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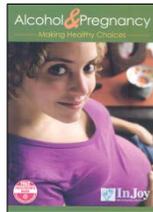
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Medical Diagnosis and Special Populations (updated)

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 addition to the collection on page 26!

Medical Diagnosis and Special Populations - 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.

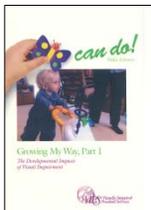
Full of hope. 18 min. (DD0206).

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.

Medical Diagnosis and Special Populations – DVDs (continued)



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.

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.

Medical Diagnosis and Special Populations - DVDs (continued)

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.

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.

Medical Diagnosis and Special Populations - DVDs (continued)

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.

ECI teleconference: working with children with vision or hearing loss. 109 min. 2002. (DD0234).

In this teleconference, Gigi Newton and Stacy Shafer from the Texas School for the Blind and Visually Impaired discuss information about working with children with vision or hearing loss. Shayne and Jennifer Holweger provide the parent perspective.

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.

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

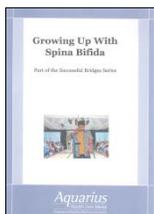
Viewers of this DVD will learn how fetal alcohol spectrum disorders are diagnosed. They will understand the primary and secondary disabilities associated with fetal alcohol spectrum disorders and the human cost of these disorders.

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.

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.

Medical Diagnosis and Special Populations - DVDs (continued)

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.

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.

NEW! Overcoming vision impairments. 12 min. 2012. (DD0698).

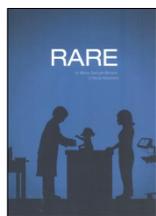
There are over 42 million people worldwide who have total or partial loss of vision and are defined as being blind. This program explains how the human eye works, examines some of the major causes of blindness, and shows how medical science and technology are helping people with impaired vision. Surgical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

NEW! 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.



NEW! 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. HPS symptoms include albinism, blindness, a bleeding disorder, and often a fatal pulmonary fibrosis. 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.

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.

Medical Diagnosis and Special Populations - DVDs (continued)



NEW! 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.

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.

Medical Diagnosis and Special Populations - DVDs (continued)

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.

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 – Books

Alex: the fathering of a premie. 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 premie. 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. (200.8 W861 2010 ECI).

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.

Medical Diagnosis and Special Populations – Books (continued)

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. (203.21 M647c 2006 ECI).

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

NEW! Children of substance-abusing parents: dynamics and treatment. Christine Huff Fewell and Shulamith Lala Ashenberg Straussner, 2011.

This book is intended as a reference for all mental health professionals and students who need to understand and treat this population. It offers a look at treatment options and programmatic interventions across the life span. The contributors include a range of experts who provide evidence-based clinical and programmatic strategies for working with children of alcohol and other substance-abusing parents of any age and in almost any practice setting. This title is available through Ebsco eBooks. Contact the library at (512) 776-7559 for more information.

NEW! Children with disabilities, 7th ed. Mark L. Batshaw, Louis Pellegrino, and Nancy Roizen, 2013.

This seventh edition of a trusted resource for professionals, families, and students presents extensive coverage of crucial developmental, clinical, educational, family, and intervention issues related to all aspects of children with disabilities including cerebral palsy, epilepsy, and blindness and visual impairments. This title is available through Ebsco eBooks. Contact the library at (512) 776-7559 for more information.

Children with spina bifida: a parent's guide, 2nd 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. 2006. (219.13 C536 2006 ECI).

This book, which is written by parents and professionals, provides the support and guidance the families of children with mild to severe visual impairments need. The contents cover these crucial areas: diagnosis and treatment, family life and adjustment, child development, early intervention and special education, literacy, orientation and mobility, legal issues, and more.

Cleft lip and palate: interdisciplinary issues and treatment. Karlind T. Moller and Clark D. Starr, 2009. (201.2 C624 2009 RHB).

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

NEW! 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, 5th ed. Kenneth R. Bzoch, 2004. (201.2 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.

Medical Diagnosis and Special Populations – Books (continued)

Comprehensive guide to intellectual and developmental disabilities. Ivan Brown and Maire Percy, 2007. (226 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.

NEW! Congenital disorders sourcebook, 3rd ed. Sandra J. Judd, 2013.

This book contains basic consumer information about nonhereditary birth defects and disorders related to prematurity, gestational injuries, prenatal and perinatal infections, maternal health conditions during pregnancy, and birth complications, including cerebral palsy, spina bifida, fetal alcohol spectrum disorders, and cleft lip and palate. This title is available through Ebsco eBooks. Contact the library at (512) 776-7559 for more information.

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

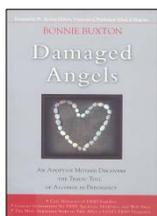
The leading cause of visual impairment among children is not a disease or condition of the eyes, but cortical visual impairment (CVI), also known as cerebral visual impairment, in which visual dysfunction is caused by damage or injury to the brain. The author has developed a set of unique assessment 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.

NEW! 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.

Cystic fibrosis: the facts. Anne H. Thomson, 2008. (208.4 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. (201.4 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.

Developmental and therapeutic interventions in the NICU. Elsie R. Vergara, 2004. (242.2 V494 2004 ECI).

This book, which provides a foundation of clinical knowledge for Neonatal Intensive Care Unit (NICU) professionals that they will need to work with at-risk newborns, combines research and practical guidelines that clinicians will use to promote the well-being of infants in the NICU and involve and support their families.

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.

Medical Diagnosis and Special Populations – Books (continued)

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, 3rd ed. Andrew N. Wilner, 2008. (203.11 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).

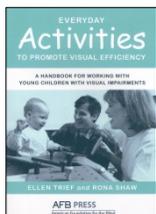
This book provides an easy-to-understand resource for people with epilepsy and for their families. Both the newly diagnosed and those living with epilepsy will find information on a wide range of medical, social, and legal issues. Topics include an explanation of, and misconceptions about, types of seizures and epilepsies, drug benefits, side effects, and risk factors. It includes a chapter specifically on children with epilepsy.

NEW! Epilepsy. 2014.

This book summarizes the knowledge and practices of expert epilepsy specialists in a concise, practical pocketbook for everyday use by treating physicians. Early intervention specialists may find the chapter on special topics in pediatric epilepsy useful. This title is available through Ebsco eBooks. Contact the library at (512) 776-7559 for more information.

NEW! Epilepsy in children and adolescents. James Wheless, 2013.

This book provides the contemporary, caring guidance professionals need to diagnose and manage seizures in a young patient. Beginning with an overview of the classification of seizure syndromes, the authors take a practical approach to a common but complex clinical challenge. Aimed at both professionals and trainees in neurology, this book will also be a useful guide for all primary health professionals caring for pediatric patients with this condition. This title is available through Ebsco eBooks. Contact the library at (512) 776-7559 for more information.



Everyday activities to promote visual efficiency: a handbook for working with young children with visual impairments. Ellen Trief, 2009. (219.13 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.

Families, infants and young children at risk: pathways to best practice. Gail L. Ensher, David A. Clark, and Nancy S. Songer, 2009. (556 E59f 2009 ECI).

This book explains the neurological and psychosocial development of children from birth to 8. It contains a chapter on the cycle of substance abuse. The chapter reviews the various in utero and neonatal problems associated with drugs.

Medical Diagnosis and Special Populations – Books (continued)

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.

NEW! Fetal Alcohol Spectrum Disorders: interdisciplinary perspectives. Jo Egerton, Carolyn Blackburn, and Barry Carpenter, 2014.

Fetal alcohol spectrum disorders (FASDs) have emerged as a major phenomenon within the education, health, criminal justice, and social care systems of many countries, with current prevalence figures suggesting that one in a hundred children and young people have FASDs. In this publication, academics, professionals, and families from around the world have shared expertise and insights on FASDs. This title is available through Ebsco eBooks. Contact the library at (512) 776-7559 for more information.

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.

Fragile beginnings: discoveries and triumphs in the newborn ICU. Adam Wolfberg, 2012. (242.2 W855 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.

NEW! Genetic disorders sourcebook, 5th ed. Sandra J. Judd, 2013.

This book provides basic consumer health information about heritable disorders, including disorders resulting from abnormalities in specific genes, such as hemophilia, sickle cell disease, cystic fibrosis, and chromosomal disorders such as Down syndrome. This title is available through Ebsco eBooks. Contact the library at (512) 776-7559 for more information.

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 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. (226 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.

Medical Diagnosis and Special Populations – Books (continued)

Medical and psychosocial aspect of chronic illness and disability. Donna R. Falvo, 2009. (080 F197 2009 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. Myron G. Eisenberg, 2011. (200 M489 2011 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. (200 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. (322.1 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.

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.



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. (242.1 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.

Medical Diagnosis and Special Populations – Books (continued)

A parents' guide to special education for children with visual impairments. Susan LaVenture, 2007. (219.13 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. (208.4 B995p 2007 RHB).

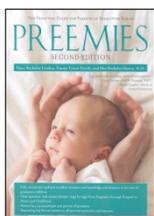
Born in 1972, twins who share this life-threatening disease give an honest portrayal of their struggle to live normal lives, their interdependence, day-to-day health care, the impact of chronic illness on marriage and family, and the importance of a support network to continuing survival. The library 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.

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

Having a premature baby can be a crash course in both medicine and health economics, not just in parenting. Parents face complex information, difficult decisions, and overwhelming grief and worry. As an ob/gyn, Dr. Jennifer Gunter has delivered hundreds of premature babies, but as a mother of preemie triplets, she also understands the heartbreak and challenges of prematurity. This book is a comprehensive resource, covering topics from delivery, hospitalization, and preemie development to parenting multiples, handling health issues, and finding special-needs programs. This title is available through Ebsco eBooks. Contact the library at (512) 776-7559 for more information.



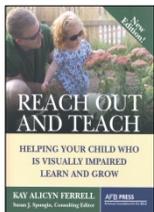
Preemies: the essential guide for parents of premature babies, 2nd ed. Dana Wechsler Linden, 2010. (242.1 L744 2010 ECI).

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. (215.5 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.

Medical Diagnosis and Special Populations – Books (continued)



NEW! Reach out and teach: helping your child who is visually impaired learn and grow. Kay Alicyn Ferrell, 2011. (HV 1626 F47 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 visually impaired children important life skills and preparing them to enter school ready to learn with their peers.

NEW! Ready for air: a journey through premature motherhood. Kate Hopper, 2013.

For Kate Hopper, pregnancy is downright unpleasant. She is tired and heavy and worried, and she wants her wine and caffeine back. But then, at a routine checkup, her doctor frowns at her chart and says, “I’m worried about a couple of things” and unpleasant suddenly seems like paradise. What follows is a harrowing, poignant, and occasionally hysterical journey through premature motherhood, from the starting point of “leaking a little protein” to the early delivery of her tiny daughter because of severe preeclampsia and the beginning of a new chapter of frightful, lifelong love. This title is available through Ebsco eBooks. Contact the library at (512) 776-7559 for more information.

Redesigning health care for children with disabilities: strengthening inclusion, contribution, and health.

Heidi M. Feldman, 2013.

One in five families has a child with special health care needs, but medical and human service professionals often don’t get the training they need to provide long-term, integrated care for these children. This textbook and training tool presents a comprehensive, interdisciplinary framework for delivering effective health care to children with disabilities and chronic illnesses. This title is available through Ebsco eBooks. Contact the library at (512) 776-7559 for more information.

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. (271.6 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 and much more.

Medical Diagnosis and Special Populations – Books (continued)

Tactile strategies for children who have visual impairments and multiple disabilities: promoting communication and learning skills. Deborah Chen, 2006. (219.13 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 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 fetal alcohol syndrome. 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. (515 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. (271.5 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.

Understanding physical, health and multiple disabilities. 2009. (200.8 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.

Medical Diagnosis and Special Populations – Books (continued)

Your premie baby: caring for your premature baby. Su Laurent, 2012.

Having a baby is a life-changing event for parents, and giving birth prematurely can bring a complex set of challenges and emotions to an already intense experience. In this book, Dr. Su Laurent guides parents through having a premature baby, giving them the tools they need to parent confidently. This title is available through Ebsco eBooks. Contact the library at (512) 776-7559 for more information.

Medical Diagnosis and Special Populations – Children’s Books

All kinds of friends, even green! Ellen B. Senisi, 2002. (805.1 S477 2002).

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.

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

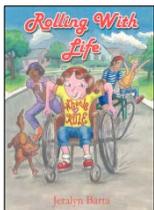
While volunteering with her mother at a community center, a seven-year-old girl befriends Suhana, also seven, whose cerebral palsy makes it difficult for her to communicate or control her movements. The author includes facts about cerebral palsy.

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. (805.1 P985o 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.



Rolling along: the story of Taylor and his wheelchair. Jamee Riggio Heelan and Nicola Simmonds, 2000. (804 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 leaves her confined to 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 – Websites

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

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

Cerebral Palsy – information for children: http://kidshealth.org/kid/health_problems/brain/cerebral_palsy.html

Cleft Palate Foundation: <http://www.cleftline.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 – Kids Club from Epilepsy Foundation:

<http://www.epilepsyfoundation.org/kidsclub/nonflash/home/index.html>

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>
- **NICHCY** Fact Sheets for Specific Disabilities – Each fact sheet defines the disability, describes its characteristics, and offers tips for parents or teachers: <http://nichcy.org/disability/specific>
- NIH **Genetics Disorders**: <http://ghr.nlm.nih.gov>

WEBSITES ON SPECIAL POPULATIONS:

Fetal Alcohol Syndrome – The FASD Center: <http://fasdcenter.samhsa.gov>

Fetal Alcohol Syndrome – National Organization on Fetal Alcohol Syndrome: <http://www.nofas.org>

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

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

Fetal Alcohol Syndrome – MedlinePlus: <http://www.nlm.nih.gov/medlineplus/fetalalcoholsyndrome.html>

Fetal Alcohol Syndrome – National Institutes of Health: <http://www.nih.gov/news/health/feb2013/niaaa-20.htm>

Texas Alliance for **Drug Endangered Children**: <http://www.texasdec.org>

Pregnancy and substance abuse – MedlinePlus: <http://www.nlm.nih.gov/medlineplus/pregnancyandsubstanceabuse.html>

Medical Diagnosis and Special Populations – Websites (continued)

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

Prematurity – Healthy Children.org (Reactions to the NICU): <http://www.healthychildren.org/English/ages-stages/baby/preemie/Pages/Common-Parent-Reactions-to-the-NICU.aspx>

Prematurity – Healthy Children.org (Preemie milestones): <http://www.healthychildren.org/English/ages-stages/baby/preemie/pages/Preemie-Milestones.aspx>

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/twinstriplesmultiplebirths.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>

Medical Diagnosis and Special Populations – Selected Journal Articles

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Assessing health-related quality of life in children with spina bifida. Rocque BG, Bishop ER, Scogin MA, et al. *J Neurosurg Pediatr.* 2015;15(2):144-9.

Object: The purpose of this study is to explore various aspects of health-related quality of life (HRQOL) in children with spinal dysraphism. **Methods:** The authors enrolled a prospective cohort of 159 patients from the multidisciplinary spina bifida clinic. Surveys were distributed to caregivers of patients with spina bifida who were 5 years old and older. Data were collected using the Health Utilities Index Mark 3 focusing on vision, speech, hearing, dexterity, ambulation, cognition, emotions, and pain. Each participant received an overall HRQOL utility score and individual domain subscores. These were correlated with demographic and treatment variables.

Analysis was done using SPSS statistics (version 21). **Results:** There were 125 patients with myelomeningocele, 25 with lipomyelomeningocele, and 9 with other dysraphisms. Among patients with myelomeningocele, 107 (86%) had CSF shunts in place, 14 (11%) had undergone Chiari malformation Type II decompression, 59 (47%) were community ambulators, and 45 (36%) were nonambulatory. Patients with myelomeningocele had significantly lower overall HRQOL scores than patients with closed spinal dysraphism. Among patients with myelomeningocele, younger patients had higher HRQOL scores. Patients with impaired bowel continence had lower overall HRQOL scores. History of a ventriculoperitoneal shunt was associated with worse HRQOL (overall score, ambulation, and cognition subscores). History of Chiari malformation Type II decompression was associated with worse overall, speech, and cognition scores. Patients who could ambulate in the community had higher overall and ambulation scores. A history of tethered cord release was correlated with lower pain subscore. No association was found between sex, race, insurance type, or bladder continence and HRQOL. **Conclusions:** Patients with myelomeningocele have significantly lower HRQOL scores than those with other spinal dysraphisms. History of shunt treatment and Chiari decompression correlate with lower HRQOL scores.

Keywords: CM-II = Chiari malformation Type II; COA = Children's of Alabama; CPC = choroid plexus cauterization; ETV = endoscopic third ventriculostomy; HRQOL = health-related QOL; HUI3 = Health Utilities Index Mark 3; QOL = quality of life; VP = ventriculoperitoneal; congenital; hydrocephalus; lipomyelomeningocele; myelomeningocele; quality of life; shunt; spina bifida.

Medical Diagnosis and Special Populations – Selected Journal Articles

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Auditory localization and precedence effect: an exploratory study in infants and toddlers with visual impairment and normal vision. Hüg MX, Arias C, Tommasini FC, Ramos OA. *Res Dev Disabil.*

2014;35(9):2015-25.

The precedence effect is a spatial hearing phenomenon implicated in sound localization on reverberant environments. It occurs when a pair of sounds, with a brief delay between them, is presented from different directions; listeners give greater perceptual weight to localization cues coming from the first-arriving sound, called lead, and suppress localization cues from the later-arriving reflection, called lag. Developmental studies with sighted infants show that the first responses to precedence effect stimuli are observed at 4-5 months of life. In this exploratory study, we use the minimum audible angle (MAA) paradigm in conjunction with the observer-based psychophysical procedure to test the ability of infants and toddlers, with visual impairment and normal vision, to discriminate changes in the azimuthal position of sounds configured under precedence effect conditions. The results indicated that similar and, in some conditions, higher performances were obtained by blind toddlers when compared to sighted children of similar age, and revealed that the observer-based psychophysical procedure is a valuable method to measure auditory localization acuity in infants and toddlers with visual impairment. The video records showed auditory orienting behaviors specific of the blind children group.

Australasian Cystic Fibrosis Bronchoalveolar Lavage Study Investigators. Costs of bronchoalveolar lavage-directed therapy in the first 5 years of life for children

with cystic fibrosis. Moodie M, Lal A, Vidmar S, et al. *J Pediatr.* 2014;165(3):564-569.e5.

Objectives: To determine whether bronchoalveolar lavage (BAL)-directed therapy for infants and young children with cystic fibrosis (CF), rather than standard therapy, was justified on the grounds of a decrease in average costs and whether the use of BAL reduced treatment costs associated with hospital admissions. Study design: Costs were assessed in a randomized controlled trial conducted in Australia and New Zealand on infants diagnosed with CF after newborn screening and assigned to receive either BAL-directed or standard therapy until they reached 5 years of age. A health care funder perspective was adopted. Resource use measurement was based on standardized data collection forms administered for patients across all sites. Unit costs were obtained primarily from government schedules. Results: Mean costs per child during the study period were Australian dollars (AUD)92 860 in BAL-directed therapy group and AUD90 958 in standard therapy group (mean difference AUD1902, 95% CI AUD-27 782 to 31 586, $P = .90$). Mean hospital costs per child during the study period were AUD57 302 in the BAL-directed therapy group and AUD66 590 in the standard therapy group (mean difference AUD-9288; 95% CI AUD-35 252 to 16 676, $P = .48$). Conclusions: BAL-directed therapy did not result in either lower mean hospital admission costs or mean costs overall compared with managing patients with CF by a standard protocol based upon clinical features and oropharyngeal culture results alone. Following on our previous findings that BAL-directed treatment offers no clinical advantage over standard therapy at age 5 years, flexible bronchoscopy with BAL cannot be recommended for the routine management of preschool children with CF on the basis of overall cost savings.

Cerebral palsy among children born moderately and late preterm. Hirvonen M, Ojala R, Korhonen P, et al. *Pediatrics.* 2014;134(6):e1584-93.

To compare the incidence of and risk factors for cerebral palsy (CP) in moderately preterm (MP) (32(+0)-33(+6) weeks) and late preterm (LP) (34(+0)-36(+6) weeks) infants with those in very preterm (VP) (<32(+0) weeks) and term infants (≥ 37 weeks). Methods: The national register study included all live-born infants in Finland from 1991 to 2008. Infants who died before the age of 1 year, had any major congenital anomaly, or had missing data were excluded. A total of 1 018 302 infants were included in the analysis and they were analyzed in 4 subgroups (VP, MP, LP, and term) and 3 time periods (1991-1995, 1996-2001, and 2002-2008). Results: By the age of 7 years, 2242 children with CP were diagnosed (0.2%). CP incidence was 8.7% in the VP, 2.4% in the MP, 0.6% in the LP, and 0.1% in the term group. The risk of CP was highest in the study period 1991-1995 in all groups. Factors predictive of an increased CP risk in the MP and LP groups included resuscitation at birth (odds ratio 1.60; 95%

Medical Diagnosis and Special Populations – Selected Journal Articles

(continued)

CI 1.01-2.53 and 1.78; 1.09-2.90), antibiotic treatment during the first hospitalization (1.63; 1.08-2.45 and 1.67; 1.13-2.44), 1-minute Apgar score <7 (1.70; 1.15-2.52 and 1.80; 1.21-2.67) and intracranial hemorrhage (7.18; 3.60-14.3 and 12.8; 5.58-29.2). Conclusions: The incidence of CP is higher in LP and MP infants compared with term infants. There is a nonlinear decrease in incidence over time and with increasing gestational age.

Cognitive and epilepsy outcomes after epilepsy surgery caused by focal cortical dysplasia in children: early intervention maybe better. Chen HH(1), Chen C, Hung SC, et al. *Childs Nerv Syst.* 2014; 30(11):1885-95.

Focal cortical dysplasia (FCD) is a specific malformation of cortical development harboring intrinsic epileptogenicity, and most of the patients develop drug-resistant epilepsy in early childhood. The detrimental effects of early and frequent seizures on cognitive function in children are significant clinical issues. In this study, we evaluate the effects of early surgical intervention of FCD on epilepsy outcome and cognitive development. Methods: From 2006 to 2013, 30 children younger than 18 years old underwent resective surgery for FCDs at Taipei Veterans General Hospital. The mean age at surgery was 10.0 years (range 1.7 to 17.6 years). There were 21 boys and 9 girls. In this retrospective clinical study, seizure outcome, cognitive function, and quality of life were evaluated. To evaluate the effects to outcomes on early interventions, the patients were categorized into four groups according to age of seizure onset, duration of seizure before surgery, and severity of cognitive deficits. Results: Eleven of 22 (50 %) patients demonstrated developmental delay preoperatively. The Engel seizure outcome achievements were class I in 21 (70 %), class II in 2 (7 %), class III in 6 (20 %), and class IV in 1 (3 %) patients. The locations of FCDs resected were in the frontal lobe in 18 cases, temporal lobe in 7, parietal lobe in 2, and in bilobes including frontoparietal lobe in 2 and parieto-occipital lobes in 1. Eight cases that had FCDs involved in the rolandic cortex presented hemiparesis before surgical resection. Motor function in four of them improved after operation. The histopathological types of FCDs were type Ia in 1, type Ib in 7, type IIa in 7, type IIb in 12, and type III in 3 patients. FCDs were completely resected in 20 patients. Eighteen (90 %) of them were seizure free ($p < 0.001$) with three patients that received more than one surgery to accomplish complete resection. The patients who had early seizure onset, no significant cognitive function deficit, and early surgical intervention with complete resection in less than 2 years of seizure duration showed best outcomes on seizure control, cognitive function, and quality of life. Conclusion: Delay in cognitive development and poor quality of life is common in children treated for FCDs. Early surgical intervention and complete resection of the lesion help for a better seizure control, cognitive function development, and quality of life. FCDs involved eloquent cortex may not prohibit complete resection for better outcomes.

Determinants of gross motor skill performance in children with visual impairments. Haibach PS, Wagner MO, Lieberman LJ. *Res Dev Disabil.* 2014;35(10):2577-84.

Children with visual impairments (CWVI) generally perform poorer in gross motor skills when compared with their sighted peers. This study examined the influence of age, sex, and severity of visual impairment upon locomotor and object control skills in CWVI. Participants included 100 CWVI from across the United States who completed the Test of Gross Motor Development II (TGMD-II). The TGMD-II consists of 12 gross motor skills including 6 object control skills (catching, kicking, striking, dribbling, throwing, and rolling) and 6 locomotor skills (running, sliding, galloping, leaping, jumping, and hopping). The full range of visual impairments according to United States Association for Blind Athletes (USABA; B3=20/200-20/599, legally blind; B2=20/600 and up, travel vision; B1=totally blind) were assessed. The B1 group performed significantly worse than the B2 ($0.000 \leq p \leq 0.049$) or B3 groups ($0.000 \leq p \leq 0.005$); however, there were no significant differences between B2 and B3 except for the run ($p=0.006$), catch ($p=0.000$), and throw ($p=0.012$). Age and sex did not play an important role in most of the skills, with the exception of boys outperforming girls striking ($p=0.009$), dribbling ($p=0.013$), and throwing ($p=0.000$), and older children outperforming younger children in dribbling ($p=0.002$). The significant impact of the severity of visual impairment is likely due to decreased experiences and opportunities for children with more severe visual impairments. In addition, it is likely that these reduced experiences explain the lack of age-related

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(continued)

differences in the CWVI. The large disparities in performance between children who are blind and their partially sighted peers give direction for instruction and future research. In addition, there is a critical need for intentional and specific instruction on motor skills at a younger age to enable CWVI to develop their gross motor skills.

Evaluation of stress and pain in young children with cerebral palsy during early developmental intervention programs: a descriptive study. Zhao X, Chen M, Du S, Li H, Li X. *Am J Phys Med Rehabil.* 2015;94(3):169-75; quiz 176-9.

Objective: The aim of this study was to use the Face, Legs, Activity, Cry, Consolability Scale; salivary cortisol levels; and withdrawal reflex thresholds to assess pain, stress, and pain sensitivity in young children with cerebral palsy during early developmental intervention programs. Design: A total of 40 children with cerebral palsy (age range, 1-4 yrs) participated in the early intervention programs, which included neurodevelopmental treatment, neuromuscular electrical stimulation, occupational therapy, head acupuncture, and Chinese traditional manipulation five times per week for 3 wks. The Face, Legs, Activity, Cry, Consolability Scale was applied during the course of each treatment, and salivary cortisol samples were obtained from each child 10 mins before and 10 mins after each treatment. Withdrawal reflex thresholds were assessed via mechanical stimulation of the foot with von Frey hairs. Results: All treatment programs caused some degree of pain. In descending order, the extents of the pain caused by each treatment were head acupuncture, neurodevelopmental treatment, neuromuscular electrical stimulation, Chinese traditional manipulation, and occupational therapy. There were statistically significant increases in salivary cortisol levels after the head acupuncture ($P < 0.001$), neurodevelopmental treatment ($P < 0.001$), neuromuscular electrical stimulation ($P < 0.001$), and Chinese traditional manipulation ($P < 0.001$) treatments. No significant changes were found in the withdrawal reflex thresholds during the study ($P > 0.05$). Conclusions: The results of this study demonstrate that early developmental intervention programs cause pain and stress in young children with cerebral palsy.

Evolution of lung function during the first year of life in newborn screened cystic fibrosis infants. Nguyen TT, Thia LP, Hoo AF, et al. *Thorax.* 2014;69(10):910-7.

Rationale: Newborn screening (NBS) for cystic fibrosis (CF) allows early intervention. Design of randomised controlled trials (RCT) is currently impeded by uncertainty regarding evolution of lung function, an important trial end point in such infants. Objective: To assess changes in pulmonary function during the first year of life in CF NBS infants. Methods: Observational longitudinal study. CF NBS infants and healthy controls were recruited between 2009 and 2011. Lung Clearance Index (LCI), plethysmographic lung volume (plethysmographic functional residual capacity (FRCpleth)) and forced expired volume ($FEV_{0.5}$) were measured at 3 months and 1 year of age. Main results: Paired measurements were obtained from 72 CF infants and 44 controls. At 3 months, CF infants had significantly worse lung function for all tests. $FEV_{0.5}$ improved significantly (0.59 (95% CI 0.18 to 0.99) z-scores; $p < 0.01$) in CF infants between 3 months and 1 year, and by 1 year, $FEV_{0.5}$ was only 0.52 (0.89 to 0.15) z-scores less than in controls. LCI and FRCpleth remained stable throughout the first year of life, being on average 0.8 z-scores higher in infants with CF. Pulmonary function at 1 year was predicted by that at 3 months. Among the 45 CF infants with entirely normal LCI and $FEV_{0.5}$ at 3 months, 80% remained so at 1 year, while 74% of those with early abnormalities remained abnormal at 1 year. Conclusions: This is the first study reporting improvements in $FEV_{0.5}$ over time in stable NBS CF infants treated with standard therapy. Milder changes in lung function occurred by 1 year than previously reported. Lung function at 3 months predicts a high-risk group, who should be considered for intensification of treatment and enrolment into RCTs.

Frequent behavioural challenges in children with fetal alcohol spectrum disorder: a needs-based assessment reported by caregivers and clinicians. Green CR, Roane J, Hewitt A, et al. *J Popul Ther Clin Pharmacol.* 2014;21(3):e405-20.

Objective: Despite substantial research characterizing the brain injury, a significant gap still exists in providing timely and effective care for children with Fetal Alcohol Spectrum Disorder (FASD). The objective of this study

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was to conduct a needs assessment that could help inform intervention programs and appropriate strategies to manage challenging behaviours targeted to families impacted by FASD. Methods: Sixty caregivers and 26 clinicians from across Canada completed a semi-structured telephone interview. Results: Caregivers reported that the most challenging behaviour categories were “Externalizing Behaviours”, “Cognitive Difficulties”, and “Social Difficulties/Maladjustment”, whereas the most successful parenting strategies were “Parental Reflection”, “Routine/Structure/Consistency”, and “Environmental Modification”. Clinicians reported that “Insufficient Support/Knowledge from Health and Social Professionals and Agencies” and “Behavioural Difficulties/Challenges” were the most common concerns from caregivers of children with FASD. Conclusions: The number and extent of challenges reported make it evident that there are many unmet needs that compromise the quality of life for these caregivers, their children, and their families. These data will be used to inform the development of an intervention program that will provide a family-centered approach to training, education, and support for children with FASD and their families.

Improving executive functioning in children with fetal alcohol spectrum disorders. Nash K, Stevens S, Greenbaum R, Weiner J, Koren G, Rovet J. *Child Neuropsychol.* 2015;21(2):191-209.

An extensive body of literature has documented executive function (EF) impairments in children with fetal alcohol spectrum disorders (FASD); however, few studies have aimed specifically at improving EF. One treatment program that shows promise for children with FASD is the Alert Program for Self-Regulation®, which is a 12-week treatment specifically designed to target self-regulation, a component of EF. The present study sought to examine if Alert would produce improvements in self-regulation that would generalize to other aspects of EF, behavior, and social skills in children with FASD. Twenty-five children aged 8-12 years diagnosed with an FASD were assigned in alternating sequence to either an immediate treatment (TXT) or a delayed treatment control (DTC) group. Both groups received a comprehensive evaluation of EF at baseline and upon completing therapy (TXT), or after a 12- to 14-week interval from baseline (DTC). Parents also completed questionnaires assessing EF and behavior at both time points. For the TXT group only, parent questionnaires were readministered at 6-month follow-up. At the 12-week follow-up, the TXT group displayed significant improvements in inhibitory control and social cognition. Parents of children in the TXT group reported improved behavioral and emotional regulation, as well as reduced externalizing behavior problems. These behavioral improvements along with further improved parent-rated inhibitory control was maintained at the 6-month follow-up. The EF disabilities in children with FASD can be remediated through a targeted treatment approach aimed at facilitating self-regulation skills.

Increasing incidence of the neonatal abstinence syndrome in U.S. neonatal ICUs. Tolia VN, Patrick SW, Bennett MM, et al. *N Engl J Med.* 2015;372(22):2118-26.

Objective: The incidence of the neonatal abstinence syndrome, a drug-withdrawal syndrome that most commonly occurs after in utero exposure to opioids, is known to have increased during the past decade. However, recent trends in the incidence of the syndrome and changes in demographic characteristics and hospital treatment of these infants have not been well characterized. Methods: Using multiple cross-sectional analyses and a deidentified data set, we analyzed data from infants with the neonatal abstinence syndrome from 2004 through 2013 in 299 neonatal intensive care units (NICUs) across the United States. We evaluated trends in incidence and health care utilization and changes in infant and maternal clinical characteristics. Results: Among 674,845 infants admitted to NICUs, we identified 10,327 with the neonatal abstinence syndrome. From 2004 through 2013, the rate of NICU admissions for the neonatal abstinence syndrome increased from 7 cases per 1000 admissions to 27 cases per 1000 admissions; the median length of stay increased from 13 days to 19 days ($P < 0.001$ for both trends). The total percentage of NICU days nationwide that were attributed to the neonatal abstinence syndrome increased from 0.6% to 4.0% ($P < 0.001$ for trend), with eight centers reporting that more than 20% of all NICU days were attributed to the care of these infants in 2013. Infants increasingly received pharmacotherapy (74% in 2004-2005 vs. 87% in 2012-2013, $P < 0.001$ for trend), with morphine the most commonly used drug (49% in 2004 vs. 72% in 2013, $P < 0.001$ for trend). Conclusions: From 2004 through 2013, the neonatal abstinence syndrome

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was responsible for a substantial and growing portion of resources dedicated to critically ill neonates in NICUs nationwide.

Management of the late preterm infant: not quite ready for prime time. Horgan MJ. *Pediatr Clin North Am.* 2015;62(2):439-51.

Preterm births account for 12.5% of all births in the United States. The preterm birth rate has increased by 33% over the last 2 decades. Late and premature infants do not develop the serious and chronic conditions of the extreme premature infant. However, there is growing evidence that these infants are not as healthy as previously thought and do in fact have an increase in morbidity and mortality compared with term infants. This article summarizes the epidemiology of late preterm infants and the associated morbidities associated with their prematurity.

Misdiagnosis and missed diagnoses in foster and adopted children with prenatal alcohol exposure.

Chasnoff IJ, Wells AM, King L. *Pediatrics.* 2015;135(2):264-70.

Objective: The purpose of this article is to assess the rate of misdiagnosis and missed diagnoses of fetal alcohol spectrum disorders (FASD) among a population of foster and adopted youth referred to a children's mental health center. Methods: Data were collected from a sample of 547 children who underwent a comprehensive multidisciplinary diagnostic evaluation. Utilizing current diagnostic criteria, children were diagnosed, as appropriate, with fetal alcohol syndrome, partial fetal alcohol syndrome, alcohol-related neurodevelopmental disorder, or alcohol-related birth defects. Changes in rates of alcohol exposure-related diagnoses and co-occurring mental health disorders pre- and post-assessment were analyzed by using McNemar's test for dependent proportions. Results: Among 156 children and adolescents who met criteria for a diagnosis within the fetal alcohol spectrum, 125 had never been diagnosed as affected by prenatal alcohol exposure, a missed diagnosis rate of 80.1%. Of the 31 who had been recognized before referral as affected by prenatal alcohol exposure, 10 children's FASD diagnoses were changed within the spectrum, representing a misdiagnosis rate of 6.4%. The remaining 21 (13.5%) children's diagnoses stayed the same. There also were significant changes in the rate of mental health diagnosis, and learning disorders, communication disorders, and intellectual disability, objective signs of neurocognitive damage, were not recognized in a significant number of children with FASD. Conclusions: Within this clinical sample, 86.5% of youth with FASD had never been previously diagnosed or had been misdiagnosed. These high rates of missed diagnoses and misdiagnosis have significant implications for intervention and therapeutic services.

The National Spina Bifida Patient Registry: profile of a large cohort of participants from the first 10 clinics.

Sawin KJ, Liu T, Ward E, et al. *J Pediatr.* 2015;166(2):444-50.e1.

Objective: To use data from the US National Spina Bifida Patient Registry (NSBPR) to describe variations in Contexts of Care, Processes of Care, and Health Outcomes among individuals with spina bifida (SB) receiving care in 10 clinics. Study design: Reported here are baseline cross-sectional data representing the first visit of 2172 participants from 10 specialized, multidisciplinary SB clinics participating in the NSBPR. We used descriptive statistics, the Fisher exact test, χ^2 test, and Wilcoxon rank-sum test to examine the data. Results: The mean age was 10.1 (SD 8.1) years with slightly more female subjects (52.5%). The majority was white (63.4%) and relied upon public insurance (53.5%). One-third had sacral lesions, 44.8% had mid-low lumbar lesions, and 24.9% had high lumbar and thoracic lesions. The most common surgery was ventricular shunt placement (65.7%). The most common bladder-management technique among those with bladder impairment was intermittent catheterization (69.0%). Almost 14% experienced a pressure ulcer in the last year. Of those ages 5 years or older with bowel or bladder impairments, almost 30% were continent of stool; a similar percentage was continent of urine. Most variables were associated with type of SB diagnosis. Conclusion: The NSBPR provides a cross section of a predominantly pediatric population of patients followed in specialized SB programs. There were wide variations in the variables studied and major differences in Context of Care, Processes of Care, and Health

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Outcomes by type of SB. Such wide variation and the differences by type of SB should be considered in future analyses of outcomes.

Neurodevelopmental outcomes of preterm singletons, twins, and higher-order gestations: a population-based cohort study. Gnanendran L, Bajuk B, Oei J, Lui K, Abdel-Latif ME.

Arch Dis Child Fetal Neonatal Ed. 2015;100(2):F106-14.

Objective: To study the neurodevelopmental outcomes of multiple (twins, triplets, quads) compared with singleton extremely preterm infants <29 weeks gestation. Design: Population-based retrospective cohort study. Setting: A network of 10 neonatal intensive care units in a geographically defined area of New South Wales and the Australian Capital territory. Patients: 1473 infants <29 weeks gestation born between 1 January 1998 and 31 December 2004. Intervention: At 2-3 years of corrected age, a neurodevelopmental assessment was conducted using either the Griffiths Mental Developmental Scales or the Bayley Scales of Infant Development II. Main outcome measure: Moderate-severe functional disability was defined as developmental delay (Griffiths Mental Developmental Scales General Quotient or Bayley Scales of Infant Development-II Mental Development Index >2 SDs below the mean), moderate cerebral palsy (unable to walk without aids), sensorineural or conductive deafness (requiring amplification) or bilateral blindness (visual acuity <6/60 in the better eye). Results: Of the 1081 singletons and 392 multiples followed-up, singletons demonstrated higher rates of systemic infections, steroid treatment for chronic lung disease and birth weight <10th percentile. Moderate-severe functional disability did not differ significantly between singletons and multiples (15.8% vs 17.6%, OR 1.14; 95% CI 0.84 to 1.54; p=0.464). Further subgroup analysis of twins, higher-order gestations, 1st-born multiples, 2nd or higher-born multiples, same and unlike gender multiples, did not demonstrate statistically higher rates of functional disability compared with singletons. Conclusions: Premature infants from multiple gestation pregnancies appear to have comparable neurodevelopmental outcomes to singletons.

Outcomes of cleft lip repair for internationally adopted children. Mulliken JB, Zhu DR, Sullivan SR.

Plast Reconstr Surg. 2015;135(5):1439-47.

Large numbers of international children with cleft lip-cleft palate are adopted in the United States; many underwent their first operation before arrival. Methods: The authors reviewed records of internationally adopted children with cleft lip-cleft palate treated by one surgeon over 25 years. This study focused on anatomical types, frequency/methods of repair, correction of unrepaired deformities, and secondary procedures in this country. Results: Of 105 internationally adopted children with cleft lip-cleft palate, 91 percent were Asian; 75 percent had labial or labiopalatal closure in their native country. Of repaired unilateral cleft lips, 43 percent required complete revision, 49 percent required minor revisions, and 8 percent required no revision. All repaired bilateral cleft lips were revised; 90 percent were complete and 10 percent were minor. "Delayed" primary nasal correction was always necessary in both unilateral and bilateral forms. Labial closure was scheduled first in young infants with an unrepaired unilateral defect, whereas palatal closure took precedence in older children. Premaxillary setback and palatoplasty were scheduled first in older children with unrepaired bilateral cleft lip-cleft palate. Of children arriving with repaired palate, 43 percent required a pharyngeal flap. Conclusions: Whenever cleft lip-cleft palate is repaired in another country, revision rates are high for both unilateral and bilateral types. Nevertheless, primary closure in the native country may increase the likelihood for adoption. Traditional surgical protocols often are altered for an adoptee with an unrepaired cleft lip-cleft palate, particularly the sequence of labial and palatal closure, depending on the child's age and type of defect.

Prevalence and characteristics of fetal alcohol spectrum disorders. May PA, Baete A, Russo J, et al.

Pediatrics. 2014;134(5):855-66.

Objectives: To determine the prevalence and characteristics of fetal alcohol spectrum disorders (FASD) among first grade students (6- to 7-year-olds) in a representative Midwestern US community. Methods: From a consented sample of 70.5% of all first graders enrolled in public and private schools, an oversample of small

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children (\leq 25th percentile on height, weight, and head circumference) and randomly selected control candidates were examined for physical growth, development, dysmorphology, cognition, and behavior. The children's mothers were interviewed for maternal risk. Results: Total dysmorphology scores differentiate significantly fetal alcohol syndrome (FAS) and partial FAS (PFAS) from one another and from unexposed controls. Alcohol-related neurodevelopmental disorder (ARND) is not as clearly differentiated from controls. Children who had FASD performed, on average, significantly worse on 7 cognitive and behavioral tests and measures. The most predictive maternal risk variables in this community are late recognition of pregnancy, quantity of alcoholic drinks consumed 3 months before pregnancy, and quantity of drinking reported for the index child's father. From the final multidisciplinary case findings, 3 techniques were used to estimate prevalence. FAS in this community likely ranges from 6 to 9 per 1000 children (midpoint, 7.5), PFAS from 11 to 17 per 1000 children (midpoint, 14), and the total rate of FASD is estimated at 24 to 48 per 1000 children, or 2.4% to 4.8% (midpoint, 3.6%). Conclusions: Children who have FASD are more prevalent among first graders in this Midwestern city than predicted by previous, popular estimates.

Risk for cerebral palsy in infants with total serum bilirubin levels at or above the exchange transfusion threshold: a population-based study. Wu YW, Kuzniewicz MW, Wickremasinghe AC, et al. *JAMA Pediatr.* 2015;169(3):239-46.

Exchange transfusion is recommended for newborns with total serum bilirubin (TSB) levels thought to place them at risk for cerebral palsy (CP). However, the excess risk for CP among these infants is unknown. Objective: To quantify the risks for CP and CP consistent with kernicterus that are associated with high TSB levels based on the 2004 American Academy of Pediatrics exchange transfusion threshold (ETT) guidelines. Design, setting, and participants: We enrolled 2 cohorts from a population of 525,409 infants in the Late Impact of Getting Hyperbilirubinemia or Phototherapy (LIGHT) birth cohort. Eligible infants were born at a gestational age of at least 35 weeks at 15 hospitals within the Kaiser Permanente Northern California integrated medical care delivery system from January 1, 1995, through December 31, 2011. Exposures: The exposed cohort included all 1833 infants with at least 1 TSB measurement at or above the ETT based on age at testing, gestational age, and results of direct antiglobulin testing. The unexposed cohort was a 20% random sample of 104 716 infants with TSB levels below the ETT. Main outcomes and measures: A pediatric neurologist blinded to the TSB levels reviewed medical records to determine the presence of CP, defined as a nonprogressive congenital motor dysfunction with hypertonia or dyskinesia. Cerebral palsy was judged to be consistent with kernicterus if magnetic resonance imaging of the brain revealed bilateral globus pallidus injury in the setting of dyskinetic CP. Results: We identified CP in 7 of 1833 exposed (0.4%) vs 86 of 104 716 unexposed (0.1%) infants (relative risk, 4.7 [95% CI, 2.2-10.0]). Absolute risk differences were 0.2% (95% CI, 0%-0.5%) for a TSB level 0 to 4.9 mg/dL above the ETT ($n = 1705$), 0.9% (95% CI, 0.1%-5.3%) for a TSB level 5.0 to 9.9 mg/dL above the ETT ($n = 102$), and 7.6% (95% CI, 2.1%-24.1%) for a TSB level 10 mg/dL or more above the ETT ($n = 26$). Cerebral palsy consistent with kernicterus occurred in 3 infants (incidence, 0.57 per 100,000 births); all 3 had TSB levels of more than 5.0 mg/dL above the ETT and at least 2 risk factors for neurotoxicity, such as prematurity, glucose-6-phosphate dehydrogenase deficiency, or hypoxia-ischemia. Conclusions and relevance: Cerebral palsy consistent with kernicterus occurred only in infants with 2 or more risk factors for neurotoxicity and TSB levels of more than 5 mg/dL above the ETT. Among infants with lower degrees of TSB level elevation, the excess risk for CP is minimal.

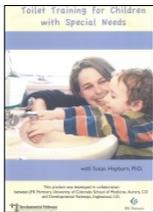
Sociodemographic attributes and spina bifida outcomes. Schechter MS, Liu T, Soe M, Swanson M, Ward E, Thibadeau J. *Pediatrics.* 2015;135(4):e957-64.

Background: A National Spina Bifida Patient Registry (NSBPR) was begun in 2009 to help understand the natural history of spina bifida (SB) and the effects of treatments provided by SB clinics. We used the NSBPR to explore the relationship of sociodemographic characteristics with SB outcomes. Methods: Using NSBPR data collected in 2009 to 2012, we examined the unadjusted association between demographic characteristics and 4 SB

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outcomes: bowel continence, bladder continence, mobility, and presence of pressure sores. We then developed multivariable logistic models to explore these relationships while controlling for SB clinic, SB type, and level of lesion. Results: Data were available on 2054 patients <22 years of age from 10 SB clinics. In the multivariable models, older age groups were more likely to have continence and pressure sores and less likely to be community ambulatory. Males and patients without private insurance were less likely to be continent and community ambulatory. Non-Hispanic blacks were less likely to be continent. Level of lesion was associated with all outcomes; SB type was associated with all but pressure sores; and all outcomes except community ambulation showed significant variation across clinic sites. Conclusions: Sociodemographic attributes are associated with SB outcomes. In particular, males, non-Hispanic blacks, and patients without private insurance have less favorable outcomes, and age has an impact as well. These characteristics need to be considered by clinicians who care for this patient population and factored into case-mix adjustment when evaluating variation in clinical and functional outcomes among different SB clinics.

New Addition – DVD



Toilet training for children with special needs. 120 min. (DD0705). 2009.

This DVD provides families of children with disabilities an overview of practical toilet training techniques. Vignettes take viewers through the core principles, routines, and habits that lead to successful toilet learning.

Early CHILDHOOD Report

Children With Special Needs & Their Families

VOLUME 26, ISSUE 7

JULY 2015

LEGAL SPOTLIGHT

YOU BE THE JUDGE

Does this parent's verbal opposition to special education require district to cease services? **Page 2**

WASHINGTON WATCH

Lawmakers reintroduce universal pre-K bill, hoping momentum is on their side; diversity key to preschool quality, experts say. **Page 7**

DECISIONS & GUIDANCE

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

Quick Tip

Fathers of children with disabilities want to be actively involved in their child's early learning experience, research shows. But many fathers don't know where or how to start.

To facilitate their participation:

- Encourage them to take an active role in center activities.
- Ask them about how they want to be involved.
- Get staff on board with your efforts.

Find additional tips on **page 9**.

COVER STORY

Statement on early childhood inclusion provokes alarm in certain quarters

Opportunities to serve young children with disabilities in an inclusive setting have not kept pace with the growth of the preschool sector.

That is according to a statement released May 18 by OSEP and the Health and Human Services Department. The message: Inclusion should be the default, and programs that are accustomed to sending children out for specialized services should find ways to provide those services on site.

While some organizations praise the document, others take exception to the way it describes specialized programs as "segregated" — "an ugly word that raises ugly visions of the past," according to the National Association for Private Special Education Centers.

Read comments on both sides of the issue and learn about one Washington, D.C., preschool where bringing special ed services in, rather than sending children out is already the norm. **Full story, pages 4 & 5.**

A growing sector

As preschool becomes more widespread, the issue of inclusion will become easier to solve, says the National Institute for Early Education Research. **See page 5.**

HIGHLIGHTS

Identify, intervene with children impacted by trauma

Understand the signs and symptoms of childhood trauma to better assist trauma-affected children and their families. Plus recognize when a child may need additional support such as therapy to address trauma. **Page 3**

Eye on Autism: Tailor intervention for girls with autism

Failing to address the unique needs of girls with autism early in their lives can set them up for later challenges. Follow these steps to help build their social-communication and self-advocacy skills. **Page 6**

Familiarize staff with simple methods to collect data

Share with staff these quick-hitting tips to select the most practical method of data collection available to better understand the nature of a student's challenging behavior. **Page 8**

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Infant Mental Health Journal – July/August 2015

Examining long-term effects of an infant mental health home-based early head start program on family strengths and resilience (pages 353–365). Lorraine Mckelvey, Rachel F. Schiffman, Holly E. Brophy-Herb, Erika London Bocknek, Hiram E. Fitzgerald, Thomas M. Reischl, Shelley Hawver and Mary Cunningham Deluca

Narrative and meta-analytic review of interventions aiming to improve maternal–child attachment security (pages 366–387). Nicole Letourneau, Panagiota Tryphonopoulos, Gerald Giesbrecht, Cindy-Lee Dennis, Sanjit Bhogal and Barry Watson

The working model of the child interview: stability of the disrupted classification in a community intervention sample (pages 388–398). Alison Niccols, Ainsley Smith and Diane Benoit

The prenatal parental reflective functioning questionnaire: exploring factor structure and construct validity of a new measure in the finn brain birth cohort pilot study (pages 399–414). Marjukka Pajulo, Mimmi Tolvanen, Linnea Karlsson, Elina Halme-Chowdhury, Camilla Öst, Patrick Luyten, Linda Mayes and Hasse Karlsson

Maternal mental health moderates the relationship between oxytocin and interactive behavior (pages 415–426). Simcha Samuel, Barbara Hayton, Ian Gold, Nancy Feeley, C. Sue Carter and Phyllis Zelkowitz

Factors associated with indiscriminate friendliness in high-risk children (pages 427–445). Leighanne Love, Helen Minnis and Suzy O'connor

Baby empathy: infant distress and peer prosocial responses (pages 446–458). Mitzi-Jane E. Liddle, Ben S. Bradley and Andrew Mcgrath

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Inclusive Care and Education in Early Childhood Programs

ARTICLES

Future Topics. Topics in Early Childhood Special Education August 2015 35: 67.

Glen Dunlap. Note From the Editor. Topics in Early Childhood Special Education August 2015 35: 68.

Erin E. Barton and Barbara J. Smith. Advancing High-Quality Preschool Inclusion: A Discussion and Recommendations for the Field. Topics in Early Childhood Special Education August 2015 35: 69-78.

Frances Lai Mui Lee, Alexander Seeshing Yeung, Danielle Tracey, and Katrina Barker. Inclusion of Children With Special Needs in Early Childhood Education: What Teacher Characteristics Matter. Topics in Early Childhood Special Education August 2015 35: 79-88.

Soo Hoon Lee and Lay Wah Lee. Promoting Snack Time Interactions of Children With Autism in a Malaysian Preschool. Topics in Early Childhood Special Education August 2015 35: 89-101.

Kelly Whalon, Jose R. Martinez, Darbianne Shannon, Colleen Butcher, and Mary Frances Hanline. The Impact of Reading to Engage Children With Autism in Language and Learning (RECALL). Topics in Early Childhood Special Education August 2015 35: 102-115.

V. Mark Durand and Lauren Moskowitz. Functional Communication Training: Thirty Years of Treating Challenging Behavior. Topics in Early Childhood Special Education August 2015 35: 116-126.

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