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Medical Diagnosis and Special Populations (updated)

This month we are featuring resources on cerebral palsy, cleft palate, cystic fibrosis, seizure disorders, and spina bifida. We are also covering special populations such as infants who are premature, those who have visual impairments, multiple births, and children who have been affected by alcohol or drugs.

Check out the new additions to the collection on pages 22-23!

Medical Diagnosis and Special Populations – Selected Journal Articles

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

Association of spouse deployment on pregnancy outcomes in a U.S. military population. Tarney CM, Berry-Caban C, Jain RB, Kelly M, Sewell MF, Wilson KL. *Obstet Gynecol.* 2015;126(3):569-74.

Objective: To evaluate the association of spousal deployment during the antenatal period on maternal and neonatal outcomes and to estimate whether group prenatal care may be beneficial in reducing adverse outcomes when spouses are deployed. Methods: Primigravid women who delivered at Womack Army Medical Center, Fort Bragg, North Carolina, were prospectively enrolled and selected for participation on a random basis between January 2013 and January 2014. Women whose spouses were deployed to a combat zone during the entire pregnancy (deployed group) were compared with women whose spouses were not deployed during the pregnancy (nondeployed group). Pregnancy and neonatal outcomes were compared between groups. Results: Three hundred ninety-seven women were enrolled with 183 (46.1%) in the deployed group and 214 (53.9%) in the nondeployed group. Spouse deployment was associated with increased risk of preterm delivery (38 [20.8%] compared with 16 [7.5%], $P < .001$) and postpartum depression (30 [16.4%] compared with 13 [6.1%], $P = .001$) when compared with women in the nondeployed group. There were no differences in the

Incidence of preterm delivery and postpartum depression for women in the deployed group who participated in group prenatal care when compared with women participating in traditional care (preterm delivery 6 [14.6%] compared with 32 [22.5%], $P=.38$; postpartum depression 4 [9.8%] compared with 26 [18.3%], $P=.24$).

Conclusion: Women who have a spouse deployed during their pregnancy are at increased risk for preterm birth and postpartum depression. Larger studies are needed to evaluate whether spouse deployment during pregnancy has other perinatal effects and whether group prenatal care may have a positive effect on adverse perinatal outcomes in this population. Level of evidence: II.

Australian national birthweight percentiles by sex and gestational age for twins, 2001-2010. Li Z, Umstad MP, Hilder L, Xu F, Sullivan EA. *BMC Pediatr.* 2015;15:148.

Birthweight remains one of the strongest predictors of perinatal mortality and disability. Birthweight percentiles form a reference that allows the detection of neonates at higher risk of neonatal and postneonatal morbidity. The aim of the study is to present updated national birthweight percentiles by gestational age for male and female twins born in Australia. Methods: Population data were extracted from the Australian National Perinatal Data Collection for twins born in Australia between 2001 and 2010. A total of 43,833 women gave birth to 87,666 twins in Australia which were included in the study analysis. Implausible birthweights were excluded using Tukey's methodology based on the interquartile range. Univariate analysis was used to examine the birthweight percentiles for liveborn twins born between 20 and 42 weeks gestation. Results: Birthweight percentiles by gestational age were calculated for 85,925 live births (43,153 males and 42,706 females). Of these infants, 53.6% were born preterm (birth before 37 completed weeks of gestation) while 50.2% were low birthweight (<2500 g) and 8.7% were very low birthweight (<1500 g). The mean birthweight decreased from 2462 g in 2001 to 2440 g in 2010 for male twins, compared with 2485 g in 1991-94. For female twins, the mean birthweight decreased from 2375 g in 2001 to 2338 g in 2010, compared with 2382 g in 1991-94. Conclusions: The birthweight percentiles provide clinicians and researchers with up-to-date population norms of birthweight percentiles for twins in Australia.

Be vigilant for neonatal abstinence syndrome. Thompson J. *Practitioner.* 2015;259(1786):5.

Neonatal abstinence syndrome is a serious condition of neonates that have been exposed to psychoactive drugs in utero. Exposure to opioid substances is responsible for the majority of cases, and while use of illicit opioids and opioid substitute treatments in opioid dependence are associated with a high incidence of the condition, concerns have been raised about increasing use of prescribed opioid analgesia during pregnancy. While data show that the general use of opioid analgesics is increasing in a wide range of countries, specific data about use in pregnancy are available in Norway and the US where 6% and 14-22% of women respectively are reported to have filled at least one prescription for opioid analgesia while pregnant.

Birth prevalence of cerebral palsy: a population-based study. Van Naarden Braun K, Doernberg N, Schieve L, Christensen D, Goodman A, Yeargin-Allsopp M. *Pediatrics.* 2016;137(1). doi: 10.1542/peds.2015-2872. Epub 2015 Dec 9.

Objective: Population-based data in the United States on trends in cerebral palsy (CP) birth prevalence are limited. The objective of this study was to examine trends in the birth prevalence of congenital spastic CP by birth weight, gestational age, and race/ethnicity in a heterogeneous US metropolitan area. Methods: Children with CP were identified by a population-based surveillance system for developmental disabilities (DDs). Children with CP were included if they were born in metropolitan Atlanta, Georgia, from 1985 to 2002, resided there at age 8 years, and did not have a postneonatal etiology ($n = 766$). Birth weight, gestational age, and race/ethnicity subanalyses were restricted to children with spastic CP ($n = 640$). Trends were examined by CP subtype, gender, race/ethnicity, co-occurring DDs, birth weight, and gestational age. Results: Birth prevalence of spastic CP per 1000 1-year survivors was stable from 1985 to 2002 (1.9 in 1985 to 1.8 in 2002; 0.3% annual average prevalence; 95% confidence interval [CI] -1.1 to 1.8). Whereas no significant trends were observed by gender, subtype, birth weight, or gestational age overall, CP prevalence with co-occurring moderate to severe intellectual disability significantly decreased (-2.6% [95% CI -4.3 to -0.8]). Racial disparities persisted over time between non-Hispanic

black and non-Hispanic white children (prevalence ratio 1.8 [95% CI 1.5 to 2.1]). Different patterns emerged for non-Hispanic white and non-Hispanic black children by birth weight and gestational age. Conclusions: Given improvements in neonatal survival, evidence of stability of CP prevalence is encouraging. Yet lack of overall decreases supports continued monitoring of trends and increased research and prevention efforts. Racial/ethnic disparities, in particular, warrant further study.

Caregiver responses to early cleft palate care: a mixed method approach. Sischo L, Clouston SA, Phillips C, Broder HL. *Health Psychol.* 2016;35(5):474-82.

Objective: This study sought to understand caregivers' (CGs') responses to early cleft lip/palate care for their infants. Method: A prospective, mixed methods multicenter longitudinal study was conducted among CGs (N = 118) seeking treatment for their infants' cleft lip and palate or cleft lip only at 1 of 6 cleft treatment centers in the United States. Participants were in 1 of 2 treatment groups: traditional care only or nasoalveolar molding (NAM) plus traditional care. The CGs completed semistructured interviews and standardized questionnaires assessing psychosocial well-being and family impact at 3 time points: the beginning of treatment (~1 month of age), prelip surgery (~3-5 months of age), and postpalate surgery (~12-13 months of age). Multilevel modeling was used to longitudinally assess CGs' psychosocial outcomes. Results: Although the first year was demanding for all CGs, NAM onset and the child's lip surgery were particularly stressful times. CGs used optimism, problem-solving behavior, and social support to cope with this stress. Qualitatively, CGs' ability to balance cleft treatment demands with their psychosocial resources and coping strategies influenced family adaptation. Qualitative and quantitative results indicated CGs of NAM-treated infants experienced more rapid declines in anxiety and depressive symptoms and better coping skills over time than CGs whose infants had traditional care. Conclusion: CGs of NAM-treated infants experienced more positive psychosocial outcomes than CGs whose infants had traditional care. Results from the mixed model support the family adjustment and adaptation response model as used in pediatric chronic condition research.

Characterisation of CASPR2 deficiency disorder--a syndrome involving autism, epilepsy and language impairment. Rodenas-Cuadrado P, Pietrafusa N, Francavilla T, La Neve A, Striano P, Vernes SC. *BMC Med Genet.* 2016;17:8.

Background: Heterozygous mutations in CNTNAP2 have been identified in patients with a range of complex phenotypes including intellectual disability, autism and schizophrenia. However heterozygous CNTNAP2 mutations are also found in the normal population. Conversely, homozygous mutations are rare in patient populations and have not been found in any unaffected individuals. Case presentation: We describe a consanguineous family carrying a deletion in CNTNAP2 predicted to abolish function of its protein product, CASPR2. Homozygous family members display epilepsy, facial dysmorphism, severe intellectual disability and impaired language. We compared these patients with previously reported individuals carrying homozygous mutations in CNTNAP2 and identified a highly recognisable phenotype. Conclusions: We propose that CASPR2 loss produces a syndrome involving early-onset refractory epilepsy, intellectual disability, language impairment and autistic features that can be recognized as CASPR2 deficiency disorder. Further screening for homozygous patients meeting these criteria, together with detailed phenotypic and molecular investigations will be crucial for understanding the contribution of CNTNAP2 to normal and disrupted development.

The cleft team social worker. Kaye A, Lybrand S. *Soc Work Health Care.* 2016;55(4):280-95.

The birth of a child with significant medical problems poses challenges for most families. Congenital orofacial clefting is a common condition affecting families worldwide. Orofacial clefting requires long-term medical care and can affect multiple body systems. Having a child with a chronic medical condition such as cleft lip or palate creates many psychosocial ramifications for a family. This article describes the importance of medical social work involvement in the coordinated care for children with cleft lip and palate. Specific cases spanning prenatal care through adolescence are used to highlight the variety of complex psychosocial situations encountered in the multidisciplinary cleft team setting.

Comparison of black-white disparities in preterm birth between Canada and the United States. McKinnon B, Yang S, Kramer MS, Bushnik T, Sheppard AJ, Kaufman JS. *CMAJ*. 2016;188(1):E19-26.

Background: A higher risk of preterm birth among black women than among white women is well established in the United States. We compared differences in preterm birth between non-Hispanic black and white women in Canada and the US, hypothesizing that disparities would be less extreme in Canada given the different historical experiences of black populations and Canada's universal health care system. Methods: Using data on singleton live births in Canada and the US for 2004-2006, we estimated crude and adjusted risk ratios and risk differences in preterm birth (< 37 wk) and very preterm birth (< 32 wk) among non-Hispanic black versus non-Hispanic white women in each country. Adjusted models for the US were standardized to the covariate distribution of the Canadian cohort. Results: In Canada, 8.9% and 5.9% of infants born to black and white mothers, respectively, were preterm; the corresponding figures in the US were 12.7% and 8.0%. Crude risk ratios for preterm birth among black women relative to white women were 1.49 (95% confidence interval [CI] 1.32 to 1.66) in Canada and 1.57 (95% CI 1.56 to 1.58) in the US (p value for heterogeneity [pH] = 0.3). The crude risk differences for preterm birth were 2.94 (95% CI 1.91 to 3.96) in Canada and 4.63 (95% CI 4.56 to 4.70) in the US (pH = 0.003). Adjusted risk ratios for preterm birth (pH = 0.1) were slightly higher in Canada than in the US, whereas adjusted risk differences were similar in both countries. Similar patterns were observed for racial disparities in very preterm birth. Interpretation: Relative disparities in preterm birth and very preterm birth between non-Hispanic black and white women were similar in magnitude in Canada and the US. Absolute disparities were smaller in Canada, which reflects a lower overall risk of preterm birth in Canada than in the US in both black and white populations.

Expanding the frontiers of orientation and mobility for infants and toddlers in New Mexico and Utah.

Phangia Dewald H, Faris C, Borg K, et al. *J Vis Impair Blind*. 2015;109(6):502-50.

Early intervention services provide very young children, typically aged birth to 3 years, and their families "early and appropriate learning experiences to facilitate the child's learning and development" in their natural environment (Chen, 2014, p. 3). Teachers of students with visual impairments and certified orientation and mobility (O&M) specialists provide vision-related expertise to families and the early intervention team to address the vision needs of children. These services are integrated with other early intervention services as part of an individualized family service plan (IFSP). This collaboration enhances the quality of services and informs families and early intervention colleagues so they are better prepared to provide adequate recommendations and options for the transition into preschool of young children with visual impairments

Global birth prevalence of spina bifida by folic acid fortification status: a systematic review and meta-analysis. Atta CA, Fiest KM, Frolkis AD, et al. *Am J Public Health*. 2016;106(1):e24-34.

Background: Birth defects remain a significant source of worldwide morbidity and mortality. Strong scientific evidence shows that folic acid fortification of a region's food supply leads to a decrease in spina bifida (a birth defect of the spine). Still, many countries around the world have yet to approve mandatory fortification through government legislation. Objectives: We sought to perform a systematic review and meta-analysis of period prevalence of spina bifida by folic acid fortification status, geographic region, and study population. Search methods: An expert research librarian used terms related to neural tube defects and epidemiology from primary research from 1985 to 2010 to search in EMBASE and MEDLINE. We searched the reference lists of included articles and key review articles identified by experts. Selection criteria: Inclusion criteria included studies in English or French reporting on prevalence published between January 1985 and December 2010 that (1) were primary research, (2) were population-based, and (3) reported a point or period prevalence estimate of spina bifida (i.e., prevalence estimate with confidence intervals or case numerator and population denominator). Two independent reviewers screened titles and abstracts for eligible articles, then 2 authors screened full texts in duplicate for final inclusion. Disagreements were resolved through consensus or a third party. Data collection and analysis: We followed Preferred Reporting Items for Systematic Reviews and Meta-Analyses, or PRISMA, abstracting data related to case ascertainment, study population, folic acid fortification status, geographic region, and prevalence estimate independently and in duplicate. We extracted overall data and any subgroups reported by age, gender, time period, or type of spina bifida. We classified each period prevalence estimate as "mandatory" or "voluntary" folic acid fortification according to each country's folic acid fortification status at the time data were collected (as determined by a well-recognized fortification monitoring body, Food Fortification

Initiative). We determined study quality on the basis of sample representativeness, standardization of data collection and birth defect assessment, and statistical analyses. We analyzed study-level period prevalence estimates by using a random effects model (α level of < 0.05) for all meta-analyses. We stratified pooled period prevalence estimates by birth population, fortification status, and continent. Results: Of 4078 studies identified, we included 179 studies in the systematic review and 123 in a meta-analysis. In studies of live births (LBs) alone, period prevalences of spina bifida were (1) lower in geographical regions with mandatory (33.86 per 100,000 LBs) versus voluntary (48.35 per 100,000 LBs) folic acid fortification, and (2) lower in studies of LBs, stillbirths, and terminations of pregnancy in regions with mandatory (35.22 per 100,000 LBs) versus voluntary (52.29 per 100,000 LBs) fortification. In LBs, stillbirths, and terminations of pregnancy studies, the lowest pooled prevalence estimate was in North America (38.70 per 100,000). Case ascertainment, surveillance methods, and reporting varied across these population-based studies. Conclusions: Mandatory legislation enforcing folic acid fortification of the food supply lags behind the evidence, particularly in Asian and European countries. This extensive literature review shows that spina bifida is significantly more common in world regions without government legislation regulating full-coverage folic acid fortification of the food supply (i.e., Asia, Europe) and that mandatory folic acid fortification resulted in a lower prevalence of spina bifida regardless of the type of birth cohort. African data were scarce, but needed, as many African nations are beginning to adopt folic acid legislation.

Increasing self-regulation and classroom participation of a child who is Deafblind. Nelson C, Hyte HA, Greenfield R. *Am Ann Deaf.* 2016;160(5):496-509.

Self-regulation has been identified as essential to school success. However, for a variety of reasons, its development may be compromised in children and youth who are Deafblind. A single-case multiple-baseline study of a child who was Deafblind examined the effects of three groups of evidence-based interventions on variables thought to be associated with self-regulation. The dependent variables were (a) frequency and duration of behaviors thought to indicate dysregulation, (b) active participation in school activities, and (c) time from onset of behaviors indicating dysregulation until achievement of a calm, regulated state. The interventions, which included provision of meaningful, enjoyable, and interactive activities, anticipatory strategies, and calming strategies, significantly influenced the dependent variables and are described in detail.

Lung clearance index and structural lung disease on computed tomography in early cystic fibrosis.

Ramsey KA, Rosenow T, Turkovic L, et al. *Am J Respir Crit Care Med.* 2016;193(1):60-7.

Rationale: The lung clearance index is a measure of ventilation distribution derived from the multiple-breath washout technique. It has been suggested as a surrogate for chest computed tomography to detect structural lung abnormalities in individuals with cystic fibrosis (CF); however, the associations between lung clearance index and early structural lung disease are unclear. Objectives: We assessed the ability of the lung clearance index to reflect structural lung disease on the basis of chest computed tomography across the entire pediatric age range. Methods: Lung clearance index was assessed in 42 infants (ages 0-2 yr), 39 preschool children (ages 3-6 yr), and 38 school-age children (7-16 yr) with CF before chest computed tomography and in 72 healthy control subjects. Scans were evaluated for CF-related structural lung disease using the Perth-Rotterdam Annotated Grid Morphometric Analysis for Cystic Fibrosis quantitative outcome measure. Measurements and main results: In infants with CF, lung clearance index is insensitive to structural disease ($\kappa = -0.03$ [95% confidence interval, -0.05 to 0.16]). In preschool children with CF, lung clearance index correlates with total disease extent. In school-age children, lung clearance index correlates with extent of total disease, bronchiectasis, and air trapping. In preschool and school-age children, lung clearance index has a good positive predictive value (83-86%) but a poor negative predictive value (50-55%) to detect the presence of bronchiectasis. Conclusions: These data suggest that lung clearance index may be a useful surveillance tool to monitor structural lung disease in preschool and school-age children with CF. However, lung clearance index cannot replace chest computed tomography to screen for bronchiectasis in this population.

Neuroimaging effects of prenatal alcohol exposure on the developing human brain: a magnetic resonance imaging review. Donald KA, Eastman E, Howells FM, et al. *Acta Neuropsychiatr.* 2015;27(5):251-69.

Objective: This paper reviews the magnetic resonance imaging (MRI) literature on the effects of prenatal alcohol exposure on the developing human brain. Method: A literature search was conducted through the following

databases: PubMed, PsycINFO and Google Scholar. Combinations of the following search terms and keywords were used to identify relevant studies: 'alcohol', 'fetal alcohol spectrum disorders', 'fetal alcohol syndrome', 'FAS', 'FASD', 'MRI', 'DTI', 'MRS', 'neuroimaging', 'children' and 'infants'. Results: A total of 64 relevant articles were identified across all modalities. Overall, studies reported smaller total brain volume as well as smaller volume of both the white and grey matter in specific cortical regions. The most consistently reported structural MRI findings were alterations in the shape and volume of the corpus callosum, as well as smaller volume in the basal ganglia and hippocampi. The most consistent finding from diffusion tensor imaging studies was lower fractional anisotropy in the corpus callosum. Proton magnetic resonance spectroscopy studies are few to date, but showed altered neurometabolic profiles in the frontal and parietal cortex, thalamus and dentate nuclei. Resting-state functional MRI studies reported reduced functional connectivity between cortical and deep grey matter structures. Discussion: There is a critical gap in the literature of MRI studies in alcohol-exposed children under 5 years of age across all MRI modalities. The dynamic nature of brain maturation and appreciation of the effects of alcohol exposure on the developing trajectory of the structural and functional network argue for the prioritisation of studies that include a longitudinal approach to understanding this spectrum of effects and potential therapeutic time points.

Opioids in pregnancy. Volkow ND. *BMJ*. 2016 January 12;352:i19.

The steep increase in the number of opioid prescriptions dispensed in the United States has been associated with a parallel rise in their misuse, fatal overdoses, and heroin use. More recently, attention has been focused on the large increase in the number of infants born with neonatal abstinence syndrome (NAS). In the US, between 2000 and 2009, the incidence of NAS increased from 1.20 to 3.39 per 1000 live births,¹ and between 2004 and 2013 the total percentage of days spent in intensive care because of NAS increased from 0.6% to 4.0%.²

Predictors of independent walking in young children with cerebral palsy. Begnoche DM, Chiarello LA, Palisano RJ, Gracely EJ, McCoy SW, Orlin MN. *Phys Ther*. 2016;96(2):183-92.

Background: The attainment of walking is a focus of physical therapy intervention in children with cerebral palsy (CP) and may affect their independence in mobility and participation in daily activities. However, knowledge of determinants of independent walking to guide physical therapists' decision making is lacking. Objective: The aim of this study was to identify child factors (postural control, reciprocal lower limb movement, functional strength, and motivation) and family factors (family support to child and support to family) that predict independent walking 1 year later in young children with CP at Gross Motor Function Classification System (GMFCS) levels II and III. Design: A secondary data analysis of an observational cohort study was performed. Methods: Participants were 80 children with CP, 2 through 6 years of age. Child factors were measured 1 year prior to the walking outcome. Parent-reported items representing family factors were collected 7 months after study onset. The predictive model was analyzed using backward stepwise logistic regression. Results: A measure of functional strength and dynamic postural control in a sit-to-stand activity was the only significant predictor of taking ≥ 3 steps independently. The positive likelihood ratio for predicting a "walker" was 3.26, and the negative likelihood ratio was 0.74. The model correctly identified a walker or "nonwalker" 75% of the time. Limitations: Prediction of walking ability was limited by the lack of specificity of child and family characteristics not prospectively selected and measurement of postural control, reciprocal lower limb movement, and functional strength 1 year prior to the walking outcome. Conclusions: The ability to transfer from sitting to standing and from standing to sitting predicted independent walking in young children with CP. Prospective longitudinal studies are recommended to determine indicators of readiness for independent walking.

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).

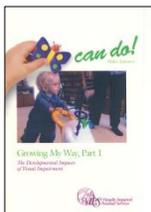
It is tempting for parents to do too much for children who are blind. This DVD encourages parents to teach their children how to feed, dress, and care for themselves.

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.



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.

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 alcoholico fetal. 16 min. 2010. (DV0505).

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

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

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

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

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

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

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

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

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

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.

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

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

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

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

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

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

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

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

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

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

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

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

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

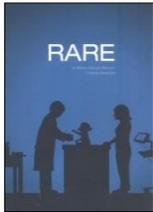
There are over 42 million people worldwide who have total or partial loss of vision and are defined as being blind. This program explains how the human eye works, examines some of the major causes of blindness, and shows how medical science and technology are helping people with impaired vision. Surgical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

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

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

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

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

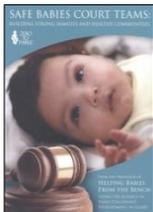


Rare. 56 min. 2012. (DD0659).

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



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.

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 preemie. Jeff Stimpson, 2004. (242.1 S859a 2004 ECI).

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

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

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

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

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

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

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

Children 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.

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.

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

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

Coming home from the NICU: a guide for supporting families in early infant care and development.

Kathleen A. VandenBerg, 2013. (WS 410 V227 2013 ECI).

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

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

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

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

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

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. J. Stuart Elborn, 2014.

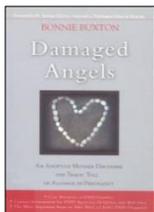
Cystic fibrosis (CF) is one of the most common hereditary diseases. The discovery of the cystic fibrosis transmembrane conductance regulator (CFTR) gene 25 years ago set the stage for unraveling the pathogenesis of CF lung disease, continuous refinement of symptomatic treatments and the development of mutation-specific therapies, which are now becoming available for a subgroup of patients. This ERS Monograph provides information on all aspects of CF lung disease, from infancy to adulthood, including details of the disease process, improvements in early diagnosis and monitoring, therapeutic approaches, and patient care. It discusses the steps that will be required for further improvement of the life expectancy and quality of life of CF patients. This title is available through Ebsco eBooks. Contact the library at (512) 776-7559 for more information.

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. (WI 820 T482c 2008 RHB).

Cystic fibrosis affects the respiratory and digestive systems. This book explores all aspects of the disease from basic clinical information to conventional treatments. Patient experiences and answers to frequently asked questions are included.



Damaged angels: an adoptive mother discovers the tragic toll of alcohol in pregnancy.

Bonnie Buxton, 2005. (WQ 211 B991d 2005 ECI).

Part heartfelt memoir, part practical guide, this book recounts the author's struggles to raise an adopted daughter whom she did not realize was afflicted with fetal alcohol syndrome. The book offers guidance to parents who have children with fetal alcohol syndrome.

Double duty: the parents' guide to raising twins, from pregnancy through the school years.

Christina Baglivi Tinglof, 2009. (515 T588 2009 ECI).

This book covers practical questions parents may have when they discover they are going to have twins. It covers pregnancy, various stages throughout infancy, toddlers, and school age concerns.

Early intervention with multi-risk families: an integrative approach. Sarah Landy, 2006. (271 L264 2006 ECI).

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

Epilepsy. 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.

Epilepsy: 199 answers: a doctor responds to his patients' questions, 3rd ed. Andrew N. Wilner, 2008. (WL 385 W744 2008 RHB).

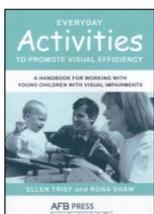
Epilepsy is a brain disorder characterized by recurrent seizures. The experience of epilepsy is different for each person who has it. This book addresses the needs of everyone with the disorder, whether their epilepsy is mild or severe.

Epilepsy: patient and family guide. Orrin Devinsky, 2008. (203.11 D496 2008 RHB).

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

Epilepsy in children and adolescents. James Wheless, 2013.

This book provides 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. (WW 276 T825e 2009 ECI).

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

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

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

Fetal Alcohol 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 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. (WS 410 W855F 2012 ECI).

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

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. (WB 320.2 H236 2009 RHB).

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

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

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

Medical and psychosocial aspect of chronic illness and disability. Donna R. Falvo, 2009. (WT 500 F197m 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. (WT 500 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. (WS 107 M489 2006 RHB).

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

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

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

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

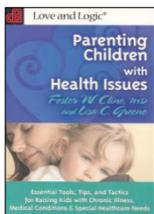
This book begins by discussing the development of an infant and child's brain. Exposure to drugs or alcohol, as well as abuse or neglect, affect the child's developing nervous system. The author outlines a problem-solving approach to behavior management of these "at risk" children. He provides policy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

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

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

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

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



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

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

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

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

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

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

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

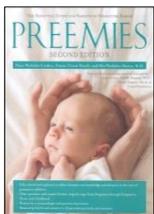
Born in 1972, twins who share this life-threatening disease give an honest portrayal of their struggle to live normal lives, their interdependence, day-to-day health care, the impact of chronic illness on marriage and family, and the importance of a support network to continuing survival. The library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

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

This book reveals the world of premie 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 premie 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 premie triplets, she also understands the heartbreak and challenges of prematurity. This book is a comprehensive resource, covering topics from delivery, hospitalization, and premie 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.

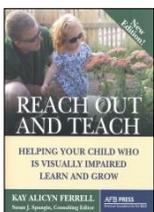


Preemies: the essential guide for parents of premature babies, 2nd ed. Dana Wechsler Linden, 2010. (WS 410 L744p 2010 ECI).

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

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

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



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

This book presents research on how visually impaired children learn and develop at different ages and in the various developmental domains: sensory development, communication, movement, manipulation, and comprehension. It provides a guide to teaching young children with visual impairments important life skills and preparing them to enter school ready to learn with their peers.

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. (WS 107.5 R5 R311s 2007 ECI).

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

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

In order to promote their growth, development, and ability to communicate, young children who are visually impaired and have additional disabilities need to learn to use their sense of touch effectively and develop skills that are not necessarily based on the use of vision. This manual provides essential information about alternative communication and countless practical strategies and insights to create effective solutions for working with children. Teachers, early interventionists, and parents will find valuable techniques 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. (WS 105.5 S282t 2009 ECI).

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

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

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

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

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

Your preemie 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. (WB 320 S477 2002 ECI).

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

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

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

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

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

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

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

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

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



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>
- 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>

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

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

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

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

Twins, Triplets, Multiple Births – MedlinePlus: <http://www.nlm.nih.gov/medlineplus/twinstripletsmultiplebirths.html>

Visual impairments – FamilyConnect for Parents of Children with Visual Impairments: This website has articles in both English and Spanish: <http://www.familyconnect.org/parentsitewhome.asp>

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

Visual Impairments – Parental Advice from the Texas School for the Blind and Visually Impaired:

<http://www.tsbvi.edu/component/content/article/7-instructional-resources/3717-dosanddnts>

New Additions – DVD

Parenting: emotional health and positive discipline: birth to 6 months. 9 min. 2016. (DD0736).

A young mom gives advice on how to help a baby feel loved, how to comfort a crying baby, and how to stay calm while caring for a baby. Self-calming techniques are detailed along with reasons for not spanking children.

Parenting: emotional health and positive discipline: 7-12 months. 10 min. 2016. (DD0737).

A young mom explains why feeling loved is good for a baby, age-appropriate behavior for babies, and how to use positive discipline and positive language as an alternative to angry language and spanking.

Parenting: fatherhood: birth to 6 months. 11 min. 2016. (DD0734).

Viewers learn what babies need from fathers, how fathers can deal with the stress, and how fathers can have healthy relationships with their children and the mothers of their children.

Parenting: fatherhood: 7 to 12 months. 11 min. 2016 (DD0735).

Fathers learn how to spend time with babies, how to make their own lives less stressful, and the importance of healthy communication with Moms.

Parenting: health and safety: birth to 6 months. 12 min. 2016. (DD738).

A young mom explains how to keep a baby healthy through well-baby visits, vaccines, and hygiene. She also gives advice on when to call the doctor or go to the ER. She also describes the best ways to keep a baby safe by having a safe crib, safe car seat, and a safe child-proofed home. Parents learn more about SIDS.

Parenting: health and safety: 7 to 12 months. 11 min. 2016. (DD0739).

Parents of older babies are given advice about keeping their young children healthy and preventing accidents in the home and outside of the home. They are urged to use car seats and keep choking hazards and poisons out of the reach of children.

Parenting: play and milestones: birth to 6 months. 10 min. 2016. (DD0740).

Babies are shown playing as they reach the typical milestones. Babies spend their first two months gazing, hearing, interacting, playing on their tummies, lifting their heads, and smiling. By their third and fourth months typical infants spend their times cooing, gurgling, reaching, and smiling. By their fifth and sixth months babies are able to recognize their caregivers, sit with support, hold onto objects, push up their forearms, and roll over. Parents are cautioned about limiting time in car seats and in front of TV and electronic device screens.

Parenting: play and milestones: 7 to 12 months. 11 min. 2016. (DD0741).

Parents receive advice on nurturing babies milestones through play. By their seventh and eighth months babies are usually sitting up, rolling over, babbling, and gaining some eye-hand coordination. By months nine and ten they are starting to display memory and object permanence, stranger anxiety, and use of the pincer grasp. They are beginning to explore and crawl. The eleventh and twelfth months mean babies are starting to wave, clap, say their first words, pull up to a stand, cruise, take their first steps, and crawl up stairs.

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Jennifer R. Ledford, Erin E. Barton, Jessica K. Hardy, Katie Elam, Jordan Seabolt, Meredith Shanks, M. L. Hemmeter, and Ann Kaiser

What Equivocal Data From Single Case Comparison Studies Reveal About Evidence-Based Practices in Early Childhood Special Education

Journal of Early Intervention June 2016 38: 79-91

Katie C. Hart, Paulo A. Graziano, Kristine M. Kent, Aparajita Kuriyan, Alexis Garcia, Madison Rodriguez, and William E. Pelham, Jr.

Early Intervention for Children With Behavior Problems in Summer Settings: Results From a Pilot Evaluation in Head Start Preschools

Journal of Early Intervention June 2016 38: 92-117

Michelle MacRoy-Higgins, Valerie L. Shafer, Katlin J. Fahey, and Elyssa R. Kaden

Vocabulary of Toddlers Who Are Late Talkers

Journal of Early Intervention June 2016 38: 118-129

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Zero to Three – May 2016

Chronic Stress and Complex Trauma

“If You Brave Enough to Live it, The Least I Can Do is Listen”: Overcoming the Consequences of Complex Trauma

Lucy Hudson, Sarah Beilke, and Michele Many

Trauma and Boys, Birth to 3: What’s Different?

Paula Golding and Hiram E. Fitzgerald

Making Sense of the Past Creates Space for the Baby: Perinatal Child-Parent Psychotherapy for Pregnant Women with Childhood Trauma

Angela J. Narayan, Griselda Oliver Bucio, Luisa M. Rivera, and Alicia F. Lieberman

The Trauma of Hurricane Katrina: Developmental Impact on Young Children

Joy D. Osofsky, Tonya Cross Hansel, Michelle B. Moore, Kristin L. Callahan Jennifer B. Hughes, and Amy B. Dickinson

A Framework for Trauma-Sensitive Schools: Infusing Trauma-Informed Practices Into Early Childhood Education Systems

Neena McConnico, Renee Boynton-Jarrett, Courtney Bailey, and Meghna Nandi

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This Issue and Why it Matters

Stefanie Powers

Jargon Buster: A Glossary of Selected Terms