences as giving them a sense of purpose or higher meaning. Ambiguous loss theory provided a non-deficit lens to better understand this group of fathers of children with DS.

Effect of early multisensory massage intervention on visual functions in infants with Down syndrome.

Purpura G, Tinelli F, Bargagna S, Bozza M, Bastiani L, Cioni G. *Early Hum Dev*. 2014;90(12):809-13.

Background: Down syndrome is a frequent cause of intellectual disability, with severe impact on the quality of life of affected individuals and their families, and high social costs. Intervention programs should start soon after birth

Down Syndrome – Selected Journal Articles (continued)

but no consensus exists on specific types and timing of early interventions in this population. Aim: This pilot study explores the effects of an early multi-sensory intervention, based on body massage, on the development of visual function in infants with Down syndrome. Method: Infants were randomly allocated to either a massage or a control group. Intervention consisted of only standard care (Control Group) or standard care plus infant massage (Massaged Group). Visual acuity was assessed by Teller Acuity Cards and stereopsis by the Frisby Stereopsis Screening Test at 5, 6, 9 and 12 months. Results: Massaged Group Infants showed a significantly higher visual acuity at 6 months of age and an accelerated development up to at least 12 months; compared to Controls, stereopsis had an earlier onset in the Massaged Group followed by a faster maturation. Conclusion: Environmental enrichment, in the tested form of infant massage, seems to affect maturation of visual functions in human infants, also in the presence of a genetic disability, when applied during a period of high brain plasticity.

How parents introduce new words to young children: the influence of development and developmental disorders. Adamson LB, Bakeman R, Brandon B. *Infant Behav Dev.* 2015;39:148-58.

This study documents how parents weave new words into on-going interactions with children who are just beginning to speak. Dyads with typically developing toddlers and with young children with autism spectrum disorder and Down syndrome (n=56, 23, and 29) were observed using a Communication Play Protocol during which parents could use novel words to refer to novel objects. Parents readily introduced both labels and sound words even when their child did not respond expressively or produce the words. Results highlight both how parents act in ways that may facilitate their child's appreciation of the relation between a new word and its referent and how they subtly adjust their actions to suit their child's level of word learning and specific learning challenges.

Obstructive sleep apnea in young infants with Down syndrome evaluated in a Down syndrome specialty clinic. Goffinski A, Stanley MA, Shepherd N, Duvall N, Jenkinson SB, Davis C, Bull MJ, Roper RJ. *Am J Med Genet A.* 2015;167A(2):324-30.

Children with Down syndrome (DS) experience congenital and functional medical issues that predispose them to obstructive sleep apnea (OSA). Research utilizing stringent age criteria among samples of infants with DS and OSA is limited. This study examines clinical correlates of OSA among infants with DS. A retrospective chart review was conducted of infants ≤ 6 months of age referred to a DS clinic at a tertiary children's hospital over five-years (n = 177). Chi-square tests and binary logistic regression models were utilized to analyze the data. Fifty-nine infants underwent polysomnography, based on clinical concerns. Of these, 95% (56/59) had studies consistent with OSA. Among infants with OSA, 71% were identified as having severe OSA (40/56). The minimum overall prevalence of OSA among the larger group of infants was 31% (56/177). Significant relationships were found between OSA and dysphagia, congenital heart disease (CHD), prematurity, gastroesophageal reflux disease (GERD), and other functional and anatomic gastrointestinal (GI) conditions. Results indicate that odds of OSA in this group are higher among infants with GI conditions in comparison to those without. Co-occurring dysphagia and CHD predicted the occurrence of OSA in 36% of cases with an overall predictive accuracy rate of 71%. Obstructive sleep apnea is relatively common in young infants with DS and often severe. Medical factors including GI conditions, dysphagia and CHD may help to identify infants who are at greater risk and may warrant evaluation. Further studies are needed to assess the impact of OSA in infants with DS.

Overnight pulse oximetry for evaluation of sleep apnea among children with trisomy 21. Coverstone AM, Bird M, Sicard M, Tao Y, Grange DK, Cleveland C, Molter D, Kemp JS. *J Clin Sleep Med.* 2014 15;10(12):1309-15.

Study objectives: For children with trisomy 21, polysomnography at age 4 to assess obstructive sleep disordered breathing (OSDB) is the standard of care. Oximetry alone has been used to screen for disease among children without trisomy 21. This study evaluates the potential usefulness of oximetry scoring in diagnosing OSDB among children with trisomy 21. Methods: A McGill oximetry score from 1 to 4 was derived from a full overnight PSG done on 119 consecutive pediatric subjects with trisomy 21. Most were referred to the sleep laboratory because of suspicion for OSDB. Oximetry scorers were blinded to the child's full PSG and clinical course. Results of the

Down Syndrome – Selected Journal Articles (continued)

complete PSG were then compared to oximetry scores. Results: Obstructive apnea-hypopnea index (OAHl) was ≥ 2.5 for 50% of all subjects. Fifty-nine subjects (49.6%) had McGill Score 1 (“inconclusive”); median OAHl was 1.0 (IQR 0.4-3.3). McGill Score was 2 for 43 subjects (36.1%); median OAHl was 4.5 (IQR 1.3-8.8). Seventeen subjects (14.3%) had McGill Scores of 3 or 4; median OAHl was 16.1 (IQR 9.3-45.5, range 2.1 to 101.1). Ten percent of subjects had a considerable number of central events (≥ 2.5 respiratory events/h but OAHl < 2.5), including 7 with McGill Score 2. Conclusions: In a retrospective cohort of children with trisomy 21, McGill oximetry scores of 3 or 4 reliably identified patients with marked OSDB. The possibility of central apneas causing hypoxemia must be considered in those with McGill Score 2. With these caveats, oximetry screening should be considered when developing streamlined protocols for early intervention to treat OSDB in this population.

Preschoolers with Down syndrome do not yet show the learning and memory impairments seen in adults with Down syndrome. Roberts L, Richmond J. *Dev Sci.* 2015;18(3):404-419.

Individuals with Down syndrome (DS) exhibit a behavioral phenotype of specific strengths and weaknesses, in addition to a generalized cognitive delay. In particular, adults with DS exhibit specific deficits in learning and memory processes that depend on the hippocampus, and there is some suggestion of impairments on executive function tasks that depend on the prefrontal cortex. While these functions have been investigated in adults with DS, it is largely unclear how these processes develop in young children with DS. Here we tested preschoolers with DS and typically developing children, age-matched on either receptive language or non-verbal scores as a proxy for mental age (MA), on a battery of eye-tracking and behavioral measures that have been shown to depend on the hippocampus or the prefrontal cortex. Preschoolers with DS performed equivalently to MA-matched controls, suggesting that the disability-specific memory deficits documented in adults with DS, in addition to a cognitive delay, are not yet evident in preschoolers with DS, and likely emerge progressively with age. Our results reinforce the idea that early childhood may be a critical time frame for targeted early intervention.

The prevalence of congenital hearing loss in neonates with Down syndrome. Tedeschi AS, Roizen NJ, Taylor HG, Murray G, Curtis CA, Parikh AS. *J Pediatr.* 2015;166(1):168-71.

Objective: To determine the prevalence of hearing loss in newborns with Down syndrome. Study design: We performed a cross-sectional, retrospective chart review of all infants with Down syndrome born at a university-affiliated hospital ($n = 77$) or transferred in to the associated pediatric hospital ($n = 32$) following birth at an outlying hospital between 1995 and 2010. We determined the rate of failure of newborn hearing screens, the proportion of infants lost to follow-up, and the rate of confirmed hearing loss, as well as the associations of risk factors for hearing loss with confirmed hearing loss. Results: Of the 109 patients with hearing screening data, 28 failed their newborn hearing screen. Twenty-seven infants were referred for audiologic evaluation, and 19 completed the evaluation. Fifteen of these 19 infants (79%) had confirmed hearing loss. The prevalence of congenital hearing loss in this sample of neonates with Down syndrome was 15%. Exposure to mechanical ventilation was the sole known risk factor associated with hearing loss. In this study, the loss to follow-up rate for infants with positive hearing screens was 32%. Conclusion: Newborns with Down syndrome have a higher prevalence of congenital hearing loss compared with the total neonatal population (15% vs 0.25%). Continued monitoring of hearing is needed in children with Down syndrome.

Requesting and verbal imitation intervention for infants with Down syndrome: generalization, intelligibility, and problem solving. Bauer S, Jones E. *J Dev & Phys Disabil.* 2015;27(1):37-66.

Part of the Down syndrome behavioral phenotype is significant impairment in expressive communication. This begins early with impairments in verbal imitation and requesting observed in infants with Down syndrome. In contrast, social interaction is a relative strength. We replicated intervention procedures using social reinforcement and prompting (Feeley et al. 2011) to teach infants with Down syndrome to imitate sounds and engage in increasingly sophisticated forms of social and instrumental requests and examined generalization and collateral changes in intelligibility and problem solving. Infants learned to imitate verbalizations and make requests. They

Down Syndrome – Selected Journal Articles (continued)

showed generalization by imitating novel sounds and requesting with different toys and on a semi structured assessment. Infants also showed verbal imitation that was intelligible to a naïve listener and improvements in problem solving, suggesting this intervention may have broader effects than just requesting and verbal imitation.

Self-Regulation and infant-directed singing in infants with Down Syndrome. de l'Etoile SK. *J Music Ther.* 2015;52(2):195-220.

Background: Infants learn how to regulate internal states and subsequent behavior through dyadic interactions with caregivers. During infant-directed (ID) singing, mothers help infants practice attentional control and arousal modulation, thus providing critical experience in self-regulation. Infants with Down syndrome are known to have attention deficits and delayed information processing as well as difficulty managing arousability, factors that may disrupt their efforts at self-regulation. Objective: The researcher explored responses to ID singing in infants with Down syndrome (DS) and compared them with those of typically developing (TD) infants. Behaviors measured included infant gaze and affect as indicators of self-regulation. Methods: Participants included 3- to 9-month-old infants with and without DS who were videotaped throughout a 2-minute face-to-face interaction during which their mothers sang to them any song(s) of their choosing. Infant behavior was then coded for percentage of time spent demonstrating a specific gaze or affect type. Results: All infants displayed sustained gaze more than any other gaze type. TD infants demonstrated intermittent gaze significantly more often than infants with DS. Infant status had no effect on affect type, and all infants showed predominantly neutral affect. Conclusions: Findings suggest that ID singing effectively maintains infant attention for both TD infants and infants with DS. However, infants with DS may have difficulty shifting attention during ID singing as needed to adjust arousal levels and self-regulate. High levels of neutral affect for all infants imply that ID singing is likely to promote a calm, curious state, regardless of infant status.

Services and supports for young children with Down syndrome: parent and provider perspectives.

Marshall J, Tanner J, Kozyr Y, Kirby R. *Child Care Health Dev.* 2015;41(3):365-373.

Background: As individuals with Down syndrome are living longer and more socially connected lives, early access to supports and services for their parents will ensure an optimal start and improved outcomes. The family's journey begins at the child's diagnosis, and cumulative experiences throughout infancy and childhood set the tone for a lifetime of decisions made by the family regarding services, supports and activities. Methods: This study utilized focus groups and interviews with seven nurses, five therapists, 25 service co-ordinators, and 10 English- and three Spanish-speaking parents to better understand family experiences and perceptions on accessing Down syndrome-related perinatal, infant and childhood services and supports. Results: Parents and providers reflected on key early life issues for children with Down syndrome and their families in five areas: prenatal diagnosis; perinatal care; medical and developmental services; care co-ordination and services; and social and community support. Conclusions: Systems of care are not consistently prepared to provide appropriate family-centred services to individuals with Down syndrome and their families. Individuals with disabilities require formal and informal supports from birth to achieve and maintain a high quality of life.

Should we mend their broken hearts? The history of cardiac repairs in children with Down syndrome.

Champagne CR, Lewis M, Gilchrist DM. *Pediatrics.* 2014;134(6):1048-50.

In May 2014, Evans et al reported that children with Down syndrome had lower rates of in-hospital death after cardiac surgery, compared with children without Down syndrome. Forty years ago, these results would have been unthinkable, as heart defects were not repaired in the majority of children with Down syndrome. However, as the field of cardiac surgery evolved, equal postoperative outcomes were reported between children with Down syndrome and those without. The historical question of whether we ought to offer cardiac repairs to infants with Down syndrome was influenced by a complex web of ethical, social, and legal considerations that changed over time, resulting in the current standard of care in which children with and without Down syndrome have the same opportunity for cardiac repair.

Down Syndrome – Selected Journal Articles (continued)

Socialization and nonverbal communication in atypically developing infants and toddlers. Konst MJ, Matson JL, Goldin RL, Williams LW. *Res Dev Disabil.* 2014;35(12):3416-22.

Emphasis on early identification of atypical development has increased as evidence supporting the efficacy of intervention has grown. These increases have also directly affected the availability of funding and providers of early intervention services. A majority of research has focused on interventions specific to an individual's primary diagnoses. For example, interventions for those with cerebral palsy (CP) have traditionally focused on physiological symptoms, while intervention for individuals with Autism Spectrum Disorder (ASD) focus on socialization, communication, and restricted interests and repetitive behaviors. However deficits in areas other than those related to their primary diagnoses (e.g., communication, adaptive behaviors, and social skills) are prevalent in atypically developing populations and are significant predictors of quality of life. Therefore, the purpose of the current study was to examine impairments in socialization and nonverbal communication in individuals with Down's syndrome (DS), CP, and those with CP and comorbid ASD. Individuals with comorbid CP and ASD exhibited significantly greater impairments than any diagnostic group alone. However, individuals with CP also exhibited significantly greater impairments than those with DS. The implications of these results are discussed.

Why dose frequency affects spoken vocabulary in preschoolers with Down syndrome. Yoder PJ, Woynaroski T, Fey ME, Warren SF, Gardner E. *Am J Intellect Dev Disabil.* 2015;120(4):302-14.

In an earlier randomized clinical trial, daily communication and language therapy resulted in more favorable spoken vocabulary outcomes than weekly therapy sessions in a subgroup of initially nonverbal preschoolers with intellectual disabilities that included only children with Down syndrome (DS). In this reanalysis of the dataset involving only the participants with DS, we found that more therapy led to larger spoken vocabularies at post-treatment because it increased children's canonical syllabic communication and receptive vocabulary growth early in the treatment phase.

Early CHILDHOOD Report

Children With Special Needs & Their Families

VOLUME 26, ISSUE 10

OCTOBER 2015

LEGAL SPOTLIGHT

YOU BE THE JUDGE

Must district develop BIP for disruptive preschooler with disabilities? **Page 2**

WASHINGTON WATCH

Preschool grants become Exhibit A in push to lift budget caps; children with LD have extra stake in pre-K funding debate, group says; more. **Page 7**

DECISIONS & GUIDANCE

Read recent legal decisions in early childhood cases. **Pages 10-12**

Quick Tip

Failing to adequately educate substitutes about a student's BIP can quickly land your program in hot water.

To ensure that substitutes implement students' behavioral interventions:

- Develop written procedures for informing substitutes about students' needs.
- Place a copy of students' plans or BIPs in substitutes' files.
- Don't forget to also alert cafeteria workers and other staff members about students' BIPs.

Get additional tips on **page 9**.

COVER STORY

Consider home visits to boost family engagement in child's learning

Home visits help early childhood practitioners build relationships with families of children with special needs. By taking time to plan such visits and engage families, your staff can better understand how to meet the individual needs of each child in your early education program.

"When I worked for Head Start, home visits were an essential component of the early childhood program," says Jasmine Zachariah, co-teacher at the Indiana University Campus Children's Center in Bloomington. "That's where I came to realize the importance of home visits and how they bridge the gaps between home and school for both children and parents." **Full story, page 4.**

Be flexible

If families are uncomfortable meeting in their home, set up an alternate location such as a local park. Also, be respectful of the family's schedule and preferences. **See page 4.**

HIGHLIGHTS

Preschools eager to use data, but challenges abound

Early childhood programs could benefit from streamlined data collection systems and training on how to best use and share data, researchers suggest. **Page 3**

Eye on Autism: Adapt social-skills curriculum to needs

It may be challenging to address all social difficulties of young children with autism in a bustling early childhood classroom. Follow these steps to determine young kids' most prevalent needs and plan ways to reinforce their lessons. **Page 5**

Take collaborative approach to emergency planning

Seek input from staff, parents, and your local police and fire departments to help ensure that young students of all abilities are adequately prepared in the event of an emergency situation. **Page 6**

Avoid child find lapses when parents first express concern

A recent case shows that the wrong response to a parent's disability-related concerns can lead to consequences even 11 years later. Discuss these points about child find with your staff. **Page 8**

If you would like to receive copies of articles, please contact the library staff at (512) 776-7260, toll-free: 1-888-963-7111 ext. 7260, fax: (512) 776-7474, e-mail: avlibrary@dshs.state.tx.us.

Topics in Early Childhood Special Education – November 2015

Coaching to Support Practice Implementation

Future topics. Topics in Early Childhood Special Education November 2015 35: 131.

Editorial

Glen Dunlap. Note From the Editor. Topics in Early Childhood Special Education November 2015 35: 132.

ARTICLES

Patricia A. Snyder, Mary Louise Hemmeter, and Lise Fox. Supporting Implementation of Evidence-Based Practices Through Practice-Based Coaching. Topics in Early Childhood Special Education November 2015 35: 133-143.

Mary Louise Hemmeter, Jessica K. Hardy, Alana G. Schnitz, Jessie Morris Adams, and Kiersten A. Kinder. Effects of Training and Coaching With Performance Feedback on Teachers' Use of Pyramid Model Practices. Topics in Early Childhood Special Education November 2015 35: 144-156.

Kellie M. Krick Oborn and LeAnne D. Johnson. Coaching Via Electronic Performance Feedback to Support Home Visitors' Use of Caregiver Coaching Strategies. Topics in Early Childhood Special Education November 2015 35: 157-169.

Crystal D. Bishop, Patricia A. Snyder, and Robert E. Crow. Impact of Video Self-Monitoring With Graduated Training on Implementation of Embedded Instructional Learning Trials. Topics in Early Childhood Special Education November 2015 35: 170-182.

Kathleen Artman-Meeker, Angel Fettig, Erin E. Barton, Ashley Penney, and Songtian Zeng. Applying an Evidence-Based Framework to the Early Childhood Coaching Literature. Topics in Early Childhood Special Education November 2015 35: 183-196.

If you would like to receive copies of articles, please contact the library staff at (512) 776-7260, toll-free: 1-888-963-7111 ext. 7260, fax: (512) 776-7474, e-mail: avlibrary@dshs.state.tx.us.

Young Exceptional Children – September 2015

Message From the DEC Executive Board: Young Exceptional Children September 2015 18: 3.

Angi Stone-MacDonald. Using iPad Applications to Increase Literacy Skills for Children PreK to Grade 3 With Disabilities. Young Exceptional Children September 2015 18: 3-18.

LeAnne D. Johnson and Emily Monn. Bridging Behavioral Assessment and Behavioral Intervention: Finding Your Inner Behavior Analyst. Young Exceptional Children September 2015 18: 19-35.

Mary-alayne Hughes, Christine M. Spence, and Michaelene M. Ostrosky. Early Childhood Mental Health Consultation: Common Questions and Answers. Young Exceptional Children September 2015 18: 36-51.

Natalie Danner, Catherine Corr, and Camille Catlett. Resources Within Reason. Resources for Professionals Working with Young Children with Disabilities Who Have Experienced Abuse or Neglect
Young Exceptional Children September 2015 18: 52-53.

DEC Announcements. DEC Recommended Practices. Young Exceptional Children September 2015 18: 54.