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October 2016

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possibility because of language difficulties in this group. Method: Three groups of children with a mean MA between 36 and 60 months participated in the study: children with Down syndrome (n = 32), children with a

## **Down Syndrome Resources (updated)**

*This month we are featuring books, videos, children's books, websites, and journal articles about Down syndrome. New books on all topics are listed on page 11.*

## **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](mailto:avlibrary@dshs.state.tx.us)

**Baby sign but not spontaneous gesture predicts later vocabulary in children with Down syndrome.** Özçalışkan Ş, Adamson LB, Dimitrova N, Bailey J, Schmuck L. *J Child Lang.* 2016 ;43(4):948-63.

Early spontaneous gesture, specifically deictic gesture, predicts subsequent vocabulary development in typically developing (TD) children. Here, we ask whether deictic gesture plays a similar role in predicting later vocabulary size in children with Down Syndrome (DS), who have been shown to have difficulties in speech production, but strengths in spontaneous gesture and baby sign use. We compared the gestures and baby signs produced by twenty-three children with DS (Mage = 2;6) and twenty-three TD children (Mage = 1;6), in relation to their expressive spoken vocabulary size one year later. Children with DS showed significant deficits in gesture production, particularly for deictic gestures, but strengths in baby sign production, compared to their typically developing peers. More importantly, it was the baby signs produced by children with DS, but not deictic gestures, that predicted their spoken vocabulary size one year later. Our results further highlight the important role baby signs can play in language development in children with developmental disorders. It discusses the principles that can be applied to different areas of development. Section two gives practical advice and activities for supporting the development of skills that may be more difficult for babies with Down syndrome to develop independently.

**Delay of gratification: a comparison study of children with Down syndrome, moderate intellectual disability and typical development.**

Cuskelly M, Gilmore L, Glenn S, Jobling A. *J Intellect Disabil Res.* 2016;60(9):865-73.

Background: Self-regulation has been found to be an important contributor to intellectual disability irrespective of aetiology, or whether it presents a particular problem for those with Down syndrome. The latter was considered a

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moderate intellectual disability from a cause other than Down syndrome (n = 26) and typically developing children (n = 50). Children completed a series of measures of language and cognitive functioning and participated in a delay of gratification task. Results: The group of children with Down syndrome delayed for a significantly shorter time than either of the other two groups that did not differ from each other. Receptive language was associated with delay time for the children with Down syndrome but not for the typically developing group, nor for the group with moderate intellectual disability. Conclusions: Children with Down syndrome appear to have a particular difficulty with delay of gratification. Language abilities would seem to be implicated in this difficulty, although further examination of this hypothesis is required.

**Growth charts for children with Down syndrome in the United States.** Zemel BS, Pipan M, Stallings VA, Hall W, Schadt K, Freedman DS, Thorpe P. *Pediatrics*. 2015;136(5):e1204-11.

Background and objectives: Children with Down syndrome (DS) have lower birth weights and grow more slowly than children without DS. Advances in and increased access to medical care have improved the health and well-being of individuals with DS; however, it is unknown whether their growth has also improved. Our objective was to develop new growth charts for children with DS and compare them to older charts from the United States and more contemporary charts from the United Kingdom. Methods: The Down Syndrome Growing Up Study (DSGS) enrolled a convenience sample of children with DS up to 20 years of age and followed them longitudinally. Growth parameters were measured by research anthropometrists. Sex-specific growth charts were generated for the age ranges birth to 36 months and 2 to 20 years using the LMS method. Weight-for-length and BMI charts were also generated. Comparisons with other curves were presented graphically. Results: New DSGS growth charts were developed by using 1520 measurements on 637 participants. DSGS growth charts for children <36 months of age showed marked improvements in weight compared with older US charts. DSGS charts for 2- to 20-year-olds showed that contemporary males are taller than previous charts showed. Generally, the DSGS growth charts are similar to the UK charts. Conclusions: The DSGS growth charts can be used as screening tools to assess growth and nutritional status and to provide indications of how growth of an individual child compares with peers of the same age and sex with DS.

**Improved survival in Down syndrome over the last 60 years and the impact of perinatal factors in recent decades.** Glasson EJ, Jacques A, Wong K, Bourke J, Leonard H. *J Pediatr*. 2016;169:214-20.

Objective: To calculate the survival of people with Down syndrome over the past 60 years and the influence of major perinatal factors by using linked population-based data. Study design: A data linkage between 2 Western Australian (WA) data sets (the Register for Developmental Anomalies and the Intellectual Disability Exploring Answers database) was used to identify 772 children born with Down syndrome in WA from 1980-2010. Perinatal and mortality data were extracted from the WA Midwives Information System and WA death registrations and compared with the remaining WA population born during that same era. An additional 606 children with Down syndrome living in WA prior to 1980 were available from a disability services database and were used for predicting survival into adulthood. Results: Overall, for cases born 1953-2010, 88% (95% CI 86%, 90%) survived to 5 years of age, 87% (95% CI 85%, 89%) to 10 years, and 83% (95% CI 80%, 85%) to 30 years. Children live-born with Down syndrome were significantly more likely (all  $P > .001$ ) to have mothers older than 35 years (32.7% vs 13.4%), a gestational age less than 37 weeks (23.8% vs 7.9%), a cesarean delivery (28.9% vs 23.0%), and a birth weight less than 2500 g (20.4% vs 6.1%). Down syndrome survival was reduced in the presence of a cardiovascular defect, younger gestational age, low birth weight, or earlier birth years. Conclusions: Improved survival for children born with Down syndrome over the last 60 years has occurred incrementally, but disparities still exist for children who are preterm or have low birth weight.

**The management of children with Down syndrome and profound hearing loss.** Phelan E, Pal R, Henderson L, Green KM, Bruce IA. *Cochlear Implants Int*. 2016;17(1):52-7.

Introduction: Although the association between Down syndrome (DS) and conductive hearing loss is well recognized, the fact that a small proportion of these children may have a severe to profound sensorineural hearing loss that could benefit from cochlear implantation (CI) is less well understood. The management of significant co-morbidities in children with DS can delay initial diagnosis of hearing impairment and assessment of suitability for CI can likewise be challenging, due to difficulties conditioning to behavioural hearing tests. Methods:

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We performed a retrospective case note review of three children with DS referred to the Manchester Cochlear Implant Programme. Results: Three illustrative cases are described including CI in a 4 years old. Using conventional outcome measurement instruments, the outcome could be considered to be suboptimal with a Categories of Auditory Performance score of 4 at 6 months post-op and at last follow up. In part, this is likely to reflect the delay in implantation, but the role of cognitive impairment must be considered. The cases described emphasize the importance of comprehensive radiological and audiological assessment in children with DS being considered for CI. Conclusion: The influence of cognitive impairment upon outcome of CI must be taken into account, but should not be considered a contra-indication to implantation in children with DS. Benefit that might be considered limited when quantified using existing general outcome measurement instruments, may have a significant impact upon psychosocial development and quality of life in children with significant cognitive impairment, or other additional needs.

**Mothers' talk to children with Down syndrome: language impairment, or typical development about familiar and unfamiliar nouns and verbs.** Kay-Raining Bird E, Cleave P. *J Child Lang.* 2016;43(5):1072-102.

This study investigated how forty-six mothers modified their talk about familiar and unfamiliar nouns and verbs when interacting with their children with Down Syndrome (DS), language impairment (LI), or typical development (TD). Children (MLUs < 2.7) were group-matched on expressive vocabulary size. Mother-child dyads were recorded playing with toy animals (noun task) and action boxes (verb task). Mothers of children with DS used shorter utterances and more verb labels in salient positions than the other two groups. All mothers produced unfamiliar target nouns in short utterances, in utterance-final position, and with the referent perceptually available. Mothers also talked more about familiar nouns and verbs and labelled them more often and more consistently. These findings suggest that mothers of children in the early period of language development fine-tune their input in ways that reflect their children's vocabulary knowledge, but do so differently for nouns and verbs.

**Parents' translations of child gesture facilitate word learning in children with autism, Down syndrome and typical development.** Dimitrova N, Özçalışkan Ş, Adamson LB. *J Autism Dev Disord.* 2016;46(1):221-31.

Typically-developing (TD) children frequently refer to objects uniquely in gesture. Parents translate these gestures into words, facilitating children's acquisition of these words (Goldin-Meadow et al. in *Dev Sci* 10(6):778-785, 2007). We ask whether this pattern holds for children with autism (AU) and with Down syndrome (DS) who show delayed vocabulary development. We observed 23 children with AU, 23 with DS, and 23 TD children with their parents over a year. Children used gestures to indicate objects before labeling them and parents translated their gestures into words. Importantly, children benefited from this input, acquiring more words for the translated gestures than the not translated ones. Results highlight the role contingent parental input to child gesture plays in language development of children with developmental disorders.

**Screening for hematological disorders in mosaic Down syndrome: parent report of experiences.** Santoro SL, Martin LJ, Hopkin RJ. *Clin Pediatr (Phila).* 2016 May;55(5):421-7.

Children with Down syndrome (DS) have increased risk for multiple medical conditions with published health care guidelines. Current guidelines do not specify whether or not they apply to mosaic DS (mDS). We surveyed families of patients with mDS regarding screening, including monitoring practices as well as complications identified. Hematological complications were similar to those reported in nonmosaic DS. Of 91 parents of children with mDS surveyed, only 69% had ever had a screening lab; only 57% had ever had a screening complete blood count (CBC). Younger children were less likely to be screened (for CBC, 50% of 0- to 3-year-olds vs 90% of 4- to 12-year-olds;  $P = 0.0036$ ). Screening practices are suboptimal, with the youngest children at greatest risk. Comparing reported screening practices with physician adherence, there was discrepancy between perceptions of adherence and perceptions of practice. Children with mDS should be monitored on the same schedule as other children with DS.

**Sleep-disordered breathing in children with Down syndrome: usefulness of home polysomnography.**

Brockmann PE, Damiani F, Nuñez F, Moya A, Pincheira E, Paul MA, Lizama M. *Int J Pediatr Otorhinolaryngol.* 2016;83:47-50.

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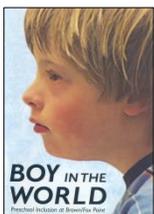
**Objective:** To investigate the technical feasibility of unattended home polysomnography (HPSG) in children with Down syndrome. **Methods:** Data from children with Down syndrome under 10 years of age referred to a diagnostic sleep study was analyzed. A full sleep-lab based polysomnography (PSG) or a HPSG with a portable device was performed. Uninterpretable HPSGs were defined as: recordings with (i) loss of  $\geq 2$  of the following channels: nasal flow, or thoracoabdominal sensors, or (ii) HPSG with less than 4h of artifact-free recording time or (iii) less than 4h SpO<sub>2</sub> (peripheral capillary oxygen saturation) signal. **Results:** A total of 44 children (68% males) were included in the study, with a mean age of 3.6 (0.1-10) years. PSG was performed in 8 cases and HPSG in 36 cases. Six HPSG recordings were classified as uninterpretable and had to be repeated. Age, gender and BMI were no significant predictors of uninterpretability of the HPSG. Obstructive sleep apnea (OSA) was present in 61% (n=27) of all subjects, and classified as mild, moderate, and severe in 43% (n=19), 11% (n=5), and 7% (n=3) of cases, respectively. Interpretable and technically acceptable HPSGs were obtained in 30 subjects (83%). Age, gender and BMI were no significant predictors for interpretability of the HPSG. **Discussion:** This study demonstrates that a portable polysomnographic home device may be helpful for diagnosing OSA in children with Down syndrome. Considering the potential consequences of untreated OSA, this screening test may be helpful for early diagnosis of OSA in children with Down syndrome.

### **Understanding the causes of obesity in children with trisomy 21: hyperphagia vs physical inactivity.**

Foerste T, Sabin M, Reid S, Reddihough D. *J Intellect Disabil Res.* 2016;60(9):856-64.

**Background:** Individuals with intellectual disabilities are at increased risk of becoming overweight or obese. This is particularly evident in people with trisomy 21 and Prader-Willi syndrome (PWS). Although metabolic factors are known to contribute to obesity in trisomy 21 and hyperphagia plays a primary role in PWS, hyperphagia has not yet been investigated as a possible contributing factor to obesity in trisomy 21. **Methods:** Participants comprised three diagnostic groups: trisomy 21 (T21 group), PWS (PWS group) and lifestyle-related obesity (LRO group). They were required to be aged 6-18 years and have a body mass index over the 85th percentile for age and gender. A parent of each participant completed the Hyperphagia Questionnaire and the Children's Leisure Activity Study Survey. Mean scores for each domain and across all domains of the Hyperphagia Questionnaire and the Children's Leisure Activity Study Survey were compared between diagnostic groups using linear regression analysis. **Results:** The study group consisted of 52 young people (23 men and 29 women) aged 6-18 years (mean 12.5 years; T21 group n = 17, PWS group n = 16 and LRO group n = 19). As hypothesised, the PWS group had the highest mean scores across all domains of the Hyperphagia Questionnaire, and the LRO group had the lowest. Food-seeking behaviour was more pronounced in the PWS group than the T21 group (mean score 13.2 vs. 8.6, p = 0.008). The LRO group spent more hours per week engaged in physical activity (14.7) in comparison with the other groups (9.6 and 9.7), whereas between the groups, differences in time spent in sedentary activities were less pronounced. **Conclusions:** Preoccupation with food and low levels of physical activity may contribute to the development of overweight and obesity in some individuals with trisomy 21. These factors warrant consideration in the clinical context.

## **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.

**NEW! Development in practice: activities for babies with Down syndrome.** 77 min. 2007. (DD0716).

This DVD focuses on practical activities to promote development that can be woven into everyday family routines and activities. Section one describes the important elements of development and demonstrates significant

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behaviors and activities for very young babies. It discusses the principles that can be applied to different areas of development. Section two gives practical advice and activities for supporting the development of skills that may be more difficult for babies with Down syndrome to develop independently.

**NEW! Development in practice: speech and language activities for preschool children with Down syndrome.** 76 min. 2007. (DD0717).

This film explains and demonstrates activities for promoting communication, speech and language development for preschool children with Down syndrome from 18 months to 4 years. It focuses on practical strategies to promote speech and language development that can be woven into everyday play, routines, and activities.

**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.



**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 title is also available as a streaming video. Contact the library at (512) 776-7260 for more information.



**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.

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**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).

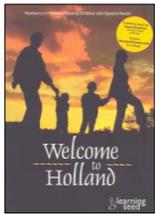
This program focuses on the keys to successful inclusion from a student's point of view. A classroom of education students ask Karen Gaffney about inclusive classroom settings and what worked for her. Karen delivers a polished presentation full of important information for both families and educators.

**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.

**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,** 7<sup>th</sup> 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.

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**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.

**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,** 3<sup>rd</sup> 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).

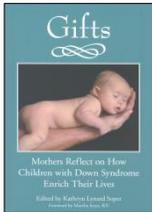
This book tells the story of a mother expecting a baby with Down syndrome. She learns that having her baby with special needs teaches her very important lessons she never learned at Harvard and that there are many experiences that cannot be explained solely by science. This title is also available as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

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**NEW! Fine motor skills in children with Down syndrome: a guide for parents and professionals, 3<sup>rd</sup> ed.**

Maryanne Bruni, 2016. (WS 107 B896f 2015 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.



**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.

**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.

**Gross motor skills for children with Down syndrome: a guide for parents and professionals, 2<sup>nd</sup> ed.**

Patricia C. Winders, 2014. (WS 107 J15p 2016 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.

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

The authors of this book share their experiences and guide the reader through life as parents of children with Down syndrome. Advice is given from diagnosis to adulthood. Readers learn ways to support the child through major milestones, nurture development, and ensure behavioral, social and cognitive success.

**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).

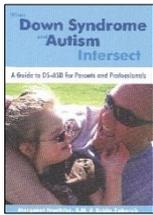
Writer George Estreich describes how raising a child with Down syndrome impacted everything else in his life, including his approach to writing and the way he now perceives other events in his own life and in the lives of his family members.

**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

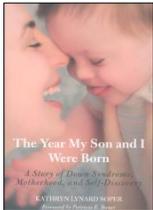
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behaviors, characteristics, and genetics associated with both syndromes. It will also help professionals apply the techniques where appropriate with individuals with other disabilities such as autism.



**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.



**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

**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.

**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.

**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.

**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. (WS 107 W867 2003 ECI).

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

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**Russ and the almost perfect day.** Janet E. Rickert, 2000. (WS 107 R539p 2000 ECI).

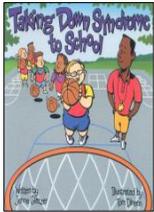
Russ, a student with Down syndrome, is having a perfect day until he realizes that the five-dollar bill he has found probably belongs to a classmate.

**Russ and the apple tree surprise.** Janet E. Rickert, 1999. (WS 107 R539a 2000 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. (WS 107 R539f 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. (WS 107 G541t 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 provides 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/>

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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/](http://www.teach-nology.com/teachers/special_ed/disabilities/down/).

## **New Additions – Books**

**The encyclopedia of infant and toddler activities: for children birth to 3.** 2006. (LB 1139 E56 2006 ECI). This book of activities was written by teachers for teachers. It includes activities for all parts of the day and to stimulate all types of learning by very young children.

**Focus on babies: how-tos and what-to-dos when caring for infants.** Jennifer Karnopp, 2012. (LB 1139 K18b 2012 ECI).

Complete with tips for creating a developmentally appropriate environment and experiences that stimulate infants' muscles and minds, this book gives readers the tools to craft a quality learning environment. Topics include the caregiver's role, setting up the space, daily planning, child growth and development, addressing multiple intelligences, and evaluating the program.

**A practical guide to reflective supervision.** 2009. (LC 4109.3 P895 2009 ECI).

This book outlines the key steps in creating a system of reflective supervision within an early childhood program to improve services, support staff, and better meet the needs of children and families. It provides answers to the critical questions that every program needs to know to launch reflective supervision.

**Reflective supervision and leadership in infant and early childhood programs.** Mary Claire Heffron, 2010. (LC 4109.3 H461r 2010 ECI).

This book illustrates the foundations and frameworks of reflective practice and outlines ways to support reflective supervision in a wide variety of work settings. It discusses the roles of the reflective supervisor, the knowledge and skills necessary, tips for providing group reflective supervision and vignettes outlining common supervisory dilemmas.

**Teaching Pyramid Observation Tool (TPOT) for preschool classrooms manual.** Mary Louise Hemmeter, 2014. (LB 3051 H489t 2013 ECI).

This manual gives clear instructions on administering the TPOT tool, scoring it, and summarizing and interpreting scores. It will help early childhood programs use the TPOT effectively to promote positive social-emotional outcomes for young children. It is for programs who use the Pyramid Model for Promoting Social Emotional Competence in Infants and Young Children.

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*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](mailto:avlibrary@dshs.state.tx.us).*

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## **Early Childhood Report – October 2016**

Legal Spotlight: You Be the Judge

May speech pathologist also play role of early childhood teacher at IEP meeting?

Washington Watch

ED issues request for proposal for Pay for Success pilots

Decisions & Guidance

Evaluations: Casual observation of student neglects IDEA evaluation requirements

Stay-put: Parent can't use stay-put to obtain public funding for preferred placement

Services & Supports: Principal cannot make unilateral decision to refuse requested services

Behavior management: informal nature of behavior supports makes their appropriateness dubious.

Cover Story

Help staff identify, understand complex trauma in early learners

Highlights

Boost school readiness for early learners

Eye on Autism: Encourage kids to monitor own behaviors

Strengthen parents' advocacy skills

Help children master handwriting to boost motor skills

Take problem-solving approach to field trip concerns

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## **Texas Early Child Care – Fall 2016**

Kindergarten: Getting ready for big school  
Elizabeth Morgan Russell

Creating a caring community of learners

Talking with parents: How play promotes school readiness

Fostering critical thinking in young children  
Hannah Mills Mechler

The classroom as a teaching tool: Evolving spaces to meet children's needs  
Zlata Stankovic-Ramirez and Catherine Dutton

Start early to prevent linger baby fat

Departments

Back to basics: Physical impairments

Early Childhood Intervention: Handling challenging behavior by teaching better behavior

Child Care Licensing: Minimum standards review

Building a business: Scam alert: Ignore IRS phone calls/ Limits on employee cell phone use?/Look for changes in food labels by mid-2018

Texas Parenting News: Get a heads-up on lice treatment/Hello, Teacher! Yes, you!/Diapers: Disposable or cloth?

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## **Topics in Early Childhood Special Education – November 2016**

### **Positive Behavior Support in Early Childhood Programs**

Future Topics. Topics in Early Childhood Special Education November 2016 36: 131.

Editorial

Glen Dunlap. Topics in Early Childhood Special Education November 2016 36: 132.

### **ARTICLES**

Mary Louise Hemmeter, Patricia A. Snyder, Lise Fox, and James Algina. Evaluating the Implementation of the Pyramid Model for Promoting Social-Emotional Competence in Early Childhood Classrooms. Topics in Early Childhood Special Education November 2016 36: 133-146.

Angel Fettig and Kathleen Artman-Meeker. Group Coaching on Pre-School Teachers' Implementation of Pyramid Model Strategies: A Program Description. Topics in Early Childhood Special Education November 2016 36: 147-158.

Megan Vinh, Phil Strain, Sarah Davidon, and Barbara J. Smith. One State's Systems Change Efforts to Reduce Child Care Expulsion: Taking the Pyramid Model to Scale. Topics in Early Childhood Special Education November 2016 36: 159-164.

Rosemarie Allen and Elizabeth A. Steed. Culturally Responsive Pyramid Model Practices: Program-Wide Positive Behavior Support for Young Children. Topics in Early Childhood Special Education November 2016 36: 165-175.

Sharon L. Doubet and Michaelene M. Ostrosky. Parents' Experiences When Seeking Assistance for Their Children With Challenging Behaviors. Topics in Early Childhood Special Education November 2016 36: 176-185.