Greetings to all SODBP members. I enjoyed meeting members at the 2012 AAP National Conference and Exhibition (NCE). Under the program leadership of Bob Voigt we had a very successful section program on the developmental and behavioral consequences of exposure to trauma during childhood. Immediately after the section program, at lunchtime, we had our section business meeting and round table discussions which provided a tremendous opportunity for members to meet with each other and SODBP leaders for informal discussions about topics of mutual interest. For the 2013 AAP NCE we are collaborating with the Council on Children with Disabilities (COCWD) for a program on mental health and psychopharmacology in children with disabilities. We hope many of you will plan to attend that program and our section business meeting and round table discussions.

Please join me in welcoming our newest executive committee member, Dr. Nerissa Bauer, from Riley Hospital for Children in Indianapolis. In addition, I would like to thank Dr. Jill Fussell for 6 years of energetic service to the section and Drs. Franklin Trimm, Elizabeth Allen, Beth Ellen Davis, Quentin Humberd, Robyn Mehlenbeck, and Preventive Services.

Notes from the Chair
Nathan J. Blum, MD, FAAP
Philadelphia, PA

Please visit Our Section Web site...
Caring for the Child with Down Syndrome in the Medical Home
Intellectual Disability: New Name, Forgotten Disability
ASHA Connections: Enhancing the Efficacy of Hearing Screening Programs
An Introduction to Treatment Manuals for Behavioral Interventions
Children’s Mental Health and Medical Home: An Update from the Mental Health Leadership Work Group
International Developmental-Behavioral Pediatrics: Autism Care Nepal
My Journey to Developmental-Behavioral Pediatrics
AAP Department of Federal Affairs Update
Coding Conundrums
Selected SODBP NCE Sponsored Sessions

Table of Contents
Notes from the Chair .............................................................. 1-2
Please Visit Our Section Web site........................................ 2
Caring for the Child with Down Syndrome in the Medical Home .......... 3-4
Intellectual Disability: New Name, Forgotten Disability ............... 5-6
ASHA Connections: Enhancing the Efficacy of Hearing Screening Programs .......... 6-7
An Introduction to Treatment Manuals for Behavioral Interventions .......... 8-11
Children’s Mental Health and Medical Home:
An Update from the Mental Health Leadership Work Group ............. 11
International Developmental-Behavioral Pediatrics:
Autism Care Nepal .......................................................... 12-13
My Journey to Developmental-Behavioral Pediatrics .................. 14-15
AAP Department of Federal Affairs Update ......................... 15-17
Coding Conundrums .................................................. 18-19
Selected SODBP NCE Sponsored Sessions ........................................ 20

continued on page 2

Statements and opinions expressed are those of the authors and not necessarily those of the American Academy of Pediatrics.
and Carol Weitzman for the very well received 2012 DB:PREP conference. Dr. Fussell will not get much of a break as she will be joining the DB:PREP planning committee for the 2014 course, along with Drs. Karen Miller, James Van Decar and Beth Wildman.

Since the last newsletter we have had our first competition to offer scholarships for SODBP members to attend advocacy trainings conducted by the AAP Department of Federal Affairs (DOFA). I am pleased to announce that we awarded 4 scholarships: Dr. Margaret Ellis McKenna from Savannah, GA; Dr. Marie Ann Clark from New York City, NY; Dr. Eric Joel Weil from Baton Rouge, LA; and Dr. Laura A. Jana from Omaha, NE. Congratulations to the recipients who each had an exciting and unique interest in advocacy. In the next few newsletters you will be hearing from these advocacy scholarship recipients about their experiences in attending these trainings. We are in discussions with the DOFA about the possibility of conducting a developmental-behavioral pediatrics specific advocacy training so stay tuned to hear about more opportunities for advocacy training.

The SODBP is enhanced by its membership. Please encourage your colleagues, fellows, and residents interested in developmental and behavioral challenges for children to join the section. A strength of our field is our interdisciplinary collaborations. Please promote affiliate membership to those that you work with in related fields such as nursing, occupational therapy, physical therapy, psychology, psychiatry, speech language pathology, and social work.

In addition to the number of members, the vitality of the SODBP is dependent on the active involvement of our members and the SODBP continues to work on ways to engage members in our activities. In addition to the round table discussions and advocacy trainings discussed above, we have an excellent discussion board led by Dr. Damon Korb. Since the last newsletter the number of members who have signed up for the discussion board has more than doubled to over 200. Information on how to sign up for the discussion board is available on the SODBP Web site, DBPeds.org (https://www2.aap.org/sections/dbpeds/membersonly.asp). In addition Dr. Stephen Contompasis is working to update and enhance the offerings on our Web site. Please let us know the things that you would like to see on the Web site to help your practice, as well as your patients and their families.

If you have other ideas about activities or projects that would be of benefit or about SODBP activities in which you would like to participate, we want to hear from you. So send me an email, introduce yourself at meetings, and let us know what excites you about the field.

Best Regards,

Nathan Blum, MD
blum@email.chop.edu

Please Visit Our Section Web site

Dbpeds.org, sponsored by the AAP Section on Developmental and Behavioral Pediatrics (SODBP), is aimed at professionals interested in child development and behavior, especially in the clinical setting. Explore the pages to learn about practice management resources; upcoming educational events; relevant policy statements; links to more information on developmental issues; and much, much more. Please bookmark the page and visit us often to stay up to date on developmental and behavioral resources and events.

Recent highlights include:

- Access to our SODBP Discussion Board where members can connect on questions and discussions related to ADHD, developmental delays, screening, and more.
- A New Page on Transitions and Transition Planning
- New Autism Resources
- Links to the recent AAP Policy Statement: Collaborative Role of the Pediatrician in the Diagnosis and Management of Bipolar Disorder in Adolescents
Caring for the Child with Down Syndrome in the Medical Home

By Ellen Elias, MD, FAAP

Down syndrome (DS) is the most common chromosome abnormality seen in humans; with an incidence of about 1:770 live births. Pediatricians commonly care for patients with DS, both as primary care providers and as specialists. They are frequently called to see newborns suspected of having DS, and with the increase in prenatal testing, may even be asked to counsel families when the diagnosis is made prior to delivery. The patient with DS displays a well characterized constellation of medical, developmental, and behavioral characteristics. This article reviews updated information regarding patients with DS, including recent recommendations from the AAP regarding best practices for caring for patients with DS in the medical home.

Down syndrome is caused by full Trisomy 21 in most (95%) cases. This results from an error in nondisjunction, which has a greater chance of occurring with advancing maternal age. Testing of parental chromosomes is not indicated when the child has full Tri 21. However, because some families carry an increased risk of errors of nondisjunction, there is a recurrence risk in future pregnancies, which is considered to be 1:100 plus whatever the maternal age-related risk might be. In about 2-3% of cases, DS may arise from an unbalanced translocation, where extra genetic material from Chromosome 21 is attached to another chromosome. In this case, it is important to test the parents to see if one of them carries this translocation in balanced form, as this would significantly increase the recurrence risk in future pregnancies. In about 1-2% of cases of DS, the extra Chromosome 21 is seen in some but not all of the cells counted: this is called mosaicism. Patients with Mosaic Tri 21 often display a milder phenotype than full Tri 21. Referral for formal genetic counseling is often helpful to discuss the recurrence risks in each individual family.

Prenatal screening for DS is often offered to pregnant women. First trimester screening consists of an ultrasound to assess the prominence of nuchal folds, coupled with 2 blood tests, b-HCG (human chorionic gonadotropin) and PAPP-A (pregnancy associated plasma protein A); This screening test will pick up 82-87% of fetuses with DS. The second trimester “quad” screen consists of b-HCG, estriol, AFP (alpha-fetoprotein) and inhibitin levels, and has a detection rate of about 80%. Combined, the 2 tests can detect about 95% of fetuses with DS. More invasive prenatal testing includes either chorionic villus sampling at about 12 weeks gestation, or amniocentesis at 15-16 weeks gestation. Families may contact their pediatrician if prenatal screening indicates that the fetus has DS, and it is important to provide the families with an objective picture of what this might mean for the child.

Patients with DS display characteristic physical features. Growth parameters are usually normal. Facial features include mid-face hypoplasia, and low-set dysplastic pinnae. Epicanthal folds are often present and the palpebral tissues are often up-slanting*. Other prominent features include short fingers with incurving of the 5th finger, transverse palmar creases*, and an increased space between the first and second toes. Hypotonia is a common feature on neurological exam. (* It is recommended that descriptive terms be used rather than pejorative terms such as ante-mongoloid slant or simian creases.)

If DS features are present, it is helpful to arrange to speak with the parents in a private room once the mother has recovered from the delivery. First, complement the parents on their beautiful newborn, and then let them know that you suspect the diagnosis of Trisomy 21. Make arrangements to confirm the diagnosis with blood testing (both FISH which comes back quickly, and karyotype which may take about a week, but is the gold standard confirmatory test to send). Arrange to meet with the parents to give them the results of the testing and give them further information about the diagnosis of DS at that time. Refer to the local parent support group.

Babies with DS may have birth defects which require immediate attention:

• The most common birth defect is a cardiac anomaly (Atrioventricular canal is common) and occurs in up to 50% of patients. Because of this, an echocardiogram is recommended soon after birth.

• The second most common anomaly is atresia along the GI tract, with the 2 most common sites being the esophagus and the duodenum. This generally requires immediate surgical intervention.

There are a number of medical issues which are common in the patient with DS:

• Ophthalmologic issues are common and include strabismus, nystagmus, myopia, cataracts and narrow tear ducts which become clogged. An ophthalmological evaluation is recommended within the first year of life and annually thereafter.

• Midface hypoplasia is associated with anatomic consequences including dysfunctional eustachian tubes which lead to chronic

continued on page 4
serous otitis and conductive hearing loss, and a small posterior pharynx so that even modest enlargement of the tonsils and adenoids can lead to obstructive sleep apnea. Hearing evaluation is recommended within the first year and annually thereafter, and ENT consultation is often required.

- Autoimmune disorders are seen with increased frequency in patients with DS and include hypothyroidism, celiac disease, Type 1 DM, and alopecia areata. Testing for thyroid disease with T4 and TSH is recommended at various intervals throughout life, and screening for celiac disease with TTG and IgA is recommended in early childhood.

- Hematologic disorders are more common and include myeloproliferative disorder of the newborn, leukemia, and iron deficiency anemia. Because of this, newborn CBC and annual CBC’s and ferritin levels are recommended.

- Subluxation of C1 on C2 is a neurosurgical/orthopedic emergency. X-rays to screen for this are routinely done first at age 3 years, and DTR’s should be carefully documented at each visit. Development of neck pain with change in gait and DTR’s should prompt immediate referral to ortho/neurosurgery with an MRI.

Developmentally, patients with DS generally display intellectual disabilities in the mild to moderate range, with development progressing at about $\frac{1}{2}$-$\frac{2}{3}$ the normal rate. Hypotonia is seen along a spectrum, and affects gross motor development. Hypotonia of the orofacial muscles, combined with a normal-sized tongue in too small a space, often contributes to disarticulation, making speech problems more severe than cognitive level might indicate. Teaching of sign language is strongly recommended in young patients with DS, to help overcome the expressive language disability.

Autism is seen in a very high incidence in DS, approximately 1:10 patients. Patients with the dual diagnosis of both DS and autism have a different developmental phenotype than children with DS alone. The cognitive disabilities are often more marked, and expressive language may be severely impaired. There is not a clear explanation at this time for why autism is seen so frequently in patients with DS. Other psychiatric disorders are common in DS, and include depression and early onset Alzheimer’s disease, which is associated with significant loss of functionality.

In summary, DS is a very common diagnosis, and pediatricians, whether primary care or specialists, are certain to care for patients with DS in their practices. The typical patient with DS displays intellectual disabilities in the mild/moderate range, but with excellent care of anatomic and medical issues, and good developmental services, a patient’s developmental prognosis is quite good. There is a high incidence of the dual diagnosis of DS plus autism, with a very different and more severely impaired developmental course. Recently updated recommendations for the care of the patient with DS have been published, and should be helpful in providing the best care to the patient with this diagnosis.

For more information on this topic, please see:

- Clinical Report : Health Supervision for Children with Down Syndrome, Marilyn Bull and the Committee on Genetics, Pediatrics 2011; 128;393-406
- Skotko BG, Capone GT, Kishnani PS, Down Syndrome Diagnosis Study Group. Postnatal diagnosis of Down Syndrome: synthesis of the evidence on how best to deliver the news Pediatrics 2009; 124(4) Available at www.pediatrics.org/cgi/content/full/124/4/e751

About the author:

Ellen Elias, MD, FAAP, specializes in Pediatrics, Clinical Genetics, and Neurodevelopmental Disabilities at Children's Hospital Colorado. Her research involves clinical management of children with Smith-Lemli-Opitz Syndrome.
Intellectual Disability; New Name, Forgotten Disability

By Nathan Blum, MD, FAAP

In the last decade, the disability formerly known as mental retardation has been renamed Intellectual Disability (ID), but this and other changes related to intellectual disability have gotten relatively little attention. The frequency with which children receive special education for this diagnosis; recommendations for screening for the disorder; and recommendations for evaluating individuals for the etiology of ID have all changed significantly. This article will review some of these changes.

Stigma associated with the term mental retardation led to a change in the name to ID. The American Association on Mental Retardation changed its name to the American Association on Intellectual and Developmental Disabilities in 2007 and changes of the name in federal statutes and policies were made in 2010. The diagnostic criteria for intellectual disability are identical to the criteria that were in place for a diagnosis of mental retardation and require significantly sub average cognitive functioning (IQ <70) along with deficits in adaptive behavior. The deficits need to begin prior to age 18 to meet the formal diagnostic criteria, although this age cut-off is somewhat arbitrary.

The number of children receiving special education services due to a diagnosis of ID has been steadily decreasing from about 10-12% of children receiving services in the early 1990s to about 7% today. It is very unlikely that the decline in children receiving services for ID represents a significant change in the actual prevalence of disorder. Instead, a large portion of the change is likely due to diagnostic substitution. Diagnostic substitution refers to a situation in which individuals with similar symptoms are given different diagnoses over time. It can occur due to changes in diagnostic criteria and due to socio-cultural phenomenon that lead to changes in the perceived or actual benefits associated with a specific diagnosis.

In addition to broadening of the diagnostic criteria for Autism Spectrum Disorders (ASD) when the Diagnostic and Statistical Manual of Mental Disorders 4th Edition (DSM-IV) was published in 1994, a number of other changes have had an impact of the frequency in which children receive special education services for ID. For example, in 1994 both autistic disorder and traumatic brain injury became diagnostic categories under which children could receive special education services and in 1997 developmental delay became a category under which children 3-5 years of age could receive services. Many children who currently receive services in one of these categories, may have previously received services under the ID category. In addition to the broadening of the special education eligible diagnoses, studies published in the late 1980s and early 1990s documented that some children with ASD demonstrated dramatic improvements in functioning when provided high frequency and high intensity behavioral interventions. The finding that some children with ASD need this unique type of special education services led many children with both ASD and ID to be categorized as having ASD for the purposes of special education eligibility and services. Public awareness campaigns related to autism, autism insurance laws in some states, and other factors have also contributed to the increasing diagnosis of ASD and decreasing diagnosis of ID.

In 2006 the AAP published formal recommendations that pediatricians perform developmental screening at 9, 18, and 24 or 30 months and whenever there were concerns on developmental surveillance. This screening will increase detection of children with developmental delays, many of whom are at increased risk for being diagnosed with ID. It is important to recognize that although children with global developmental delays (delays in 2 or more domains of development) are at high risk for a diagnosis of ID, not all young children with global developmental delay are later diagnosed with intellectual disability. For example, a study by Shevell and colleagues (Journal of Child Neurology, 2005;20;648-654) found that 20-30% of children diagnosed with global developmental delay at less than 5 years of age did not meet criteria for a diagnosis of intellectual disability at age 7. Nonetheless, it is important that children with developmental delays receive early intervention services. This is particularly true for children with additional psychosocial risk factors such as children living in poverty and/or living with parents with low educational levels as in these situations early intervention has been shown to improve long term educational and employment outcomes. Despite these benefits recent data suggests that only about 10 percent of children who are eligible for early intervention receive these services (Rosenberg et al. Pediatrics 2008;121:e1503-e1509).

continued on page 6
When a physician makes a diagnosis of global developmental delay or ID they should consider evaluating the child for the etiology of the disorder. The most common identifiable causes of intellectual disability are genetic disorders. In addition to potentially helping a family determine the risk of recurrence and the possibility for prenatal diagnosis, identifying the etiology can help with the early identification of associated conditions; help families access support groups, information, and research studies; and provide the family with an explanation for the disability that may help to end the search for a cause. However, if one is going to order genetic testing one must be able to educate the family and discuss potential consequences of finding out this information. For example, how will the parent react if he or she learns that the child inherited the condition from them and how will this affect the partner and their relationship? Further, if the diagnosis reveals that others in the family may be carriers will that information be shared? Genetic testing raises these and other complex issues one must be prepared to discuss with families.

The recommended genetic evaluation for children with global developmental delay or ID is changing at a rapid pace as our understanding of genetics and technology for identification of smaller and smaller deletions and duplications improves. Although practice guidelines have recommended and will continue to recommend testing for Fragile X syndrome, the most common inherited form of ID, the recommendations for other tests are in the process of changing. Banded karyotype was the primary method for identifying insertions and deletions, but this technology can only identify insertions or deletions in the 3-5 million base pair range. A newer technology, microarray based comparative genomic hybridization, is increasingly recommended in the evaluation of children with ID as it can identify duplications and deletions in the 50-500,000 base pair range and has a higher diagnostic yield. However, this test may detect deletions or duplications of uncertain clinical significance. As this is a relatively new test there is still significant variability in insurance coverage for the test.

Intellectual disability and global developmental delay are common pediatric problems. Pediatricians need to be able to detect and refer children with these conditions for needed services and to help families consider the most appropriate etiological evaluation.

About the author:
Nathan Blum, MD, FAAP, is the chairperson of the Section on Developmental and Biohavioral Pediatrics and can be reached at blum@email.chop.edu.

ASHA Connections:
Enhancing the Efficacy of Hearing Screening Programs
By Anne Oyler, AuD, CCC-A and Pam Mason, MEd, CCC-A
American Speech-Language-Hearing Association

Untreated permanent childhood hearing loss (PCHL) can lead to significant delays in speech and language skills. Significant delays in treatment can also lead to social/emotional and behavioral difficulties, poor academic achievement, and reduced future job prospects. Newborn hearing screening now makes early detection, diagnosis, and treatment possible so that children who are born with PCHL can take advantage of the early critical learning period between the ages of birth to 3. For decades infant hearing screening was attempted using various screening technologies and methods. In 1993, only 3% of children were screened for hearing loss, today over 95% are screened within the first few hours and days of life. In the past 2 decades, the average age of identification of hearing loss has gone down from 2.5 years to 6 months of age. This has certainly changed the landscape of childhood deafness in the United States.

Early Hearing Detection and Intervention (EHDI) process begins with the practice of universal newborn hearing screening prior to hospital discharge using objective screening procedures. Infants not passing this screen within 1 month of age should receive diagnostic hearing evaluation before 3 months of age and, when necessary, enrolled in early intervention programs by 6 months of age. Meeting the EDHI goals of 1-3-6 can significantly improve communication outcomes for infants and young children with permanent hearing loss. All 50 states and the District of Columbia have EHDI laws or voluntary compliance programs.

continued on page 7
However successful these universal hearing screening programs are, there still looms the formidable action to link children who fail the screening to appropriate pediatric audiologic services for full diagnosis of the hearing loss and to speech-language-hearing intervention programs. According to the Centers for Disease Control and Prevention (CDC) in 2010 over 40% of infants who failed the newborn hearing screen were “lost to follow-up” within EDHI programs. Reducing the lost to follow up is an ongoing goal of these programs and has been identified as a national health objective goal in the US Department of Health and Human Services Healthy People 2020. Success of EDHI programs and for the children (and families) identified with permanent hearing loss is more easily achieved with the support, understanding, and resources within the medical home.

One issue leading to loss to follow-up is difficulty in identifying appropriate pediatric audiology facilities with clinical expertise and equipment to meet the specific needs of infants and young children. Pediatricians and families often have difficulty in identifying the facilities with clinical expertise and equipment to meet the specific needs of infants and young children with hearing loss. This challenge creates delays in the diagnostic and intervention process, and has a negative impact on child outcomes.

In 2009, ASHA partnered with the Joint Committee on Infant Hearing (JCIH), the National Center for Hearing Assessment and Management (NCHAM), the Health Resources and Services Administration (HRSA), the Centers for Disease Control and Prevention (CDC), parents/families, and professional audiology organizations to develop the web-based Early Hearing Detection and Intervention: Pediatric Audiology Links to Services (EHDI-PALS) Web site. The EHDI-PALS Web site is a comprehensive, user-friendly online resource and searchable database designed to help guide and educate families and professionals searching for needed pediatric audiology services.

The EHDI-PALS directory is currently being populated with facilities that employ licensed audiologists and offer diagnostic, hearing aid, and cochlear implant services for children under age 5. Facility information that is collected in the EHDI-PALS directory is very detailed and is based on current best practice standards. The Web site is scheduled to go “live” in the spring of 2013. In addition to the facility directory, the Web site will have helpful educational resources for families and professionals. A call for facility data in early November 2012 yielded over 400 facility entries and the numbers are still growing. With active support from the CDC, state EHDI programs, parent advocacy groups, and audiology professional organizations, EHDI-PALS is promising to be a valuable tool in the effort to improve outcomes for young children with hearing loss. Stay tuned! It takes a village- the child’s pediatrician is a key partner in assuring that these families link to appropriate services.


Additional Resources:
Effects of Hearing Loss on Development (English and Spanish)

How Does Your Child Hear and Talk?

Joint Committee on Infant Hearing 2007 Position Statement “Establishing a Sound Beginning for Children who are Deaf or Hard of Hearing” (Ted Talk by Karl White)

Information About Early Hearing Detection and Intervention (EHDI) State Programs

About the author:

Anne Oyler, AuD, CCC-A is the Associate Director for Audiology at the American Speech-Language-Hearing Association (ASHA), in Rockford, MD and can be reached at aoyler@asha.org.

Pam Mason, MEd, CCC-A, is Director of Audiology Professional Practices at the American Speech-Language-Hearing Association (ASHA), Rockville, MD, where she has worked for the past decade. In her role, Pam leads the provision of outreach to consumers and professional support to audiologists and other health care professionals on issues related to hearing and balance. Pam also has a great deal of experience serving as an audiology and hearing expert for media. Before she worked at ASHA, Pam directed the Audiology Center at the George Washington University Hospital, Washington, DC. During her time there, Pam began a universal newborn hearing screening program and trained residents in otolaryngology and graduate students in audiology.
An Introduction to Treatment Manuals for Behavioral Interventions

By Edward R. Christophersen, PhD, FAAP (Hon) and Susan Mortweet VanScoyoc, PhD, ABPP
Children’s Mercy Hospitals and Clinics, Kansas City, Missouri

Research on the efficacy of medications requires a precise definition of the medication, dosing, how the medication was administered, by whom, when, and what benefits or side effects were noted. And, in most research on medication effects, biochemical assays are available to confirm that the medication was actually taken by the patient. In behavioral research, which is an integral part of developmental-behavioral pediatrics, maintaining the same level of rigor represents more of a challenge because of the difficulty of describing the details of intervention. For example, whereas medication dosing can be carefully calculated and monitored for appropriate dosing, behavioral interventions are much more difficult to quantify with many nuances related to execution and the definitions of successful outcomes. For that reason, Treatment Manuals (TM) have become an integral part of research on behavioral interventions. The term “Treatment Manual,” when used in this specific context, refers to a document that specifies precisely what population was included in the original study, how the participants were selected, the training of any practitioners responsible for the intervention, as well as precisely how the intervention proceeded. Treatment integrity measures are also included in the more well-designed studies to verify that the interventions were carried out as described in the manual. The benefits of TMs include allowing a more precise replication of research and treatment by others. Additionally, when referring a patient to a mental health provider, the physician may be more confident in the practices of a provider who implements evidence-based strategies such as those outlined in TMs.

A review of 5 TMs will be used as examples of how such manuals can be used in clinical practice, including: 1) the present author’s Home Chip System for use in the home with disruptive behavior disorders such as ADHD and ODD (Christophersen & VanScoyoc, 2008); 2) Ost and Ollendick’s Treatment Manual for One Session Treatment of Specific Phobias (Ollendick et al, 2009), 3) Kendall’s Coping Cat Treatment Manual for Anxiety Disorders in Children and Adolescents (Kendall & Hedtke, 2006), 4) a Treatment Manual for Selective Mutism that includes samples of letters to schools and to primary care physicians (Johnson & Wintgens, 2001), and 5) a very comprehensive Treatment Manual for Pelham’s ADHD Summer Treatment Program which includes detailed discussion of training for counselors, agendas for the classroom teacher, definitions of the behaviors and recording sheets that are used by the counselors to track the behaviors of the students enrolled, and examples of the Daily Report Cards (Pelham, et al, 2004). One cautionary note: The purpose of this review is not so the untrained provider can attempt the intervention without the proper supervised clinical training. Rather, the purpose is to familiarize readers with the evidence-based TMs available to address the mental health needs of their patients.

Christophersen and VanScoyoc’s Home Chip System (Christophersen & VanScoyoc, 2008) and 2) Ollendick, et al (2009) One Session Treatment of Specific Phobias are examples of fairly straightforward treatment protocols that, in the hands of a properly trained clinician, can be successfully implemented with result quite similar to the original research. Home Token Economies like the Home Chip System have an extensive base of research supporting their efficacy. The steps of the chip system are explained and demonstrated to a family during an office visit, which probably requires about 15 minutes to accomplish. The Home Chip System includes discussions about how to implement the Chip System, how to give and take away chips, and how to respond if the child chooses to not cooperate with the Chip System. The Home Chip System was developed for use with children ages about 3-7 who present with either ODD or with ADHD and ODD. We have also found it to be useful for children with less disruptive behavior disorders but who still require more structured consequences in the home environment than basic time-outs or reward charts. Using poker chips available at most discount stores, the therapist demonstrates how the parent is to give poker chips for appropriate behaviors such as getting started right away on a required task and practicing going to time-out, and how the child is expected to respond when he or she engages in a behavior that results in the loss of chips such as back talking or stalling. The therapist also demonstrates how the parent and child are being asked to exchange chips for any variety of rewards established together as rewarding and readily available. The Home Chip System offers explicit instruction on how to choose target behaviors and rewards to facilitate the effectiveness of the intervention. Many parents fail to execute such behavior...

continued on page 9
An Introduction to Treatment Manuals . . . continued from page 8

ior management systems effectively as often times many providers fail to discuss the critical details that make them effective. In such cases, a TM such as the Home Chip System may increase the likelihood of success in moderating the behavioral outcomes of patients and their families.

Similarly, Ollendick, et al’s (2009) “One Session Treatment of Specific Phobias” describes how a well-trained mental health clinician can effectively assist a child in dealing with a specific phobia (eg, mascots or insects in one, 3-hour treatment session). It was developed for use with children and adolescents being seen for a specific phobia without significant co-morbidities such as depression, other anxiety disorders, or behavioral problems. The One-Session Treatment, while more difficult to schedule because it typically requires a 3-hour session which may not be reimbursed in full by third-party payers, is more effective than weekly or bi-weekly treatment sessions (with a typical course lasting 6 to 10 weeks) because the patient does not have time between their appointments for their fear to return (Ollendick, et al, 2009). (An initial intake appointment as well as an explanation of the treatment process precedes the one-session treatment step). An example of how the one-session treatment would be used to address a child’s fear of mascots is described below. Information obtained prior to the session would include family history and co-morbidities, as well as details on the specifics of the phobic behavior. The therapist would then begin working with the child on coping skills such as visual imagery or muscle relaxation. When the child is able to demonstrate the ability to engage in a coping skill, and with the child’s permission, a small part of the mascot uniform such as a shoe is introduced. The entire mascot outfit can usually be obtained from a local school if the school is out of season for the sports that use the mascot. The child is then asked to engage in the coping skill, then, again with the child’s permission, the introduction of other mascot pieces such as the second shoe, one glove, both gloves, and so on until the child has been exposed to and demonstrates an ability to cope with the complete mascot outfit. Critical components of the treatment include not exposing the child to feared stimuli any faster than he or she is willing to proceed and making sure the child is completely relaxed before moving onto the next step.

Kendall’s Coping Cat. The Coping Cat program (eg, Kendall & Hedtke, 2006) is a well-established intervention for the treatment of anxiety disorders in children and adolescents, specifically separation anxiety, generalized anxiety, and social anxiety. Kendall and his colleagues have published research papers with follow up data up to 5 years after the original treatment, demonstrating reduction in symptoms for at least 50% of the participants (Kendall & Southam-Gerot, 1996). In addition to a TM for the therapist, a parent manual and workbook for the child are also used to facilitate proper execution of the intervention. The clinician’s TM includes detailed, session by session, explanations of the procedures used in their outcome research on the treatment of anxiety. For example, the first 2 treatment sessions are used to build rapport, educate the child and parent about anxiety and the treatment goals, and introduce the concept of graduated exposure and the use of the “fear thermometer.” The 3rd through 6th sessions are used to identify somatic feelings related to anxiety, introduce and practice the relaxation strategies, identify anxious/coping self-talk, and further educate the parents about the importance of the child learning to identify the onset of anxious feelings and immediately engage in their coping strategy. Although it is not necessary to compulsively follow the exact details in the manual (most clinicians develop their own style based upon the TM), following the manual is a good place to start if you want to get the kind of results that Kendall and his colleagues have published.

Johnson and Wintgen’s Resource Manual for Selective Mutism (2001). Selective Mutism is a complicated, sometimes treatment resistant disorder that typically requires multiple accommodations in order to effectively address the patient’s lack of speech at day care or school when that child is exhibiting normal speech in the home setting and with familiar adults. This TM (Johnson & Wintgens, 2001) includes examples of exposure hierarchies (eg, beginning with trips to an empty classroom to play games or to read books, then going to the same classroom with a peer the child feels comfortable with and speaks to, to going to the classroom with 2 peers, etc.), letters to teachers and to primary care physicians, and examples of procedures for parents and teachers to implement at home and school. The most effective use of a TM such as this one often requires all critical caregivers be provided a copy of the manual. Often times we encourage the school to include a copy of the TM in the child’s 504 or IEP to raise the likelihood that everyone involved in the treatment of the child is following the same basic treatment plan. As with the other TMs, careful and frequent explanation of the steps by qualified clinicians is often necessary to obtain the most benefit.

Pelham’s ADHD Summer Treatment Program (STP). One of the most comprehensive TMs available is the Pelham ADHD Summer Treatment Program manual (ADHD STP; Pelham et al, 2004). The ADHD STP Treatment Manual is 353 pages long and must be purchased from Florida International University’s (FIU) Center for Children and Families. Divided into chapters, the chapters cover: 1) Introduction and Overview, 2) The Point System, 3) Positive Reinforcement and Appropriate Commands, 4) Time-Out, 5) Peer Interventions, 6) Recreational Activity Procedures, 7) Daily Report Cards, 8) Individualized Programs, 9) Group Problem Solving
An Introduction to Treatment Manuals . . . continued from page 9

Discussions and Group Contracts, 10) Honor Roll Program, 11) Daily Procedures, 12) Record Keeping, Data Management, and Preparation, 12) Child Care During the Parent Training Sessions, 14) Friday Procedures, 15) Learning Centers, 16) Medication Assessment, 17) Treatment Integrity, Treatment Fidelity, and Accountability, and 18) Staff Information and Administrative Procedures. Most programs that are replicating the ADHD STP for the first time will arrange for a “Trainer” from the FIU STP Program to either come to the new STP site to train staff and counselors, or for a member of the STP staff to travel to FIU for training; which, necessitates that the program staff do their own training of their counselors upon return to their home site. There are now about 25 ADHD Summer Treatment Programs across the US with literally dozens of outcome research papers published by the various replications (eg, Pelham & Fabiano, 2008, Coles, et al, 2005).

The first author, Edward R. Christophersen, had direct experience implementing the ADHD STP last summer (2012) in Kansas City. As is recommended for all new programs, we chose to have one of the STP staff travel to our site in order to conduct the training. Anil Chacko, PhD, from the University of Buffalo (NY), spent 3, 10-hour days introducing our STP staff to all of the details in the STP Manual. The training included lecture and role-playing as well as quizzes over behavioral definitions in order to maintain the treatment integrity with the original model. As we progressed over the summer program, we referred to the STP TM many times a day during the 1-week of training, and at least daily during the inaugural 8-week STP. Given the complexity of the program, effective implementation would not have been possible without the guidance of the TM. The STP TM is one of the most comprehensive available today, showing the remarkable progress of TMs over the past 2 decades.

The emergence of TMs has greatly simplified the implementation of therapeutic protocols developed at many sites across the world (eg, Kendall’s Coping Cat has been validated in Australia as the Coping Koala). The most obvious advantage of using a TM is that researchers and clinicians have been able to replicate the results of treatment programs developed at other sites, increasing the likelihood that other sites and other clinicians/investigators will be able to achieve results similar to those obtained by the authors of the original program. The use of TMs also greatly facilitates the training of new practitioners. In fact, the Office of Accreditation of the American Psychological Association, the governing body for psychology internship training sites, has encouraged training programs to use evidence-based programs that include the use of TMs. Probably the most obvious limitation of a TM is that it is never a substitute for previous clinical experience. A TM read by an inexperienced clinician would probably be quite difficult to follow with, at best, questionable outcomes. Whereas a TM in the hands of a clinician experienced in the treatment of the condition detailed in the TM, would almost assuredly find the answers to a number of questions that they had had previously and would be able to modify their treatment approach in order to raise the likelihood that they will achieve outcomes similar to the outcomes experienced by the authors of the TM. In summary, primary care physicians can be reassured that behavioral researchers and clinicians are making advances in defining and refining their treatment protocols, with TMs being used to accurately and effectively disseminate evidence-based interventions for several common behavioral and emotional problems for children.

References

continued on page 11
Children’s Mental Health and Medical Home: An Update from the Mental Health Leadership Work Group

By John C Duby, MD, FAAP, CPE

In the days following the tragic events in Newtown, I pray that our country’s leadership will come to a tipping point that places children’s mental health at the top of its priorities.

Pediatricians can be at the forefront of leading interdisciplinary teams that nurture resilience, identify adverse childhood experiences and other risks to healthy psychosocial development, screen routinely for emerging symptoms and for problems in child or family functioning, and intervene when risks, concerns, or symptoms arise.

Mental health care IS mainstream pediatrics. Pediatricians, if trained and supported, are ideally positioned to identify children with mental health problems, to triage for emergencies, to initiate care, and to collaborate with specialists in facilitating a higher level of care when needed.

Many children who are served in the mental health or substance abuse specialty system—particularly those with severe and persistent mental illness requiring intensive levels of care—lose contact with their pediatric medical home. The AAP urges that pediatricians make efforts to engage these children and their families in the full range of primary care services and engage their specialty providers and other community partners (eg, schools, child care and Early Intervention providers, juvenile justice system, social services) in one collaborative, family-centered system of care that transects traditional silos.

The AAP’s Task Force on Mental Health (TFOMH) articulated (with the AAP Committee on Psychosocial Aspects of Child and Family Health) mental health competencies for primary care; developed guidance for addressing systemic and financial barriers to providing mental health care in primary care settings; and provided tools and strategies to assist pediatricians in applying chronic care principles to children with mental health problems.

The AAP Mental Health Leadership Work Group* (MHLWG) is working to facilitate integration of the TFOMH’s work into the fabric of the AAP and pediatric practice. Its activities focus on transforming systems, transforming practice, building clinician skills, disseminating clinical tools, enhancing community resources, and partnering with families and organizations. Examples include training pediatricians in the requisite mental health competencies, enlisting quality improvement methodology to implement practice changes, advocating for appropriate payment for mental health care, reducing administrative barriers, and identifying new collaborative models.

The MHLWG priorities through 2013 are to:
• Develop a public policy agenda that promotes the value of integrated mental health services in the primary care medical home and lead a national children’s mental health coalition in collaboration with the AAP Department of Federal Affairs.

continued on page 12
• Design a 2-day course on best practices for integrating children’s mental health services in the primary care medical home that includes a focus on the science of quality improvement and provides ongoing support to participants.

• Develop a curriculum for continuity clinic directors addressing the common factors approach for mild to moderate anxiety. This project is supported by the Friends of Children Fund and is well underway. The work group includes:
  o Nathan Blum, MD, FAAP, Chair, SODBP and Chief, Behavioral Pediatrics Program at The Children’s Hospital of Philadelphia
  o Cori Green, MD, MS, FAAP, Consultant, MHLWG and Associate Director, Pediatric Undergraduate Medical Education, Weill Cornell Medical Center
  o Barry Solomon, MD, MPH, FAAP, Program Director, Johns Hopkins Children’s Center
  o R. Franklin Trimm, MD, FAAP, Consultant, MHLWG and Residency Program Director, University of South Alabama

• Review existing AAP materials for families and create new materials based on the mental health clusters from the AAP’s Toolkit: Addressing Mental Health Concerns in Primary Care.

The Section on Developmental and Behavioral Pediatrics leadership is working closely with the Mental Health Leadership Work Group to assure that our efforts are aligned. Throughout 2013, we will be working closely with Academy leadership to achieve these goals and to assure that children’s mental health stays at the forefront of our efforts to achieve optimal health of all children, and to assure that our pediatricians have the knowledge, skills, and confidence to meet their needs.

For questions regarding the plans of the MHLWG, please feel free to contact Linda Paul at lpaul@aap.org or 800/433-9016, ext 7787 or John Duby, MD, FAAP at jduby@aap.net or 330-543-8790.

*Mental Health Leadership Work Group
John Duby, MD, FAAP, CPE, Chairperson
David Bromberg, MD, FAAP
Marian Earls, MD, FAAP
Jane Meschan Foy, MD, FAAP
Alain Joffe, MD, FAAP
Cori Green, MD, FAAP, Consultant
Kelly J. Kelleher, MD, MPH, FAAP, Consultant
R. Franklin Trimm, MD, FAAP, Consultant

Children’s Mental Health . . . continued from page 11

International Developmental-Behavioral Pediatrics

Autism Care Nepal

By Sunita Meleku Amatya, MD
Vibha Krishnamurti, MD, International DBP Editor

Sylvia, the first child in a well-off family in Nepal, was, according to her parents, “a very quiet little girl.” Precisely because she was a girl, her parents were not unduly concerned about her lack of speech. In Nepal, good girls are quiet girls.

As she continued to grow and remained largely non-verbal, a friend of the family broached the idea of autism. At first, Sylvia’s parents brushed the idea aside. But when other friends urged them to take her to Surya Binayak, a Hindu temple in the area, believed to have miraculous powers for children with language disorders, their anxieties grew. They read what they could on the internet, but could find no local professionals who had knowledge or experience with autism.

Sylvia’s family was not alone. As her parents became more knowledgeable about their daughter’s condition, they found other families in the same situation. Dipankar, Biraj, Krit – all diagnosed with autism after years of being assured by doctors that “Boys talk late,” “He just needs more calcium” or “Don’t worry. He’ll catch up.”

While scientists around the world research and find ways to understand this complex disorder, autism remains a mystery and a challenge.
lenge in Nepal. In Nepal, as in many resource-poor nations around the globe, ASD is widely undiagnosed and poorly understood. When children are identified and diagnosed – often after years of confusion and misdirection - treatment options are nearly nonexistent.

In 2008, Sylvia’s parents formed a registered organization called Autism Care Nepal - a parent support group for persons with autism and comprises of parents, caregivers, persons with autism, and professionals. Dipankar’s mom took the initiative to train (in neighboring India) as a Special Educator, Biraj’s mother threw herself into the task of educating other parents while Krit’s mother took on the administrative and infrastructural needs of the young organization.

They have their work cut out for them. In addition to autism being poorly understood - leading to late diagnosis and missing out on the vital years for early intervention - parents in Nepal are isolated and judged for their child’s unusual behavior. They are even told it is their own “bad karma” which is to blame. Parent denial and a desperate desire to “normalize” their child’s behavior for as long as possible contribute to the problem.

It is a lonely and difficult struggle for families and while the financial burden is daunting, it is perhaps the psychological strain that causes the most heartbreak and stress. In Nepal, where children are a part of all social gatherings, families often cut themselves off completely from the life of the community.

With non-existent social services, many parents have no option but to leave their children alone at home while they are at work. Sometimes, unsupervised children wander away from home and are hit by cars, sexually abused, kidnapped, or simply vanish.

During the diagnostic process itself, girls are also disadvantaged compared to boys as culturally, girls who are quiet – even to the point of being silent - are considered well-behaved and gender-appropriate, delaying parents’ seeking help.

Every country’s needs are different. In all of Nepal, there is only one developmental pediatrician and one child psychologist. With so few trained clinicians, we cannot expect a radical change in service provision any time in the near future. While organizations like Autism Care Nepal are beacons of hope for struggling families, much more needs to be done.

International experts could play a vital role in sharing skills, training, and providing capacity building opportunities to the professionals we do have. Research projects based in Nepal may yield interesting new approaches to this poorly understood condition.

About the authors:

Sunita Maleku Amatya is an anesthesiologist by profession and also the mother of a 7 year son with autism. Since his diagnosis, she has been actively involved in advocacy and development of services for people with autism. She is also works as a counselor for parents of newly diagnosed children with autism. She is currently the chairperson of Autism Care Nepal, which is the only active organization working for the people with autism and their caregivers in Nepal.
My Journey to Developmental-Behavioral Pediatrics

By Marisa Toomey, MD

If there is one thing that has been a constant in my life, it is the fact that my father does not cry. It is not that he has ever been one to grunt monosyllabic answers or greet my dates with a shotgun. He bakes, he likes independent films, and he always reminds me “your mother is the one in charge.” Still, he has never openly shed tears. Thus, when I saw him cry in public a few years ago, it sent me into a bit of a tailspin.

My parents and I were at a dance for my younger sister Devon and other adults with developmental disabilities. At the time Devon, who has autism, was 25. Unlike most of the other individuals there, Devon does not live in a group home. She still resides at my parents’ house.

She was diagnosed in the late 1980s, when the only pop culture reference was “Rainman” and when no one had a puzzle-piece, ribbon-shaped bumper sticker indicating their awareness. I cried all of the time back then. No one understood her, and everywhere we went, other children taunted “freak” and “retard” at her. My father always reminded me that all that mattered was that she was my sister and that we loved her just as she was.

He cried now, over 20 years later, because the hope he felt back then was gone. He saw a future for Devon that none of us wanted. An inevitable group home once my parents become too old to take care of her. A social circle of individuals who cannot always respond to my (highly verbal and incredibly outgoing) sister’s pleas for friendship. A lifetime of wishing she could be a part of something more.

For several years, I had begun to feel the same way. I had applied to medical school with the sole intent of becoming a developmental-behavioral pediatrician. I had always wanted to be my sister’s doctor, and I had always believed that my personal experience with Devon gave me an insight that would make me a more compassionate physician.

As the years passed, and as my sister left the organized world of special education and drifted into the nebulous territory of adult services, I began to wonder if it would all be too difficult. It was clear that Devon was unhappy leaving the friends she had made at her school and being forced into an adult services day program, where many of the people are older and non-verbal.

I began to think that I would be the worst kind of developmental-behavioral pediatrician if I had no hope for the future of the children of whom I took care. I convinced myself I should do anything but developmental-behavioral pediatrics and began to ponder what other field in pediatrics would better serve me.

These thoughts turned into a sensation of shame as I sat at the dance and watched my father hurriedly attempt to mask his tears with a mumbled “there’s something in my eye” as he rushed off to the men’s room. What had become of my dreams? I had let frustration and fear turn my goals into regrets. When did I give up on my sister…and myself?

As I sat at the dance that night, I saw my future as a clinician who was happy at work but never truly inspired. I saw my sister’s experience becoming a secret I would keep. I saw myself forever abandoning any attempt to advocate for changes for the better for individuals with developmental disabilities.

And then I looked over at my sister on the dance floor. She was with my mother, and it was very clear that she enjoyed the music as she swayed in time to it. I realized that I was the one who had decided the situation was completely hopeless. Devon still keeps dancing.

My passion never died – I just became scared for the future. It is not easy, and I am not going to pretend that this essay should have a neatly packaged ending. My father did not come back bright-eyed, and we did not all dance joyously together as a happy, hopeful family. The situation is very difficult, but that does not mean I should relinquish my goals of advocating for individuals like Devon so that the future can improve.

I cannot cure my father of his tears, but I can try to do something that helps individuals like Devon.

continued on page 15
About the author:

Marisa Toomey, MD graduated from Boston College and then attended medical school at Loyola University Chicago. She completed her residency in Pediatrics at Children’s Hospital of Pittsburgh of UPMC. She is currently a first year fellow in Developmental-Behavioral Pediatrics at the Children’s Hospital of Philadelphia.

Editor’s note: It is always good for all of us to reflect on our motivations and passions for choosing to be involved with developmental behavioral pediatrics. This poignant personal reflection introduces a new section of the SODBP Newsletter – contributions from trainees. Trainees are encouraged to contribute articles, perspectives, and editorials to the Newsletter.

AAP Department of Federal Affairs Update

A look back at child health policy achievements of the 112th Congress

Passage of the Combating Autism Act

In September 2011, President Obama signed into law legislation renewing the landmark Combating Autism Act (CAA), assuring continued federal support for critical autism research, services and treatment. The law is renewed through Sept. 30, 2014, at $231 million per year. Since it was signed into law in 2006, the CAA has provided a coordinated national strategy for addressing the needs of individuals with autism spectrum disorder.

To help ensure that the legislation—which was strongly supported by AAP—was taken up and reauthorized, AAP sent a letter to all members of Congress and released a press statement highlighting the importance of the bill to children’s health.

CPT Code 96110 Advocacy

Thanks in large part to a robust advocacy effort led by SODBP and AAP members, the Centers for Medicare and Medicaid Services (CMS) reversed a decision last January to stop covering services for CPT code 96110. This code is used to bill for essential developmental, behavioral, and psychosocial screenings and services. CMS responded to the Academy’s concerns by publishing RVUs for the code, thus reinstating payment for 96110. This decision allows both Medicaid and plans in the private insurance market to continue using code 96110 even though it is technically not recognized for payment by Medicare.

FDA user fee legislation signed into law

Best Pharmaceuticals for Children Act and Pediatric Research Equity Act

In July 2012, President Obama signed a law, the Food and Drug Administration Safety and Innovation Act (FDASIA) Public Law 112-144, to permanently reauthorize the Best Pharmaceuticals for Children Act (BPCA) and the Pediatric Research Equity Act (PREA).

Until BPCA and PREA were passed in 1997 and 2003 respectively, most medicines used to treat children had been tested for safety and efficacy only in adults. The BPCA and PREA have been enormously successful, resulting in more than 460 drug labels being revised with new pediatric information. By making BPCA and PREA permanent, the law ensures that children will have a permanent seat at the table for drug research and development. The laws previously needed to be reauthorized every 5 years and were scheduled to expire on September 30, 2012.

The BPCA and PREA include strong pediatric provisions negotiated after diligent advocacy by the Academy, such as: encouraging earlier pediatric study planning by drug manufacturers; giving the Food and Drug Administration (FDA) new authority to ensure PREA requirements are met on time; improving the transparency of data from pediatric studies conducted prior to 2007; making strides to prevent and address drug shortages; and increasing FDA expertise in neonatology and advancing drug studies in neonates.

There are several publicly-available documents, including an implementation timeline, that summarize and explain the final pedi-
Drug Shortages
The FDASIA addresses drug shortages by expanding existing reporting requirements for manufacturers of drugs that are life-supporting, life-sustaining, and intended for use in the prevention or treatment of a debilitating disease or condition, including those used in emergency medical care or surgery.

Consistent with AAP’s position, FDASIA calls on FDA to maintain a drug shortage list and better communicate with providers and the public in order to prevent, mitigate, and manage drug shortages. The FDASIA also requires the US Department of Health and Human Services (HHS) to establish a task force, which may include non-governmental stakeholders, in order to enhance the HHS Secretary’s response to shortages, and to create a strategic plan to address stated aspects of shortages.

During Congressional consideration of proposals to address drug shortages, the AAP submitted testimony for the record, formally commented on Senate and House proposals, and was called upon to meet with and provide technical assistance to Congressional staff drafting the final language.

A look ahead to child health policies on the horizon in the 113th Congress

Essential Health Benefits for Children
As part of health reform implementation, all health insurance plans included in health insurance exchanges as well as in the individual and small group market, must offer a standard set of essential health benefits (EHBs) beginning in 2014. There are 10 categories of EHBs, including a category of “pediatric services.”

The AAP released a report over the summer comparing benefits and costs for each of the 10 EHB categories in 5 states. For each of these states—Alabama, Colorado, Maryland, Texas, and Washington—the report also compares coverage under the Children’s Health Insurance Program (CHIP) and Medicaid. The report found geographic, cost, and coverage inconsistencies in EHBs for children, and found that of the private plans studied in the report, none approached the breadth of coverage and cost-sharing protection available under Medicaid or the states’ separate CHIP plans.

As a result of the report findings, AAP and other children’s health groups have advocated to the federal government to allow states to select their current CHIP plan as the benchmark for children’s EHBs. As additional regulations are released, the Academy will continue to advocate for EHBs that meet children’s physical and mental health needs.

Medicaid payment increase
As part of health reform implementation, qualifying pediatricians and pediatric subspecialists who treat Medicaid patients will be paid at least 100% of Medicare rates in 2013 and 2014 for primary care services. Immunization administration rates will also improve. The increase takes effect on January 1, 2013.

The increase marks the first-ever federal investment in improving payment—and thus access to care—for pediatricians and children in the Medicaid program. To learn more about the payment increase and what it means for you, please visit this resource page on aap.org, where you will find educational fact sheets, AAP News articles on the increase, and a 6-page question-and-answer document.

Children’s Hospital Graduate Medical Education
Legislation to reauthorize the Children’s Hospital Graduate Medical Education (CHGME) program is anticipated to advance in the 113th Congress. In working toward its reauthorization, the Academy will continue to build upon its successful advocacy efforts in partnership with the Children’s Hospital Association over the last 2 years to fully fund the program. The CHGME program provides 55 freestanding children’s hospitals in 30 states with critical federal support for residency and fellowship programs to sustain their teaching missions without draining resources for patient care and critical services.

Immigration Reform
The 113th Congress is expected to engage in a meaningful debate on immigration reform. Whereas past efforts have failed, the outcome of the November 6, 2012 elections, including President Obama’s remarks during his acceptance speech; the changing demo-
graphics of the electorate; and continued inaction on the Development, Relief, and Education for Alien Minors (DREAM) Act have led to increasing calls for comprehensive immigration reform. Of the country’s 11 million undocumented immigrants, approximately 2 million are children and youth.

While the specific details of President Obama’s plan have yet to be unveiled, various legislative proposals are anticipated to emerge early in the 113th Congress. The AAP, working through the Immigrant Health Special Interest Group and the Council on Community Pediatrics, will be closely monitoring and evaluating each proposal. As in past Congresses, the AAP will also be working to advance the Human Enforcement and Legal Protections for Separated Children (HELP) Act, which addresses the needs of children whose parents have been removed due to an immigration enforcement action.

Pharmacy Compounding
Pharmacy compounding is a critical component of the care pediatricians provide to patients. As a result of the ongoing fungal meningitis outbreak, which has already claimed hundreds of lives, Congress is taking aggressive action to understand and address the federal legal and regulatory framework for pharmacy compounding.

Legislative proposals have already been circulated by US Rep. Edward Markey (D-Mass.), in whose district the New England Compounding Center, which was responsible for the fungal meningitis outbreak, is located, as well as US Reps. Rosa DeLauro and Nita Lowey. Given how widespread and deadly this outbreak has been, there will be renewed energy for legislative action in the 113th Congress. The Academy will continue to work with members of Congress, their legislative staff, and the FDA to educate them about how pharmacy compounding is used in pediatric care and to ensure that it remains a safe option for pediatric patients.

Ways to get involved in federal advocacy

Sign up to be part of the AAP Department of Federal Affairs Key Contact program. As a Key Contact, you will receive weekly legislative updates on child health policies advancing at the federal level, as well as targeted requests for action when bills or issues require pediatrician advocacy. To sign up, please e-mail Jamie Poslosky in the AAP Department of Federal Affairs.

Register for the spring 2013 Legislative Conference in Washington, DC:

- Legislative Conference will take place in Washington, DC April 28-30, 2013. There, participants will learn about the Academy’s federal policy priorities, attend interactive skills-building workshops on how to help advance child health legislation at the federal level, and participate in meetings with US legislators and their staff on Capitol Hill.
- Where to learn more about the conference and how to register:
  - Download the conference brochure and visit FederalAdvocacy.aap.org/legcon2013 for more information about the conference.
  - Register online at www.pedialink.org/cmefinder (keywords: “Legislative Conference”).
Dear Coding Crew:

I shudder to ask this — when are we going to transition to ICD-10-CM and is it going to be as bad as the rumors I’m hearing? Should I retire before this happens?

Signed,

Anticipatory Dread in Annapolis Delaware

Dear ADAD:

I would worry more about the ‘fiscal cliff’ than I would worry about this! Here are the facts:

- Implementation drop dead date is October 1, 2014 (initially, it was October 1, 2013 but the government pushed it back by 1 year to allow more preparation time)
- ICD-10-CM has greater specificity than ICD-9-CM, such as severity indicators within each code
- Whereas ICD-9-CM had 17,000 codes, ICD-10-CM will initially have more than 140,000 codes

HOPEFULLY, it is anticipated that this increased diagnostic code system should result in:

- More efficient claims management
- Fewer requests for clinical information
- Fewer rejected claims due to non-specific diagnoses
- Combination diagnosis/symptom codes
  - Reducing number of codes to fully describe a condition
- Certain diseases reclassified to reflect current medical knowledge
- ICD-10-CM includes laterality to show right, left and bilateral
  - Right (1); Left (2); Bilateral (3); Unspecified (0 or 9, depending on character placement)
- ICD-10-CM is more robust and descriptive than ICD-9-CM with “one-to-many” matches in some instances
- Expanded injury (alcohol/substance abuse) codes
- Added extension for episodes of care

To give you an idea of how current ICD-9-CM codes will likely be expanded in ICD-10-CM: (See Chart on Page 19)
### Coding Conundrums continued from page 18

<table>
<thead>
<tr>
<th>ICD-9-CM</th>
<th>ICD-10-CM</th>
</tr>
</thead>
<tbody>
<tr>
<td>314: the category ‘attention deficit disorder’</td>
<td>F90: Attention deficit hyperactivity disorders</td>
</tr>
<tr>
<td>314.00: ( ) . subcategory=inattentive subtype</td>
<td><strong>Includes</strong>: attention deficit disorder with hyperactivity attention deficit syndrome with hyperactivity</td>
</tr>
<tr>
<td>314.01: ( ) . subcategory=combined type</td>
<td><strong>Excludes</strong>: anxiety disorders (F40.-, F41.-) mood [affective] disorders (F30-F39) pervasive developmental disorders (F84.-) schizophrenia (F20.-)</td>
</tr>
<tr>
<td></td>
<td>F90.0 Attention-deficit hyperactivity disorder, predominantly inattentive type</td>
</tr>
<tr>
<td></td>
<td><strong>F90.1 Attention-deficit hyperactivity disorder, predominantly hyperactive type</strong></td>
</tr>
<tr>
<td></td>
<td><strong>F90.2 Attention-deficit hyperactivity disorder, combined type</strong></td>
</tr>
<tr>
<td></td>
<td><strong>F90.8 Attention-deficit hyperactivity disorder, other type</strong></td>
</tr>
<tr>
<td></td>
<td><strong>F90.9 Attention-deficit hyperactivity disorder, unspecified type</strong></td>
</tr>
<tr>
<td></td>
<td>– Attention-deficit hyperactivity disorder of childhood or adolescence NOS</td>
</tr>
<tr>
<td></td>
<td>– Attention-deficit hyperactivity disorder NOS</td>
</tr>
<tr>
<td></td>
<td>– A behavior disorder in which the essential features are signs of developmentally inappropriate inattention, impulsivity, and hyperactivity.</td>
</tr>
</tbody>
</table>

If this looks like a huge, complicated system—rest assured: your AAP SODB-P-Society for Developmental and Behavioral Pediatrics Collaborative Coding Committee is going to crosswalk the relevant DB ICD-9-CM codes to the new ICD-10-CM codes. This will be done by the summer of 2014 so you will be ready for the October 1, 2014 start! In addition, you might want to check out the AAP Pediatric Code Crosswalk: ICD-9-CM to ICD-10-CM.

If you are in a large medical center, they have been instructed to have an implementation plan in place to help medical providers make the transition as smoothly as possible. A call to your Compliance Office should give you information about how your institution is going to train you. If you are in a small practice—or are a solo provider—you’ll want to review the information provided on various Web sites below:

- ICD-10 and HIPAA Federal Register notices

And remember, the AAP Committee on Coding and Nomenclature continues to provide resources, including the [Principles of Pediatric ICD-10-CM Coding](#) and an enduring “Transitioning to 10” column in its [AAP Pediatric Coding Newsletter](#) to help with the transition to ICD-10-CM!
### Selected NCE 2013 Section on Developmental & Behavioral Pediatrics Sponsored Sessions

#### Saturday October 26

<table>
<thead>
<tr>
<th>Time</th>
<th>Number</th>
<th>Title</th>
</tr>
</thead>
<tbody>
<tr>
<td>8:00 – 3:30 PM</td>
<td>H1017</td>
<td>Joint Program: Council on Children With Disabilities and Section on Developmental &amp; Behavioral Pediatrics—Addressing Mental Health Problems in Youth With Neurodevelopmental Disabilities</td>
</tr>
<tr>
<td>2:00 – 2:45 PM</td>
<td>F1069</td>
<td>CAM for Children With Developmental-Behavioral Disorders: The Good, the Bad, and the Ugly – Repeats as F2037 Sunday 8:30-9:15 AM</td>
</tr>
<tr>
<td>4:00 – 5:30 PM</td>
<td>S1111</td>
<td>What Do I Do With These NICU Grades? – Repeats as S2133 Sunday 4:00-4:45 PM</td>
</tr>
<tr>
<td>4:00 – 5:30 PM</td>
<td>S1114</td>
<td>Rest for the Weary: Managing Sleep Problems in Children – Repeats as S2050 Sunday 8:30-10:00 AM</td>
</tr>
<tr>
<td>4:00 – 5:30 PM</td>
<td>I1111</td>
<td>Early Detection of Neuromotor Disorders: Do We Know What to Look For? – Repeats as I2047 Saturday 8:30-10:00 AM</td>
</tr>
<tr>
<td>4:00 – 5:30 PM</td>
<td>S1113</td>
<td>Toxic Stress and the Impact on Health Outcomes: Changing the Trajectory</td>
</tr>
</tbody>
</table>

#### Sunday October 27

<table>
<thead>
<tr>
<th>Time</th>
<th>Number</th>
<th>Title</th>
</tr>
</thead>
<tbody>
<tr>
<td>7:00 – 8:00 AM</td>
<td>X2004</td>
<td>Speaking to Schools: Helping Your Patients Obtain the Special Educational Services They Need</td>
</tr>
<tr>
<td>7:00 – 8:00 AM</td>
<td>X2007</td>
<td>Beyond Time-Out: Tools for Positive Parenting</td>
</tr>
<tr>
<td>8:30 – 10:00 AM</td>
<td>S2051</td>
<td>Stop Bullying in the Medical Home – Repeats as S4078 Tuesday 2:00-3:30 PM</td>
</tr>
<tr>
<td>8:30 – 10:00 AM</td>
<td>S2054</td>
<td>Autism: What’s New and What to Do?</td>
</tr>
<tr>
<td>2:00 – 3:30 PM</td>
<td>I2094</td>
<td>Technology in Communication and Play for Children With Disabilities</td>
</tr>
<tr>
<td>2:00 – 3:30 PM</td>
<td>S2102</td>
<td>There’s No Place Like Home: Caring for Children With Complex Chronic Conditions at Home</td>
</tr>
<tr>
<td>3:00 – 3:45 PM</td>
<td>F2110</td>
<td>Victims of Violence: Diagnosis and Management</td>
</tr>
<tr>
<td>4:00 – 4:45 PM</td>
<td>F2120</td>
<td>More Common Than Autism: Identification and Management of Children With Intellectual Disability – Repeats as F3031 Monday 8:30-9:15 AM</td>
</tr>
<tr>
<td>5:00 – 5:45 PM</td>
<td>F2145</td>
<td>Words Can Hurt: The Psychological Maltreatment of Children</td>
</tr>
</tbody>
</table>

#### Monday October 28

<table>
<thead>
<tr>
<th>Time</th>
<th>Number</th>
<th>Title</th>
</tr>
</thead>
<tbody>
<tr>
<td>8:30 – 9:15 AM</td>
<td>F3032</td>
<td>Psychopharmacology Basics for Primary Care – Repeats as F3080 Monday 2:00-2:45 PM</td>
</tr>
<tr>
<td>9:30 – 10:15 AM</td>
<td>F3058</td>
<td>Putting Health Care Transition Into Practice – Repeats as F4039 Tuesday 9:30-10:15 AM</td>
</tr>
<tr>
<td>2:00 – 3:30 PM</td>
<td>S3089</td>
<td>ADHD Tricks of the Trade – Repeats as S4088 Tuesday 4:00-5:30 PM</td>
</tr>
<tr>
<td>2:00 – 3:30 PM</td>
<td>A3086</td>
<td>Quirky Normal or Normally Quirky? Inattentive, Delayed, or Autistic: You Make the Diagnosis – Repeats as A4069 Tuesday 2:00 – 3:30 PM</td>
</tr>
<tr>
<td>3:00 – 3:45 PM</td>
<td>F3104</td>
<td>The Young and the Restless: ADHD in Preschoolers – Repeats as F4013 Tuesday 8:30-9:15 AM</td>
</tr>
<tr>
<td>3:00 – 3:45 PM</td>
<td>F3102</td>
<td>Supporting the Grieving Child and Family</td>
</tr>
<tr>
<td>4:00 – 5:30 PM</td>
<td>S3123</td>
<td>Management of Behavioral Problems – Repeats as S4025 Tuesday 8:30-10:00 AM</td>
</tr>
</tbody>
</table>

#### Tuesday October 29

<table>
<thead>
<tr>
<th>Time</th>
<th>Number</th>
<th>Title</th>
</tr>
</thead>
<tbody>
<tr>
<td>7:00 – 8:00 AM</td>
<td>X4007</td>
<td>What Is Really Best for the Kids: Counseling Parents Who Divorce</td>
</tr>
<tr>
<td>9:30 – 10:15 AM</td>
<td>F4036</td>
<td>Vulnerable Populations and Obesity: What Do We Need to Know?</td>
</tr>
<tr>
<td>10:50 – 11:10 AM</td>
<td>P4045</td>
<td>Why Pediatric Management of ADHD Matters: Adult Outcomes of Childhood ADHD</td>
</tr>
<tr>
<td>11:10 – 11:30 AM</td>
<td>P4046</td>
<td>Early Screening and Diagnosis in Autism Spectrum Disorders: How Low Can We Go?</td>
</tr>
<tr>
<td>12:30 – 1:30 PM</td>
<td>X4057</td>
<td>Do You Solemnly Swear: How to Be a Good Witness in Juvenile and Family Court</td>
</tr>
<tr>
<td>4:00 – 5:30 PM</td>
<td>S4090</td>
<td>Epigenetics: Nature vs Nurture—Impact of Early Adverse Experience on Development, Learning, and Health</td>
</tr>
</tbody>
</table>

For a complete listing of SODBp sponsored sessions, please visit [www.dbpeds.org](http://www.dbpeds.org)