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July 2017



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## Medical Diagnosis and Special Populations (updated)

*This month we are featuring resources on cerebral palsy, cleft palate, cystic fibrosis, seizure disorders, and spina bifida. We are also covering special populations such as infants who are premature, those who have visual impairments, multiple births, and children who have been affected by alcohol or drugs. Check out the new additions to the collection on page 24!*

## Medical Diagnosis and Special Populations – 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.texas.gov](mailto:avlibrary@dshs.texas.gov).*

**CDC grand rounds: public health strategies to prevent neonatal abstinence syndrome.** Ko JY, Wolicki S, Barfield WD, Patrick SW, Broussard CS, Yonkers KA, Naimon R, Iskander J. *MMWR Morb Mortal Wkly Rep.* 2017;66(9):242-245.

Neonatal abstinence syndrome (NAS) is a drug withdrawal syndrome that most commonly occurs in infants after in utero exposure to opioids, although other substances have also been associated with the syndrome. NAS usually appears within 48-72 hours of birth with a constellation of clinical signs, including central nervous system irritability (e.g., tremors), gastrointestinal dysfunction (e.g., feeding difficulties), and temperature instability. Opioid exposure during pregnancy might result from clinician-approved use of prescription opioids for pain relief; misuse or abuse of prescription opioids; illicit use (e.g., heroin); or medication-assisted treatment (MAT) of opioid use disorder

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**Differences in outcomes between early and late diagnosis of cystic fibrosis in the newborn screening era.** Coffey MJ, Whitaker V, Gentin N, Junek R, Shalhoub C, Nightingale S, Hilton J, Wiley V, Wilcken B, Gaskin KJ, Ooi CY. *J Pediatr.* 2017 Feb;181:137-145.e1.

To evaluate children with cystic fibrosis (CF) who had a late diagnosis of CF (LD-CF) despite newborn screening (NBS) and compare their clinical outcomes with children diagnosed after a positive NBS (NBS-CF). Study design: A retrospective review of patients with LD-CF in New South Wales, Australia, from 1988 to 2010 was performed. Results: A total of 45 LD-CF cases were identified (39 NBS-negative and 6 NBS-positive) with 90 NBS-CF matched controls. Median age (IQR) of diagnosis for LD-CF and NBS-CF was 1.35 (0.4-2.8) and 0.12 (0.03-0.2) years, respectively ( $P < .0001$ ). Estimated incidence of LD-CF was 1 in 45 000 live births. Compared with NBS-CF, LD-CF had more respiratory manifestations at time of diagnosis (66% vs 4%;  $P < .0001$ ), a higher rate of hospital admission per year for respiratory illness (0.49 vs 0.2;  $P = .0004$ ), worse lung function (forced expiratory volume in 1 second percentage of predicted, 0.88 vs 0.97;  $P = .007$ ), and higher rates of chronic colonization with *Pseudomonas aeruginosa* (47% vs 24%;  $P = .01$ ). The LD-CF cohort also appeared to be shorter than NBS-CF controls (mean height z-score -0.65 vs -0.03;  $P = .02$ ). Conclusions: LD-CF, despite NBS, seems to be associated with worse health before diagnosis and worse later growth and respiratory outcomes, thus providing further support for NBS programs for CF.

**Effect of early intervention in infants at very high risk of cerebral palsy: a systematic review.** Hadders-Algra M, Boxum AG, Hielkema T, Hamer EG. *Dev Med Child Neurol.* 2017;59(3):246-258.

Aim: First, to systematically review the evidence on the effect of intervention applied during the first postnatal year in infants with or at very high risk of cerebral palsy (CP) on child and family outcome. Second, to assess whether type and dosing of intervention modify the effect of intervention. Method: Relevant literature was identified by searching the PubMed, Embase, and CINAHL databases. Selection criteria included infants younger than 12 months corrected age with or at very high risk of CP. Methodological quality including risk of bias was scrutinized. Results: Thirteen papers met the inclusion criteria. Seven studies with moderate to high methodological quality were analyzed in detail; they evaluated neurodevelopmental treatment only ( $n=2$ ), multisensory stimulation ( $n=1$ ), developmental stimulation ( $n=2$ ), and multifaceted interventions consisting of a mix of developmental stimulation, support of parent-infant interaction, and neurodevelopmental treatment ( $n=2$ ). The heterogeneity precluded conclusions. Yet, two suggestions emerged: (1) dosing may be critical for effectiveness; (2) multifaceted intervention may offer best opportunities for child and family. Interpretation: The literature on early intervention in very high-risk infants with sufficient methodological quality is limited, heterogeneous, and provides weak evidence on the effect. More studies are urgently needed. Suggestions for future research are provided.

**Neonatal abstinence syndrome.** McQueen K, Murphy-Oikonen J. *N Engl J Med.* 2016 Dec 22;375(25):2468-2479.

The neonatal abstinence syndrome was first described in the literature in the 1970s by Dr. Loretta Finnegan. Although this syndrome has been recognized for more than four decades, there have been substantial changes in the past 10 years, including a dramatic increase in prevalence and changes in both the exposure substance and clinical

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management. There has also been a considerable amount of research on the neonatal abstinence syndrome, and effective management strategies have been developed. However, gaps still exist, including a lack of clarity and consistency in how the syndrome is defined, measured, and managed. In addition, much of the research has focused on the infant in isolation from the mother, and many hospitals lack protocols to guide treatment. The purpose of this review is to summarize the current literature on the neonatal abstinence syndrome, including clinical characteristics, prevention, identification, and treatment. Approaches to care that recognize the importance of the infant–mother dyad are emphasized when possible.

**A preliminary evaluation of the Managing Youth Trauma Effectively program for substance-abusing women and their children.** Vanderzee KL, John SG, Edge N, Pemberton JR, Kramer TL. *Infant Ment Health J.* 2017;38(3):422-433.

This article provides a description of the development, implementation, and preliminary evaluation of feasibility and acceptability of the Managing Youth Trauma Effectively (MYTE) program and highlights perceptions of changes in mothers' trauma-informed parenting practices. The program consists of a training and consultation program for staff of the U.S. State of Arkansas' Specialized Women's Programs (SWS), and an 8-week, group psychoeducational program designed to help mothers with substance-abuse problems learn how traumatic experiences may affect their children and how they may help support their children by creating a safe and nurturing environment. A post-training evaluation with leadership and staff at SWS centers, feedback provided on consultation calls with MYTE facilitators, and a retrospective pre/post survey were used to examine feasibility, acceptability, and perceptions of changes in mothers' trauma-informed parenting practices. Preliminary results suggest that the MYTE program is feasible to implement and is acceptable to training participants, facilitators, and mothers participating in the program. Mothers reported significant growth in their perceptions of use of trauma-informed parenting practices. Future research is necessary to confirm these results and examine the effectiveness of the program using a randomized clinical trial.

**A public health response to opioid use in pregnancy.** Patrick SW, Schiff DM; Committee on substance use and prevention. *Pediatrics.* 2017;139(3). pii: e20164070. doi: 10.1542/peds.2016-4070.

The use of opioids during pregnancy has grown rapidly in the past decade. As opioid use during pregnancy increased, so did complications from their use, including neonatal abstinence syndrome. Several state governments responded to this increase by prosecuting and incarcerating pregnant women with substance use disorders; however, this approach has no proven benefits for maternal or infant health and may lead to avoidance of prenatal care and a decreased willingness to engage in substance use disorder treatment programs. A public health response, rather than a punitive approach to the opioid epidemic and substance use during pregnancy, is critical, including the following: a focus on preventing unintended pregnancies and improving access to contraception; universal screening for alcohol and other drug use in women of childbearing age; knowledge and informed consent of maternal drug testing and reporting practices; improved access to comprehensive obstetric care, including opioid-replacement therapy; gender-specific substance use treatment programs; and improved funding for social services and child welfare systems.

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**Speech and language interventions for infants aged 0 to 2 years at high risk for cerebral palsy: a systematic review.** Chorna O, Hamm E, Cummings C, Fetters A, Maitre NL. *Dev Med Child Neurol.* 2017;59(4):355-360.

Aim: We evaluated the level of evidence of speech, language, and communication interventions for infants at high-risk for, or with a diagnosis of, cerebral palsy (CP) from 0 to 2 years old. Method: We performed a systematic review of relevant terms. Results: The search terms provided 17 publications consisting of speech or language interventions. There were no interventions in the high level of evidence category. The overall level of evidence was very low. Promising interventions included Responsivity and Prelinguistic Milieu Teaching and other parent-infant transaction frameworks. Interpretation: There are few evidence-based interventions addressing speech, language, and communication needs of infants and toddlers at high risk for CP, and none for infants diagnosed with CP. Recommendation guidelines include parent-infant transaction programs.

**Successful survival of an extreme premature infant with cystic fibrosis.** Goddard T, Andersen C, Tai A. *BMJ Case Rep.* 2017. pii: bcr2016218324.

Extreme premature infants with cystic fibrosis typically do not survive the neonatal phase. This case report describes the youngest survivor of a premature infant with cystic fibrosis and highlights the importance of advanced neonatal care with cystic fibrosis therapy.

## Medical Diagnosis and Special Populations – Selected DVDs

**Alcohol and pregnancy: making healthy choices.** 10 min. 2010. (DV0741).

Viewers learn how alcohol affects the fetus, how to live an alcohol-free lifestyle, and where to find help if they are at risk for abusing alcohol.

**Can do series** (1991-2005):



**Becoming a can do kid: self-help skills.** 14 min. (DD0198).

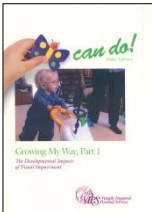
It is tempting for parents to do too much for children who are blind. This DVD encourages parents to teach their children how to feed, dress, and care for themselves.

**Full of hope.** 18 min. (DD0206).

Viewers share in the experiences of children and young adults with visual impairments. This DVD offers hope and encouragement to families and professionals who work with them. It is especially helpful to families of newly diagnosed infants and preschoolers with visual and multiple impairments.

**Going places: orientation and mobility.** 14 min. (DD0200).

Two very important skills for a child with visual impairments are orientation and mobility. This DVD teaches parents about these skills and what they can do from the time their child is very young to encourage independent and safe movement. Families and their children model a progression of skills from infancy through preschool age.



**Growing my way part 1.** 12 min. (DD0195).

This DVD follows five babies and their parents as their development is tracked at 3-month intervals, beginning at 3 months of age and ending at 18 months of age. It provides an intimate look at them as they progress through their first year and a half of life. The children include a typically developing baby, two babies with low vision conditions, and two babies who were born blind.

**Hands on experience: tactual learning and skills.** 11 min. (DD0203).

Children who are blind or visually impaired need to be able to use their other senses to gain information about the world. The sense of touch is one of the major senses that can make up for their loss of sight. However, babies, toddlers and preschoolers who are visually impaired need encouragement and opportunities to build their tactual skills. This DVD discusses the importance of tactual learning, the progression of tactual skills from infancy through preschool needed for preparing children for Braille reading, and how parents and teachers can help.

**Learning about the world: concept development.** 16 min. (DD0197).

Lack of vision can cause children who are visually impaired to miss much of what is going on around them, inhibiting their understanding of the world. This DVD helps parents appreciate the importance of early concept development and what they can do to help their child.

**Making friends: social skills and play.** 11 min. (DD0199).

Blindness can significantly impact a child's understanding of how to behave with others. This DVD explores potential social difficulties and shows parents how to help their child build the social skills that are crucial to successful living in a sighted world.

**Moving through the world: gross motor skills and play.** 10 min. (DD0202).

Visual impairment can significantly impact the development of the gross motor skills needed for young children to move beyond their environment and learn about the world. Parents and teachers can play a major role in fostering the development of gross motor skills. This DVD discusses key gross motor skills and demonstrates simple and fun play activities that parents and teachers can use to encourage a progression of skills from infancy through preschool age.

**Power at your fingertips: an introduction to learning Braille.** 22 min. (DD0205).

This DVD features instruction in the Braille alphabet and numbers, introduction to the use of contractions in Braille, and training in the use of the slate and stylus and Braille writer. It is a tutorial for parents and teachers to get started in using Braille with their children who are blind and to pursue self-instruction at their own pace.

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**Seeing things in a new way: what happens when you have a blind baby.** 16 min. (DD0196).

Parents can be devastated when they learn that their child is blind. This DVD is designed to help parents with their sense of loss and develop a positive outlook for their child's capabilities and potentials.

**Successfully adapting the preschool environment.** 12 min. (DD0204).

Children who are visually impaired can be successful in the typical preschool classroom. This DVD demonstrates a variety of adaptations that easily and effectively can be introduced to accommodate the special needs of students who are visually impaired.

**Through their eyes: an introduction to low vision.** 15 min. (DD0201).

It can be difficult to understand low vision conditions and to determine how they affect a young child's visual functioning. However, with some special adaptations in the home and preschool environment, children with low vision will be able to use their sight to their best advantage. This DVD discusses several common causes of low vision, how they affect visual function, and adaptations that can be simply incorporated into home and classroom to meet these special needs.

**Childhood epilepsy: what you need to know.** 81 min. 2008. (DV0679).

This DVD provides an overview of childhood epilepsy, including different types of seizures; diagnostic procedures; treatment options; the impact of epilepsy on development and learning; safety; epilepsy in the family and community; stigma; and the benefits of encouraging a child's unique interests and talents.

**Cystic fibrosis: a day in the life.** 26 min. 2004. (DV0188).

For a young person living with cystic fibrosis, each day is a struggle just to breathe. The lungs are clogged with thick mucus requiring constant medication and intrusive therapies. There is no cure. Without a lung transplant the disease can become a death sentence. This DVD follows the story of a young woman with cystic fibrosis and a young man whose life was saved by a lung transplant.

**Deafblind: a world without sight and sound.** 60 min. 2003. (DD0402).

In this DVD, originally a BBC broadcast, viewers explore the world of two 12 year-old boys who were born deaf and blind. Their families explain how they have learned to communicate with the boys. It also describes the experiences of two adults who are both deaf and blind after they lost their hearing after childhood. This program, by using special effects that simulate sensory deprivation and compensation, illustrates how the adults who are deaf and blind lead fulfilled, even adventurous lives.

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**Development and discovery.** 30 min. 2005. (DD0382).

This DVD presents research on newborn brain development including speed, reaction, and pain sensitivity. Methods of assessing the newborn through techniques such as the APGAR scale, random mass spectrometry, and the revised Brazelton Neonatal Assessment Scale are shown. Information on newborn reflexes along with information on changes in care of low birth weight, premature, and small for date newborns is included.

**Diagnóstico: epilepsia ¿y ahora qué?** 93 min. 2010. (DV0680).

This DVD was filmed entirely in Spanish. It provides an overview of childhood epilepsy, including different types of seizures; diagnostic procedures; treatment options; the impact of epilepsy on development and learning; safety; epilepsy in the family and community; stigma; and the benefits of encouraging a child's unique interests and talents. It also contains a bonus section of person on the street interviews and an appendix that illustrates and explains first aid for seizures.

**Don't drink for two: prevent fetal alcohol spectrum disorders / no beba por dos evite los trastornos del espectro alcohólico fetal.** 16 min. 2010. (DV0505).

In this DVD, two moms share their personal stories of sorrow after giving birth to children with Fetal Alcohol Spectrum Disorders (FASD). This DVD combines facts about FASD and information women can use to get help to quit drinking.

**Early interactions.** 45 min. 2007. (DD0150).

In this DVD, professionals observe children with disabilities as they participate in typical home activities. In the first segment, Ryan, an infant with visual impairment and cerebral palsy, carries out a range of developmental activities with the expert guidance of his mother and a physical therapist. In the second segment, Michael, a toddler with visual impairment and hearing loss, engages in play by himself and with his parents and sibling.

**ECI teleconference: fetal alcohol syndrome.** 113 min. 2008. (DD0217).

This teleconference from March 6, 2008 was presented by Toosje Thyssen VanBeveren. Dr. VanBeveren explores the effects of prenatal alcohol exposure on prenatal development.

**Epilepsy 101: information for people with seizures.** 12 min. 2004. (DV0431).

This DVD provides basic information for people who have been diagnosed with epilepsy (recurring seizures). It describes the four major treatment options and through interviews with patients and physicians offers tips on how to limit epilepsy's effects on people's lives.

**Epilepsy: one in one hundred kids.** 26 min. 2004. (DD0088).

Children and adults with epilepsy are the focus of this DVD. Two young siblings who live with the condition are interviewed along with leading experts in this field.

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**Fetal alcohol exposure: changing the future.** 31 min. 2006. (DD0087).

Viewers of this DVD will learn how fetal alcohol spectrum disorders are diagnosed. They will understand the primary and secondary disabilities associated with fetal alcohol spectrum disorders and the human cost of these disorders.

**First adventures.** 45 min. 2004. (DD0582).

In this DVD, instructors from the Western Pennsylvania School for Blind Children enhance their young students' language, concept development, visual reach, motor movement, and use of a long cane by teaching these skills in an outdoor garden designed for children who are blind.

**Foster parents working with birth parents.** 80 min. 2003. (DD0097).

In this DVD, Dr. Vera Fahlberg talks to experienced foster parents about a variety of subjects, including the increased number of children who are placed in foster care because of their birth parents' addiction to drugs.

**Growing up with spina bifida.** 46 min. 2010. (DD0466).

This DVD, produced by Texas Scottish Rite Hospital, follows the lives of children who have spina bifida. The medical, physical, intellectual, and social aspects of spina bifida are discussed.

**Including Samuel.** 58 min. 2008. (DD0226).

This DVD documentary examines the educational and social inclusion of youth with disabilities. It chronicles the Habib family's efforts to include Samuel, their son with cerebral palsy, in every facet of their lives, and also features four other families with varied inclusion experiences.

**Letting your child's wild side out.** 30 min. 2008. (DD0720).

This program shows how the family of a little girl who is blind embraced early intervention services and applied what they had learned from ECI. Five year-old Milagro is shown having fun while skiing, participating in gymnastics, rock climbing, and exploring music. Early intervention specialists can use this program to suggest recreational activities to families with young children who are visually-impaired.

**Listening heart.** 37 min. 2005. (DD0147).

This DVD chronicles the day to day life of four adoptive families who are raising children with fetal alcohol syndrome. Dr. Ira J. Chasnoff provides background medical information.

**Mothers addicted to meth.** 11 min. 2006. (DD0131).

Kristi is a 33-year-old woman battling a methamphetamine (meth) addiction, while trying to be a good mother to her small children at the same time. It isn't only meth users who are falling victim to the powerful stimulant. It profoundly affects their sons and daughters as well. Focusing on the rehabilitation of mothers addicted to meth, this DVD examines the struggles they face in staying clean and reconciling with their broken families.



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**Multiples more of everything: volume 1: prenatal and birth.** 26 min. 2009. (DD0396).

This DVD teaches parents what to expect from a multiple pregnancy and shows different delivery scenarios through four personal birth stories. Examples of a vaginal birth and a cesarean birth are included.

**Multiples more of everything: volume 2 postpartum and breastfeeding.** 29 min. 2009. (DD0397).

This DVD prepares parents for life with multiples from the NICU to the first birthday. It includes information on establishing a routine, taking time for yourself, and breastfeeding.

**No matter how small: a parent's guide to preterm infant development.** 39 min. 2006. (DD0051).

This DVD is based on research and features a diverse cast of real parents and providers. It shows parents how to support the growth and development of their baby's brain.

**Overcoming vision impairments.** 12 min. 2012. (DD0698).

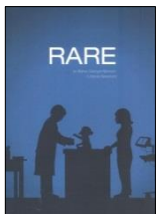
There are over 42 million people worldwide who have total or partial loss of vision and are defined as being blind. This program explains how the human eye works, examines some of the major causes of blindness, and shows how medical science and technology are helping people with impaired vision. Surgical procedures and advanced image processing technologies are also presented in this program.

**A place of our own: early childhood solutions special needs.** 97 min. 2008. (DD0326).

A young boy with a visual impairment is featured in this DVD on recognizing and understanding special needs.

**Power of two.** 94 min. 2011. (DD0657).

Inspired by their 2007 memoir of the same title (208.4 B995p 2007 RHB), this DVD portrays the bond between half-Japanese twin sisters Anabel Stenzel and Isabel Stenzel Byrnes, their battle with cystic fibrosis (CF) and survival through double lung transplants. Viewers witness their emergence as authors, athletes, and advocates for organ donation and people with CF in the U.S. and Japan. The film also examines the resistance to organ donation in Japanese culture.



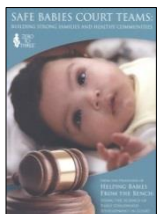
**Rare.** 56 min. 2012. (DD0659).

When Donna Appell learned that her infant daughter Ashley had an extremely rare genetic disease, she set out to track down every person in the world with Hermansky-Pudlak Syndrome (HPS). Realizing that no one was going to help cure just one child, Appell formed an advocacy group. Because the disease occurs with more frequency in Puerto Rico, she travelled to the island to recruit participants for a clinical trial. The film follows Appell and her daughter Ashley into the world of clinical research, patient advocacy, and through the course of a NIH clinical trial.

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**Recovering hope: mothers speak out about fetal alcohol spectrum disorders.** 60 min. 2005. (DD0406).

Eight mothers of children with Fetal Alcohol Spectrum Disorders (FASD) share their stories. They speak of effective new ways to parent, and how they are recovering. One mother discusses the benefits of early childhood intervention for her child with FASD. The DVD is divided into short chapters so that it can easily be used in training.



**Safe babies court teams: building strong families and healthy communities.** 55 min. 2012. (DD0681).

This DVD is divided into four segments. One of the segments, *Fetal alcohol spectrum disorders: the elephant in the courtroom*, documents the causes of fetal alcohol spectrum disorders (FASD), the effects of FASD on young children, and the value of early diagnosis. Recognizing the intergenerational nature of FASD, the video also discusses FASD in adults and how child welfare case management can provide FASD-affected parents the opportunity to succeed.

**Sensory perspectives.** 120 min. 2003. (DD0627).

This interactive DVD set addresses sensory loss related to deafness, blindness, and deaf blindness. The program includes information on sensory loss and simulations of different types of hearing, vision, and combined vision and hearing losses. The first disc on vision loss includes an introduction, a quiz, and examples of acuity loss, field loss, contrast sensitivity, processing problems, and oculomotor problems. The second disc covers combined vision and hearing loss. It includes examples of learning, communication, and social and emotional development for people who are both deaf and blind. A menu on each disc allows viewers to choose which segments they want to view.

**Substance-exposed infants.** 55 min. 2010. (DD0390).

This DVD sheds light on the physical and mental challenges faced by children who were prenatally exposed to illegal substances. It gives an honest view of their long-term prognosis and straightforward advice on nurturing these infants in a way that helps them thrive.

**Tactile learning strategies: interacting with children who have visual impairments and multiple disabilities.** 63 min. 2006. (DD0106).

This DVD illustrates effective interactions with children and provides techniques for teaching communication skills. It can be used alone or in conjunction with the book *Tactile strategies for children who have visual impairments and multiple disabilities: promoting communication and learning skills* (219.13 C518t 2006 ECI).

**Under attack: living with epilepsy.** 16 min. 2004. (DV0194).

This DVD explores epilepsy as a hidden and often misinterpreted condition. Throughout her life, Anneli has had a difficult form of epilepsy and has always been dependent upon special medical treatment. A Vagus Nerve Stimulator, a small medical device, has been implanted in Anneli's chest to limit the seizures.

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**Your premature baby: volume 1 preemie basics and medical care.** 26 min. 2008. (DD0398).

This DVD is intended to be shown to high-risk pregnant women or to parents who have just had a premature baby. Topics include defining prematurity, preemie appearance and behavior, the neonatal intensive care unit and its equipment, and common medical problems. It is also available in Spanish as DD0439.

**Your premature baby: volume 2 interacting with and feeding your preemie.** 26 min. 2008. (DD0399).

This DVD educates parents of premature babies about communication and touch cues, interaction, over-stimulation, kangaroo care, feeding, benefits of breastmilk, pumping, and learning to breastfeed. The video also instructs parents on how they can take care of themselves so as to enjoy good emotional and physical health and cope with postpartum depression. It is also available in Spanish as DD0440.

**Your premature baby: volume 3 going home.** 26 min. 2008. (DD0400).

This DVD is designed to be shown to parents as their baby nears discharge. Topics include preparing for discharge, gaining confidence, rooming-in, training for baby care, car seat/bed. Parents learn about SIDS, preventing infections, responding to crying, pre-crying signals, feeding, and sleep cycles. Early development is also covered along with corrected age, physical growth, and ways to promote healthy development. Also covered are possible long-term complications – hearing impairment, vision problems, muscle tone, learning disabilities. It is also available in Spanish as DD0441.

## **Medical Diagnosis and Special Populations – Multimedia**

**Developmental disabilities: faces, patterns, possibilities.** 2002. (CR0013).

This CD-Rom gives basic information about autism, cerebral palsy, epilepsy, and intellectual and developmental disabilities. A glossary of related terms, bibliographies, and interactive quizzes is provided.

**Early intervention in action: working across disciplines to support infants with multiple disabilities and their families.** 2008. (CR0044).

This interactive textbook with video clips covers working with children with multiple disabilities including visual impairments. It also covers infusing interdisciplinary intervention with the daily routine.

**Feeding your baby.** 2008. (CR0043).

This comprehensive feeding guide for parents, professionals, and caregivers includes demonstrations of all major cleft palate nursers and suggestions about adapting bottles, breastfeeding, and team care.

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**Substance exposure and promoting attachment.** 2007. (CA0006).

Mary Susan Rudisill, clinical psychologist, presents information about prenatal substance exposure and the early absence of consistent, loving caregivers. The first part of the session explores the interrelationship of biological and environmental risk factors as they affect attachment and development in children who were exposed to alcohol or drugs. Part two presents a comprehensive view of this multi-deficit model and innovative intervention options.

## **Medical Diagnosis and Special Populations – Selected Books**

**Alex: the fathering of a preemie.** Jeff Stimpson, 2004. (242.1 S859a 2004 ECI).

This is the story of the first years of baby Alex who was born weighing 21 ounces. It is the story of doctors, hospitals, conferences, and all the extreme emotions of parenting a preemie. It is the story as told by Alex's father.

**Alphabet kids: from ADD to Zellweger syndrome: a guide to developmental, neurobiological and psychological disorders for parents and professionals.** Robbie Woliver, 2010. (WS 107 W861 2010).

This book serves as a resource and guide for parents as they journey through the muddle of symptoms and possible diagnoses for their children. There is an extensive symptom list in each chapter. This text is not a medical text but rather gives parents a place to begin when speaking with medical experts.

**Breathing for a living.** Laura Rothenberg, 2003. (208.4 R846b 2003 RHB).

This is the autobiography of Laura Rothenberg, a woman with cystic fibrosis. It describes her life, her experience with a double lung transplant, and how she shines each day in spite of her severe illness.

**Cerebral palsy: a complete guide for caregiving.** Freeman Miller and Steven Bachrach, 2006. (WS 342 M647c 2006 ECI).

This book provides an overview of this condition along with practical advice for both physicians and parents.

**Children with spina bifida: a parent's guide,** 2<sup>nd</sup> ed. Marlene Lutkenhoff, 2008. (201.1 C536 2008 ECI).

This book provides parents with information, guidance, and support to meet their child's often intensive needs from birth through childhood.

**Children with visual impairments: a parents' guide.** (WW 276 C536 2006 ECI).

This book provides information and advice for parents of children from birth through age 7 who have visual impairments (blind or have low vision). Chapters cover what is visual impairment, medical issues, adjusting to the diagnosis, child development, daily life, family life, self-esteem, early intervention, legal issues, literacy, orientation and mobility, and the future.

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**Cleft lip and palate: interdisciplinary issues and treatment.** Karlind T. Moller and Clark D. Starr, 2009. (WV 440 C624 2009 RHB).

This textbook provides direct instruction and practical knowledge to speech pathologists in order to help patients with clefts. Information from multiple disciplines is presented.

**Coming home from the NICU: a guide for supporting families in early infant care and development.** Kathleen A. VandenBerg, 2013. (WS 410 V227 2013 ECI).

This book provides family-centered, developmentally supportive guidance in the months after the NICU. Professionals will deepen their understanding of the emotional and physical challenges of the NICU experience, and they'll get in-depth guidance on how to support parents effectively.

**Communicative disorders related to cleft lip and palate,** 5<sup>th</sup> ed. Kenneth R. Bzoch, 2004. (WV 440 C734 2004 ECI).

This textbook presents research on the general and diagnostic aspects of cleft palate along with information about early preventive and later rehabilitative speech therapy. Contributors include speech pathologists, surgeons, physicians, dental specialists, and scientists.

**Comprehensive guide to intellectual and developmental disabilities.** Ivan Brown and Maire Percy, 2007. (WB 320.2 C737 2007 RHB).

This is a core textbook and an ideal reference for any professional working with people who have disabilities. It contains information on intervention, education, family roles, health issues, and specific disabilities. It is life-span focused, with topics ranging from genetics and development to aging issues.

**Cortical visual impairment: an approach to assessment and intervention.** Christine Roman-Lantzy, 2007. (219.13 R758c 2007 ECI).

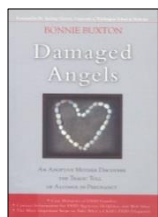
The leading cause of visual impairment among children is not a disease or condition of the eyes, but cortical visual impairment (CVI), also known as cerebral visual impairment, in which visual dysfunction is caused by damage or injury to the brain. The author has developed a set of unique assessment tools and systematic, targeted principles whose use has helped children learn to use their vision more effectively. This resource provides readers with both a conceptual framework with which to understand working with CVI and concrete strategies to apply directly in their work.

**Cystic fibrosis: a guide for patient and family.** David M. Orenstein, 2012. (WI 820 O66 2012 RHB).

This guide offers explanations, advice, and management options for patients or parents of patients with cystic fibrosis. The book explains the disease process, outlines the fundamentals of diagnosing and screening, and addresses the challenges of treatment for those living with the disease.

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**Cystic fibrosis: the facts.** Anne H. Thomson, 2008. (WI 820 T482c 2008 RHB). Cystic fibrosis affects the respiratory and digestive systems. This book explores all aspects of the disease from basic clinical information to conventional treatments. Patient experiences and answers to frequently asked questions are included.



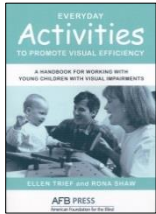
**Damaged angels: an adoptive mother discovers the tragic toll of alcohol in pregnancy.** Bonnie Buxton, 2005. (WQ 211 B991d 2005 ECI). Part heartfelt memoir, part practical guide, this book recounts the author's struggles to raise an adopted daughter whom she did not realize was afflicted with fetal alcohol syndrome. The book offers guidance to parents who have children with fetal alcohol syndrome.

**Double duty: the parents' guide to raising twins, from pregnancy through the school years.** Christina Baglivi Tinglof, 2009. (515 T588 2009 ECI). This book covers practical questions parents may have when they discover they are going to have twins. It covers pregnancy, various stages throughout infancy, toddlers, and school age concerns.

**Early intervention with multi-risk families: an integrative approach.** Sarah Landy, 2006. (271 L264 2006 ECI). Helping families who live in environments with multiple risk factors, including teen parenthood, mental illness, and substance abuse, requires that people work together to provide the best possible interventions. This book shows service providers how to help these multi-risk families by using an integrative model that brings together the most effective intervention techniques from a variety of theoretical approaches, parenting strategies, and innovative programs.

**Epilepsy: 199 answers: a doctor responds to his patients' questions,** 3<sup>rd</sup> ed. Andrew N. Wilner, 2008. (WL 385 W744 2008 RHB). Epilepsy is a brain disorder characterized by recurrent seizures. The experience of epilepsy is different for each person who has it. This book addresses the needs of everyone with the disorder, whether their epilepsy is mild or severe.

**Epilepsy: patient and family guide.** Orrin Devinsky, 2008. (203.11 D496 2008 RHB). This book provides an easy-to-understand resource for people with epilepsy and for their families. Both the newly diagnosed and those living with epilepsy will find information on a wide range of medical, social, and legal issues. Topics include an explanation of, and misconceptions about, types of seizures and epilepsies, drug benefits, side effects, and risk factors. It includes a chapter specifically on children with epilepsy.



**Everyday activities to promote visual efficiency: a handbook for working with young children with visual impairments.** Ellen Trief, 2009. (WW 276 T825e 2009 ECI).

This book explains the importance of early intervention. It includes activities for children with visual impairments, especially activities for promoting visual skills for different age groups: babies from birth to 6 weeks of age, babies from 6 weeks to 4 months, babies from 4 to 8 months, 8 to 12 months, 12 to 18 months, 18 to 24 months, and for children from 2 to 3 years of age.

**Far from the tree.** Andrew Solomon, 2012. (200.8 S65 2012 ECI).

All parenting turns on a crucial question: to what extent parents should accept their children for who they are, and to what extent they should help them become their best selves. Drawing on forty thousand pages of interview transcripts with more than three hundred families, Solomon mines the eloquence of ordinary people facing challenges. Whether considering prenatal screening for genetic disorders or cochlear implants for children who are deaf, Solomon narrates a universal struggle toward compassion.

**Fetal alcohol syndrome: guidelines for referral and diagnosis.** 2004. (201.4 F419 2004 ECI).

Guidelines for the diagnosis of fetal alcohol syndrome and other negative birth outcomes resulting from prenatal exposure to alcohol are listed in this publication. Guidance about medical, educational, social, and family services appropriate for individuals with fetal alcohol syndrome and their families are reviewed. Research on programs aimed at preventing fetal alcohol syndrome and recommendations for identifying women at risk are also presented. These guidelines are also available online at [http://www.cdc.gov/ncbddd/fasd/documents/fas\\_guidelines\\_accessible.pdf](http://www.cdc.gov/ncbddd/fasd/documents/fas_guidelines_accessible.pdf).

**Fragile beginnings: discoveries and triumphs in the newborn ICU.** Adam Wolfberg, 2012. (WS 410 W855F 2012 ECI).

The author of this book is a physician and father to a child born weighing under two pounds. He describes his daughter's birth at six months into the pregnancy. With the knowledge that their daughter could be severely impaired for life, the parents consider whether to take the baby off life-support. As they make decisions about life-saving care in the first hours of a premature infant's life, doctors and parents must grapple with profound ethical and scientific questions: Who should be saved? How aggressively should doctors try to salvage the life of a premature baby who may be severely neurologically and physically impaired? What will that child's quality of life be like after millions of dollars are spent saving him or her? These big questions are considered in the context of one father's story.

**Handbook of developmental disabilities.** Samuel L. Odom, 2009. (226 H236 2009 RHB).

This book reviews knowledge about developmental disabilities: neuroscientific and genetic foundations; the impact on health, learning, and behavior; and effective educational and

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clinical practices. Experts analyze what works in intervening with diverse children and families, from infancy through the transition to adulthood.

**Handbook of intellectual and developmental disabilities.** John W. Jacobson, James A. Mulick, and Johannes Rojahn, 2009. (WB 320.2 H236 2009 RHB).

This book has a chapter on cerebral palsy. Dr. Sarah Winter explores the diagnosis, medical management, orthopedic management, and therapeutic interventions for cerebral palsy.

**NEW! Management of preterm birth: best practices in prediction, prevention, and treatment.** 2012. (WQ 240 M266 2012).

This book covers many aspects related to preterm birth including progesterone, periodontal disease, cervical cerclage, management dilemmas, antenatal corticosteroids, antibiotics, and tocolytic therapy for acute preterm labor. The final chapter considers management of early term births.

**Medical and psychosocial aspects of chronic illness and disability,** 5<sup>th</sup> ed. Donna R. Falvo, 2014. (WT 500 F197m 2014 RHB).

This text is a reference for education programs, for service delivery agencies, and for the nonmedical practitioner who is responsible for providing for the rehabilitation needs of persons with disabilities. This book presents the language and terminology necessary for the nonmedical practitioner to understand and translate medical and psychosocial aspects of chronic illness and disability into the functional domains of living. This text blends medical information with the implications for all aspects of the individual's life.

**Medical aspects of disability: a handbook for the rehabilitation professional,** 5<sup>th</sup> ed. Myron G. Eisenberg, 2017. (WT 500 M489 2017 RHB).

This book provides a wide view of medical and psychosocial issues that affect adults and children with disabilities. It covers twenty-five different conditions or disorders, including epilepsy, cerebral palsy, spina bifida, cystic fibrosis, and visual impairments.

**Medical care for children and adults with developmental disabilities.** 2006. (WS 107 M489 2006 RHB).

This book brings together a vast amount of health information for clinical workers and teachers who work with people with developmental disabilities. It discusses systems of care as well as specific medical challenges for children and adults with spina bifida, genetic syndromes, cerebral palsy, fetal alcohol spectrum disorders, epilepsy, and infants who were born prematurely.

**My baby rides the short bus: the unabashedly human experience of raising kids with disabilities.** Yantra Bertelli, Jennifer Silverman, and Sarah Talbot, 2009. (WS 107.5 M995 2009 ECI).

This book is a collection of short stories about life with children who have disabilities. It tells the truth about the struggles and rewards of parenting children with special needs.



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**Mystery of risk: drugs, alcohol, pregnancy and the vulnerable child.** Ira J. Chasnoff, 2010. (WA 320 C487 2010 MHSA).

This book begins by discussing the development of an infant and child's brain. Exposure to drugs or alcohol, as well as abuse or neglect, affect the child's developing nervous system. The author outlines a problem-solving approach to behavior management of these "at risk" children. He provides policy recommendations for early intervention and treatment, clinical models to screen and treat women for substance use in pregnancy, and guidelines that redefine the notion of risk inside the child welfare system.

**The neurobehavioral and social-emotional development of infants and children.** Ed Tronick, 2007. (540 T853n 2007).

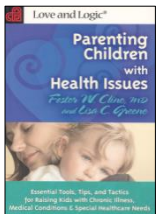
This book contains essays about the effects of prenatal cocaine exposure on infants. Additional essays cover the development of infants who were born prematurely. An accompanying CD-ROM covers the neonatal assessment of infants who were exposed to alcohol or drugs and Tronick's assessment of the still-face paradigm.

**Newborn intensive care: what every parent needs to know.** Jeanette Zaichkin, 2010. (242.2 Z21 2010 ECI).

This book provides a variety of information parents of premature infants need to know to be able to participate as a vital part of their child's medical team while the baby is in the hospital's NICU.

**NEW! Optimizing care for young children with special health care needs: knowledge and strategies for navigating the system.** 2007. (WS 107 O72 2007 ECI).

This book is a guide to all the critical issues, policies, and practices affecting medical care for children with special health care needs from birth to age 5.



**Parenting children with health issues: essential tools, tips, and tactics for raising kids with chronic illness, medical conditions, and special healthcare needs.** Foster W. Cline and Lisa C. Greene, 2007. (271.3 C641 2007 ECI).

This book explains the theories behind the love and logic approach to parenting. It then discusses how to use the approach with children who have serious health issues. It covers when this approach works well and how to modify it as needed with children who have special needs.

**Parenting your premature baby and child: the emotional journey.** Deborah L. Davis, 2004. (WS 410 D261p 2004 ECI).

This book focuses on experiences, feelings, and relationships around the delivery, hospitalization, homecoming, and long-term parenting of your premature baby and child. It provides suggestions and support for coping, adjusting, and finding your way. It shows that both mothers and fathers of premature babies are not alone in their hopes, fears, struggles, and triumphs.

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**A parents' guide to special education for children with visual impairments.** Susan LaVenture, 2007. (WW 276 P228 2007 ECI).

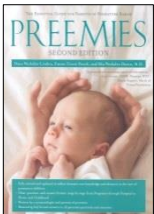
This handbook for parents, family members, and caregivers of children with visual impairments explains special education services that these children are likely to need and to which they are entitled and how to make sure that they receive them. This resource addresses the effect of visual impairment on a child's ability to learn and the services and educational programming that are essential for optimal learning. It is intended to help parents ensure that their children receive the best education possible.

**Power of two: a twin triumph over cystic fibrosis.** Isabel Stenzel Byrnes, 2007. (WI 820 B826p 2007 RHB).

Born in 1972, twins who share this life-threatening disease give an honest portrayal of their struggle to live normal lives, their interdependence, day-to-day health care, the impact of chronic illness on marriage and family, and the importance of a support network to continuing survival. The library also owns the documentary film of the same title that was inspired by the book (DD0657).

**Preemie parents: recovering from baby's premature birth.** Lisa McDermott-Perez, 2007. (242.1 M134p 2007 ECI).

This book reveals the world of preemie parents and the emotional stresses they face before and after the birth. The reader will learn how traumatic this time can be for mothers and fathers and what can help. Topics include self-talk, recognizing and coping with negative feelings, bonding, accepting that "this baby is different," dealing with going home alone, and being the baby's best advocate.

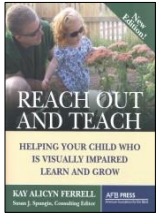


**Preemies: the essential guide for parents of premature babies, 2<sup>nd</sup> ed.** Dana Wechsler Linden, 2010. (WS 410 L744p 2010 ECI).

This is a comprehensive guide for parents of babies who are born prematurely. It is written by two mothers of preemies and a neonatologist. It includes information on prevention of premature birth, the health of twins, what to expect in the Neonatal Intensive Care Unit, when the baby can come home, breastfeeding, and guidance about the possible future development of premature babies.

**Primary care of the child with a chronic condition.** Patricia Jackson Allen, Judith A. Vessey, and Naomi A. Schapiro, 2010. (WS 200 A428p 2010 ECI).

This book provides pediatric health care professionals with the information they need in order to provide primary care to children with special health care needs. Part one discusses challenges like the transition to adulthood, family relationships, financing healthcare, and systems of care. Part two explains common chronic conditions like epilepsy, cerebral palsy, and cystic fibrosis in detail.



**Reach out and teach: helping your child who is visually impaired learn and grow.** Kay Alicyn Ferrell, 2011. (WW 276 F382r 2011 ECI).

This book presents research on how visually impaired children learn and develop at different ages and in the various developmental domains: sensory development, communication, movement, manipulation, and comprehension.

It provides a guide to teaching young children with visual impairments important life skills and preparing them to enter school ready to learn with their peers.

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

This book is a compilation of essays written by adults with many different disabilities: cerebral palsy, deafness, blindness, developmental disabilities, spina bifida, muscular dystrophy, and more. The authors were asked to write about something they wished their own parents had read or been told while they were growing up.

**The spirit catches you and you fall down: a Hmong child, her American doctors, and the collision of two cultures.** Anne Fadiman, 2012. (WA 30 F145s 2012).

This book explores the clash between a small county hospital in California and a refugee family from Laos. The clash is over the proper care of a Hmong child diagnosed with severe epilepsy. The true story explains why cross-cultural understanding and communication about medical beliefs is very important in order to obtain quality medical care. This updated edition includes a new afterword by the author.

**Stones applaud: how cystic fibrosis shaped my childhood.** Teresa Anne Mullin, 2007. (208.4 M959s 2007 RHB).

This is the autobiography of Teresa Anne Mullin that she wrote while attending Harvard University. It tells the story of her life with cystic fibrosis and how she pursued her dreams in spite of her disease.

**Supporting siblings and their families during intensive care.** Linda Rector, 2007. (WS 107.5 R5 R311s 2007 ECI).

This book is a guide to supporting siblings of infants that are in the neonatal intensive care unit (NICU). It helps guide parents as they provide their older children with information during a high-risk pregnancy. It helps parents explain what is happening in the NICU. It helps make sibling and family visits with the baby a success.

**Tactile strategies for children who have visual impairments and multiple disabilities: promoting communication and learning skills.** Deborah Chen, 2006. (WM 276 C518t 2006 ECI).

In order to promote their growth, development, and ability to communicate, young children who are visually impaired and have additional disabilities need to learn to use their sense of touch effectively and develop skills that are not necessarily based on the use of vision. This manual provides essential information about alternative communication and countless practical strategies and insights to create effective solutions for working with children. Teachers, early interventionists, and parents will find valuable techniques

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on topics ranging from how to assess a child's tactile skills to how to interact effectively with children and plan interventions. A companion DVD, *Tactile learning strategies: interacting with children who have visual impairments and multiple disabilities* (DD0106), is also available.

**Teaching motor skills to children with cerebral palsy and similar movement disorders: a guide for parents and professionals.** Sieglinde Martin, 2006. (203.21 M383t 2006 ECI).

This book is a resource that parents, therapists, and other caregivers can consult to help young children with gross motor delays learn and practice motor skills. The book offers dozens of easy-to-follow exercises with photos to assist with head control, protective reactions, proper positioning, independent sitting, transitional movements, stretching, muscle strength, balance training, and gait training.

**Teaching social skills to students with visual impairments: from theory to practice.** Sharon Sacks and Karen E. Wolffe, 2006. (219.13 T253 2006 ECI).

When a child is unable to observe visually and imitate how other people react, this complex developmental process can become fragmented and incomplete. As a result, providing specific information, direct instruction, and opportunities for social interaction to children who are blind or visually impaired is critical to their growth and education. This book explores what theory says about how children who are visually impaired become socially skilled individuals. It presents a compendium of techniques and strategies for helping youngsters, from preschoolers through young adults, including those with additional disabilities, develop and refine social skills.

**Tiny titan: a true story.** Ann Yurcek, 2006. (201 Y95t 2006 ECI).

This is the story of a baby born with Noonan syndrome as told by her mother. The family also adopts five siblings with alcohol spectrum disorders. It describes life in a large family with the struggles and joys of caring for children with special needs.

**Twin sense: a sanity-saving guide to raising twins from pregnancy through the first year.** Dagmara Scalise, 2009. (WS 105.5 S282t 2009 ECI).

There are always challenges with the arrival of a new baby but the parents of twins face different joys and frustrations. The author offers real-world advice on dealing with the many issues that arise when caring for newborn twins. It includes sections on baby-proofing, equipment, breast-feeding, getting through the night, bathing, traveling, and more.

**Understanding newborn behavior and early relationships.** J. Kevin Nugent, 2007. (WS 105.5 C3 N967u 2007 ECI).

This book helps clinicians help new mothers and fathers get to know their baby, increase their confidence and competence as parents and support their child's growth and development. A chapter on caregiving for preterm infants is included.

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**Understanding physical, health and multiple disabilities.** 2009. (WS 107 U55 2009 RHB).

This book describes various physical, health, and multiple disabilities and their educational implications. Sections are included on neuromotor impairments; orthopedic, musculoskeletal, and sensory disorders; degenerative and terminal diseases; major health impairments; and infectious diseases.

**NEW! Vision and the brain: understanding cerebral visual impairment in children.** 2015. (WW 276 V831 2015 ECI).

Cerebral visual impairment (CVI) has become the most common cause of visual impairment in children in the United States. This book is a comprehensive sourcebook of knowledge about CVI and best practices for working with affected children. Chapters illuminate the complexities of vision loss related to brain injury and neurological causes and provide readers with approaches to assessment and intervention.

## **Medical Diagnosis and Special Populations – Selected Children’s Books**

**All kinds of friends, even green!** Ellen B. Senisi, 2002. (WB 320 S477 2002 ECI).

Seven-year-old Moses, who has spina bifida and uses a wheelchair, reflects that his neighbor’s iguana, who is missing its toes, resembles him because they both have figured out how to get where they want to be in different ways than those around them.

**Evan early.** Rebecca Hogue Wojahn, 2006. (805.1 W847e 2006 ECI).

When Natalie’s baby brother is born too soon, she tries to wait patiently to teach him everything he will need to know, but she misses her parents and begins to resent the time they spend with him at the hospital.

**My friend Suhana.** Shaila Abdullah, 2014. (WS 342 A238 2014 ECI).

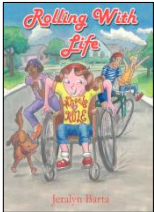
While volunteering with her mother at a community center, a seven-year-old girl befriends Suhana, also seven, whose cerebral palsy makes it difficult for her to communicate or control her movements. The author includes facts about cerebral palsy.

**Nathan’s wish.** Laurie Lears, 2005. (805.1 L438n 2005 ECI).

A boy with cerebral palsy helps out at a raptor rehabilitation center and is inspired himself when an owl that cannot fly finds another purpose in life.

**Otto the blind otter.** Sue Purkapile, 2004. (WW 276 P985 2004 ECI).

Otto’s brothers do not want to play with him because of his blindness. After Otto gets lost, his mother insists they all play together, and Oliver and Otis soon learn that Otto is special in more than one way.



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**Rolling along: the story of Taylor and his wheelchair.** Jamee Riggio Heelan and Nicola Simmonds, 2000. (WS 107 H458r 2000 ECI).

This children's book explains how having cerebral palsy affects Taylor and how getting a wheelchair makes a big difference in helping him get around, do things by himself, and even play basketball with his twin Tyler.

**Rolling with life.** Jeralyn Barta, 2010. (804 B283 2010).

A young girl was born with a limiting condition that necessitates her use of a wheelchair. Reagan experiences many struggles and hardships as she rolls through life but she teaches others what she has learned and they all embrace their differences with respect and acceptance of one another.

## Medical Diagnosis and Special Populations – Selected Ebooks

**Children of substance-abusing parents: dynamics and treatment.** Christine Huff Fewell and Shulamith Lala Ashenberg Straussner (2011).

**Children with disabilities,** 7<sup>th</sup> ed. Mark L. Batshaw, Louis Pellegrino, and Nancy Roizen, 2013.

**Chronic disease and disability in childhood.** Joav Merrick (2013).

**Congenital disorders sourcebook.** (2013).

**Cystic fibrosis.** J. Stuart Elborn (2014).

**Epilepsy.** Howard P. Goodkin (2014).

**Epilepsy in children and adolescents.** James Wheless (2013).

**Fetal Alcohol Spectrum Disorders: interdisciplinary perspectives.** Jo Egerton, Carolyn Blackburn, and Barry Carpenter (2014).

**Genetic disorders sourcebook.** Sandra J. Judd (2013).

**Kids in the syndrome mix of ADHD, LD, autism spectrum, Tourette's, anxiety, and more: the one-stop guide for parents, teachers, and other professionals.** Martin L. Kutscher (2013).

**Premature birth in the United States: a sociocultural approach.** Janet M. Bronstein (2016).

**The preemie primer: a complete guide for parents of premature babies from birth through the toddler years and beyond.** Jennifer Gunter (2010).

**Ready for air: a journey through premature motherhood.** Kate Hopper (2013).

**Redesigning health care for children with disabilities: strengthening inclusion, contribution, and health.** Heidi M. Feldman (2013).

**Your preemie baby: caring for your premature baby.** Su Laurent (2012).

## Medical Diagnosis and Special Populations – Websites

**Cerebral Palsy** – United Cerebral Palsy: <http://www.ucp.org>

Cerebral Palsy – MedlinePlus: <http://www.nlm.nih.gov/medlineplus/cerebralpalsy.html>

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Cerebral Palsy – information for children:

[http://kidshealth.org/kid/health\\_problems/brain/cerebral\\_palsy.html](http://kidshealth.org/kid/health_problems/brain/cerebral_palsy.html)

**Cleft Palate** <http://www.acpa-cpf.org/>

Cleft Palate - MedlinePlus: <http://www.nlm.nih.gov/medlineplus/cleftlipandpalate.html>

**Cystic Fibrosis** Foundation: <http://www.cff.org>

Cystic Fibrosis – MedlinePlus: <http://www.nlm.nih.gov/medlineplus/cysticfibrosis.html>

**Epilepsy** – Epilepsy Foundation: Information for parents:

<http://www.epilepsyfoundation.org/about/quickstart/parents/index.cfm>

Epilepsy – MedlinePlus: Information on epilepsy:

<http://www.nlm.nih.gov/medlineplus/epilepsy.html>

Epilepsy – MedlinePlus: Information on seizures:

<http://www.nlm.nih.gov/medlineplus/seizures.html>

**Sickle Cell** Disease Association of America: <http://www.sicklecelldisease.org>

Sickle Cell – MedlinePlus: <http://www.nlm.nih.gov/medlineplus/sicklecellanemia.html>

**Spina Bifida** Association: <http://www.spinabifidaassociation.org>

Spina Bifida – MedlinePlus: <http://www.nlm.nih.gov/medlineplus/spinabifida.html>

Spina Bifida – National Institute of Child Health and Human Development:

<http://www.nichd.nih.gov/health/topics/spinabifida/Pages/default.aspx>

## GENERAL WEBSITES ON MEDICAL DIAGNOSES:

- **Children with Chronic Conditions** – University of Michigan Health System: <http://www.med.umich.edu/yourchild/topics/chronic.htm>
- The **March of Dimes** provides web pages on many conditions of interest in this issue of the newsletter: <http://www.marchofdimes.com/pnhec/4439.asp>
- National Organization for **Rare Disorders**: <http://www.rarediseases.org>
- NIH **Genetics Disorders**: <http://ghr.nlm.nih.gov>

## WEBSITES ON SPECIAL POPULATIONS:

**Fetal Alcohol Spectrum Disorders** – The FASD Center: <http://fasdcenter.samhsa.gov>

Fetal Alcohol Spectrum Disorders – National Organization on Fetal Alcohol Syndrome:

<http://www.nofas.org>

Fetal Alcohol Spectrum Disorders – This video tells the story of one family living with FASDs:

<http://www.cdc.gov/ncbddd/fasd/videos>

Fetal Alcohol Spectrum Disorders – MedlinePlus:

<http://www.nlm.nih.gov/medlineplus/fetalalcoholsyndrome.html>

Fetal Alcohol Spectrum Disorders – National Institutes of Health:

<http://www.nih.gov/news/health/feb2013/niaaa-20.htm>

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**Pregnancy and substance abuse** – MedlinePlus:

<http://www.nlm.nih.gov/medlineplus/pregnancyandsubstanceabuse.html>

**Prematurity** – Centers for Disease Control: <http://www.cdc.gov/Features/PrematureBirth>

Prematurity – March of Dimes: <http://www.marchofdimes.com/baby/premature-babies.aspx>

Prematurity – MedlinePlus: <http://www.nlm.nih.gov/medlineplus/prematurebabies.html>

**Twins, Triplets, Multiple Births** – MedlinePlus:

<http://www.nlm.nih.gov/medlineplus/twinstripletsmultiplebirths.html>

**Visual impairments** – FamilyConnect for Parents of Children with Visual Impairments:

This website has articles in both English and Spanish:

<http://www.familyconnect.org/parentsitewhome.asp>

Visual impairments – Kids Health: <http://kidshealth.org/parent/general/eyes/vision.html>

Visual impairments – Parental Advice from the Texas School for the Blind and Visually Impaired: <http://www.tsbvi.edu/component/content/article/7-instructional-resources/3717-dosanddnts>

## **New Additions – Books**

**What to expect the first year.** Heidi Eisenberg Murkoff, 2014. (WS 105.5 C3 M977 2014 ECI).

This guide offers a multitude of practical information for new parents. It covers monthly growth and development, feeding tips, sleep strategies, ways to stimulate your baby, and more.

## **New Additions – Books on Compact Disc**

**Uniquely human: a different way of seeing autism.** 540 min. 2016. (CA0044).

Autism therapy typically focuses on ridding individuals of symptoms of autism such as difficulties interacting socially, problems in communicating, sensory challenges, and repetitive behavior patterns. Dr. Barry M. Prizant offers a compelling paradigm: the most successful approaches to autism don't aim at fixing a person by eliminating symptoms, but rather seeking to understand the individual's experience and what underlies the behavior.

**The Way I See It.** 556 min. 2013. (CA0045).

In this book on compact disc Temple Grandin, who has autism herself, explains how to relate to people with autism. She explains how and why people with autism think differently. She discusses early intervention programs that work. She covers sensory sensitivities and which behaviors are caused by a disability.



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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.texas.gov](mailto:avlibrary@dshs.texas.gov).*

## **Early Childhood Report– June 2017**

### **Legal Spotlight**

You Be the Judge

Does presenting draft IEP at team meeting cut parent out of the loop

### **Washington Watch**

Supreme court won't hear case involving psychologist's recommendation to forgo autism evaluation

### **Decisions & Guidance**

Low-tech AT meets FAPE target, enables student to progress.

Focus on unreasonable use of force shows case doesn't require exhaustion

Delay in hiring nurse forces district to weigh comp ed for homebound child

Charter school must evaluate 1<sup>st</sup>-grader prior to homebound placement

### **Cover Story**

Build relationship with families to help them overcome stress

### **Highlight**

School attorney: "We're going to have to up our game"

Eyes on autism: address students' stress

Sensory-based storytelling enhances understanding

Learn how to celebrate classroom parties without food

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## **Infant Mental Health Journal – May June 2017**

### **Assessing angels in the nursery: a pilot study of childhood memories of benevolent caregiving as protective influences**

Angela J. Narayan, Chandra Ghosh Ippen, William W. Harris and Alicia F. Lieberman

### **Implementing an attachment-based parenting intervention within home-based early head start: home-visitors' perceptions and experiences**

Allison L. West, Elizabeth M. Aparicio, Lisa J. Berlin and Brenda Jones Harden

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Collin Shepley, Justin D. Lane, Kevin Ayres, Karen H. Douglas  
pp. 86–98

### **From article to action: using mindfulness practices**

Camille Catlett  
pp. 99–100

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