American Academy of Pediatrics

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COCWD
Council on Children with Disabilities
American Academy of Pediatrics

Council on Children with Disabilities Newsletter **September 2006**

Highlights in this Issue:

Page 2	DSS Activities
Page 3	National Medical Home Autism Initiative Information
Page 4	Coding for Developmental Screening
Page 6-7	NCE News
Page 8-12	New Resources
Page 13-14	Upcoming Conferences
Page 15	Fellowship Opportunity & "Getting in the Know"
Page 16	CDC: "Delay Found in Evaluation and Diagnosis of Autism"
Page 17	EP Magazine: Position on the Use of Restraints and Aversives
Page 18	Transition Program for Adolescents and Young Adults
Page 21-22	DSS Algorithm

Newsletter Editor:
Michelle Healy, MD, FAAP

Newsletter Designer: Ginny Chanda

Chairman's Column

"ADHD:A Neurodevelopmental Disorder" by Paul H. Lipkin, MD, FAAP

I recently reviewed materials regarding ADHD and the following statement struck me: "ADHD is the most common mental health disorder in childhood." While one has a hard time arguing against this point, I always wince upon reading it. If one looks at the history of this disorder, its original construct was neurological, classified as 'minimal brain damage' (MBD). However, over the decades, it has shifted out of the academic purview of pediatrics and neurology and into the worlds of psychiatry and psychology, thus becoming a 'mental health disorder'.

Is ADHD a mental health disorder? The symptoms of inattention, hyperactivity, and impulsivity can clearly result in disruptive behaviors with associated interpersonal problems. Therefore, this does indeed meet many professional's definition of a mental health disorder. However, what has this designation offered those affected by this problem? New medications are available due to the recognition of associated neurobehavioral conditions, such as depression. We have also seen an explosion of treatments emerge from non-medical professionals, both conventional and unconventional, particularly amongst those in the mental health field. Some of these treatments have a proven benefit, such as behavioral therapies. Most, however, promise cures or improvements but usually fall short. We have also seen recognition of the role that educators could play, given the significant challenges this disorder creates in the classroom as well as the high prevalence of associated learning disabilities. Perhaps we should consider ADHD a cognitive or educational disorder.

However, in considering it a mental health disorder, the biologic underpinnings of ADHD are lost. Nevertheless, the fact remains that the greatest gains in treatment remain those attributed to the stimulant medications. We have also gained a better understanding of its foundation in the central nervous system. In recent years, investigators have recognized sleep disorders with ADHD, independent of treatment with medication. With an explosion of interest in sleep medicine, we can expect new treatment opportunities for children. We also now know that tic disorders have similar CNS roots to ADHD. New etiologies include specific chromosomal disorders and toxins such as intrauterine alcohol. Research centered on post-streptococcal infection (PANDAS) has even suggested infectious and autoimmune causes. A developmental perspective has also emerged, with the establishment and recognition of ADHD in preschoolers, adolescents, and adults.

Our Council members remain interested and treat children with ADHD across the lifespan, offering unique insights and addressing many forgotten or never considered consequences of this disorder. The original construct of MBD noted problems in behavior, but also problems in learning and motor coordination. Thanks in part to the universal adoption of special education, the educational community has incorporated ADHD and related learning disorders into programming. However, we have witnessed a loss of interest in the motor disorders seen in affected children. Given the focus on fitness, these problems need greater attention. What are the consequences of a child's inability to participate in group sports due to poor athletic skills? Can we offer new treatments when poor coordination occurs to combat these consequences? We in the disability field, including PT and OT, may be able to offer unique and fresh insights into these problems. Our special knowledge in language development and our relationships with speech-language pathologists can also create unique new insights on the social-pragmatic and cognitive consequences of ADHD.

As we move forward in the investigation and treatment of ADHD, we should recognize it as neurodevelopmental disorder, and amongst the most common. We as clinicians and investigators must push for the re-conceptualization of ADHD beyond mental health in order to address the array of disabilities that the children may experience throughout their lives.

Best Regards,
Paul

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COCWD's Developmental Surveillance and Screening Activities

Policy Statement & Algorithm

Have you seen the policy statement, **"Identifying Infants and Young Children With Developmental Disorders in the Medical Home: An Algorithm for Developmental Surveillance and Screening"** that was published in the July issue of *Pediatrics?* This policy represents a unique approach and collaboration to policy writing as the statement was co-authored by the COCWD, Section on Developmental Behavioral Pediatrics, Bright Futures Steering Committee, and Medical Home Initiatives for Children With Special Needs Project Advisory Committee. Dr. Paul Lipkin and Dr. John Duby represented the COCWD on this statement.

The policy statement provides an **algorithm** (shown on page 21-22) as a strategy to support health care professionals in developing a pattern and practice for addressing developmental concerns in children from birth through 3 years of age. You will notice that in your July issue of PEDIATRICS, the algorithm was included as a perforated tear-out for ease of use. Also included within the statement are tables of developmental screening **tools** and **CPT codes** for developmental screening.

Please visit the COCWD policy webpage to access this policy statement and algorithm, the *AAP News* article: "AAP policy, algorithm assist in early developmental screens", information about the **Developmental Surveillance and Screening Policy Implementation Project (D-PIP)**; which is looking at 17 practices across the country to determine if use of the algorithm affected developmental surveillance and screening in the practice (see below), and under **"Additional Information/ Resources"** you will be linked to other developmental surveillance and screening resources on www.medicalhomeinfo.org.

If you have any feedback, questions, or comments about the policy statement or the webpage, please e-mail Stephanie Skipper at sskipper@aap.org.

New COCWD Clinical Report

COCWD is happy to announce the publication of their newest clinical report: **"Sexuality of Children with Adolescents with Developmental Disabilities"** in the July issue of *Pediatrics*. The report was written by Dr. Ellen Roy Elias (Denver) and Dr. Nancy Murphy (Salt Lake City). Drs. Elias and Murphy are both members of the COCWD Executive Committee.

Dr. Elias

This report discusses issues of puberty, contraception, psychosexual development, sexual abuse, and sexuality education specific to children and adolescents with disabilities and their families. Pediatricians, in the context of the medical home, are encouraged to discuss issues of sexuality on a regular basis, ensure the privacy of each child and adolescent, promote self-care and social independence among persons with disabilities, advocate for appropriate sexuality education, and provide ongoing education for children and adolescents with developmental disabilities and their families.

Dr. Murphy

Please visit the **COCWD policy webpage** for access this clinical report and to the *AAP News* article: "Discuss sexuality with developmentally disabled patients". In addition, you can also find **"Additional Information/Resources"** that includes a listing of resources collected from COCWD members and beyond that include: brochures, booklets, websites, curricula, organizations, etc., that focus on sexuality issues for CYSHCN.

If you have any feedback, questions, or comments about the clinical report or the webpage, please email Stephanie Skipper at sskipper@aap.org.

Developmental Surveillance and Screening Policy Implementation Project (D-PIP)

The 17 pediatric practices selected to participate in the D-PIP began implementation of the AAP policy statement titled, "Identifying Infants and Young Children with Developmental Disorders in the Medical Home: An Algorithm for Developmental Surveillance and Screening" in July. On June 16, 2006 these 17 practices sent a team of 3 (one pediatrician plus 2 practice staff) to the national AAP to attend a training workshop on the new policy statement.

A Web site has been developed that provides materials from the training workshop, including resources to help practices implement the policy statement. The Web site is continually updated with new information and is available at http://www.medicalhomeinfo.org/screening/DPIP.html. Please contact Jill Ackermann (jackermann@aap.org), Manager, Medical Home Surveillance and Screening, if you have any questions about the D-PIP.

D-PIP
Developmental Surveillance and Screening Policy Implementation Project

NMHAI Waisman Center ■ Room A146 ■ 1500 Highland Avenue ■ Madison, Wisconsin 53705-2280 ■ Phone 608-890-0145

The National Medical Home Autism Initiative (NMHAI) is a project of the University Center for Excellence in Developmental Disabilities at the Waisman Center, University of Wisconsin - Madison. NMHAI is funded as a cooperative agreement with DHHS / HRSA / MCHB Division of Services for Children with Special Health Care Needs (DSCSHCN) / Medical Home Initiatives. The project team includes Primary Investigator: William Schwab, MD – UW Madison Department of Family Medicine; Co Investigators: Daniel Bier, MPA, MSW – Associate Director and Linda Tuchman, PhD – Waisman Center, UW Madison; Pediatric Consultant: Mark Rosenberg, MD – Chicago Illinois; and Project Coordinator: Christine Breunig, MS – Waisman Center, UW Madison.

The "priority" for this national project is to develop strategies to improve the capacity of the medical home and early intervention community to identify, appropriately serve, and integrate children with Autism Spectrum Disorders (ASD) into their communities.

With estimated prevalence rates of 1 in 166 children diagnosed with ASD (AAP: Autism A.L.A.R.M.) these conditions are now among the most common of the developmental disorders. Parents of children with ASD frequently struggle to obtain a timely and accurate diagnosis, and to gain entry into appropriate intervention programs. Similarly, child health professionals often feel challenged in meeting the needs of children with ASD and their families. The NMHAI seeks to explore and develop quality improvement models for the medical home that will effectively enhance comprehensive care and services for children with ASD.

The NMHAI is working in partnership with 10 primary care pediatric practices (8 Wisconsin, 1 Illinois and 1 South Carolina) to develop strategies and resource options that will allow primary care / medical home practices to enhance and or improve their quality of services in four key functions: 1) Developmental Screening and Diagnosis; 2) Culturally Competent Family Centered Care; 3) Ongoing Care and Treatment (including specialty care); and 4) Care Coordination.

Emphasis is given to the development of partnerships with specialty care, early intervention, ducation, family organizations and other community services, supports and resources. This is accomplished through technical assistance and resource activities and collaboration with other medical home, family, and public awareness initiatives that are specifically addressing Autism Spectrum Disorders.

Additionally this project provides support and assistance to the Maternal Child Health Bureau in its work with the Federal Interagency Autism Coordinating Committee (IACC) to review current medical care delivery models in an effort to develop and promulgate professional guidelines for Autism Spectrum Disorders services.

You can learn more about the Medical Home Partnerships, NMHAI Framework and available resources on the NMHAI website http://www.waisman.wisc.edu/nmhai/index.html including a video stream of the "*National Conversation On Disparities In Autism Diagnosis"* http://www.waisman.wisc.edu/nmhai/WHATSNEW.HTML

For more information contact Christine Breunig, NMHAI project coordinator at 608/890-0145 or breunig@waisman.wisc.edu.

Is Your One-Year-Old Communicating with You?

This brochure helps encourage parents to share any concerns they have about their baby's language development as early as possible. Provides early language and social milestones that parent can watch for in their one-year-old child.
Click here to order online. For all AAP publications visit our online bookstore at www.aap.org/bst

CORRECT CODING FOR DEVELOPMENTAL SCREENING

Lynn M. Wegner, MD, FAAP

96110: Developmental Testing Limited aka Developmental Screening or CPT 96110:
This code covers the administration of a standardized screening instrument to a parent, caretaker, teacher or other informed observer of a child. It is the CPT code we will use as we follow the recently revised AAP developmental screening policy statement recently published in *Pediatrics ("Identifying Infants and Young Children with Developmental Disorders in the Medical Home: An Algorithm forDevelopmental Surveillance and Screening" Pediatrics.2006: 118(1);405-420.)*

It is essential we all understand how to properly use this code for accurate payment for the screening service we provide our patients.

CPT 96110 was developed to cover the service of a *non-physician* administering a standardized screening instrument to the child's guardian or other observer. This might mean reading the questions to the adult(s) if they are unable to read with comprehension at a fifth grade level (the reading level of most published developmental screening instruments). It might mean giving the instrument to the adult, explaining how to mark their answers and then letting them complete the forms independently (or answering specific questions as needed.)

After the guardian completes the questions, the staff person scores the instrument and shows the results to the physician. At that point, the doctor either indicates the score is 'satisfactory' and no further investigation seems indicated or will tell the office personnel to schedule another visit for expanded history from the parent(s) and possibly standardized observations (i.e. developmental testing) or a referral to another professional for further developmental attainment assessment (e.g. referral to a speech pathologist, occupational therapist or child psychologist.) As the 96110 code is expected to be done at a 'well-child' visit (e.g. "preventive service" 99392/93) or another 'evaluation and management' appointment (e.g. 99203-5, 213-5), the brief time the physician spends reviewing the screener score and discussing with the parents the need for another visit should be included under the "evaluation and management" code. This is the reason there was no request for physician work to be included in 96110. This code did not appear to need the particular expertise of a physician and the brief physician involvement was accounted for in the description of the accompanying 'evaluation and management code.' Expecting reimbursement for physician 'work' for both codes at the same visit would be 'double dipping' and very much to be avoided.

If you look closely at the descriptor in the AMA CPT manual, you'll see mention of a 'report' in the code descriptor. Here are two very acceptable 'reports' for this service and they should be included in the note for the visit:

General Pediatrician:
Example A: "Mary's mother, Mrs. Jones, was given the PEDS to complete and her responses showed no significant concerns in any areas of Mary's developmental attainment. This concurs with my observations. Will screen again at the next preventive visit or sooner if concerns arise."

Example B: "At today's visit for Mary's recent middle ear infection, Mary's mother, Mrs. Jones, was given the PEDS to complete and her responses showed 'elevated' levels of concern for expressive language. With Mary's history of recurrent middle ear effusions, will refer for formal hearing thresholds. Mrs. Jones agrees and referral made after this visit.

(Cont'd on next page)

Correct Coding Cont'd

Subspecialist or General Pediatrician as Consultant:

Example C: "As a part of today's consultation, Mrs. Jones was asked to complete the Behavior Assessment system for Children-Parent Version (BASC-P.) Her responses showed 'clinically significant' levels of concern for the following areas: hyperactivity, attention and conduct. These results were consistent with her history of Mary's extreme distractibility and high activity level since her pre-school years. Will discuss the DSM diagnostic criteria for 'attention deficit disorder' with her."

Here is correct coding for various visits:

Example A: Preventive service visit (aka "well child check-up") with screening= 99393-25, 96110

Example B: Evaluation and Management service with screening = 99213-25 (or 214 if additional concerns about Mary's health status, developmental attainment achieved longer 'time' for the visit), 96110

Example C: Evaluation and Management Consultation service with Screening = 99244-25, 245-25, 96110

Note: You append the modifier -25 to the E/M code as it is a significant, separate service from the screening procedure

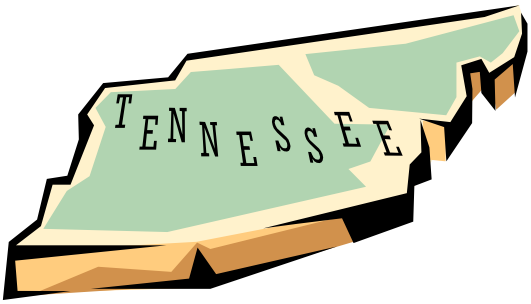
Finally, 96110 *may be coded as many times on the billing sheet as screening instruments were administered.*

Example D: E/M visit 99214 with screening instrument given to child's mother, grandmother and pre-school teacher for their observations: 99214-25, (3) 96110

You may properly code multiple units of 96110, however payers may not always agree to pay you for multiple units. Please let the AAP Committee on Coding and Nomenclature (AAP staff liaison, Linda Walsh, (lwalsh@aap.org) know if payers in your area are restricting payment to only ONE unit of 96110 per visit!

While Medicare has allocated $10.34 for each unit of 96110 (2006 data), this may seem like 'small change. If you have ever watched a 'penny jar' fill up, you'll understand how these small amounts can make a big impact over a year's revenue!

Dr. Wegner is the Chair of the AAP Section on Developmental and Behavioral Pediatrics and also a member of the COCWD



Tennessee Chapter News

The Tennessee chapter of AAP initiated a program called START to train PCPs in developmental/ behavioral screening with funding from the TNCARE bureau under an EPSDT grant in November, 2004. Over 221 physicians have been trained plus office staff and NPs. Since this program began, there has been a six-fold increase in referrals to the Tennessee Early Intervention Program. TEIS assures TNAAP that the referrals have been very appropriate. Referrals to other agencies such as PT, OT, speech and language, and counseling have also increased.

Columbia Pediatric Clinic, Columbia, TN, started a pilot project with Centerstone, a not-for-profit behavioral health organization, to coordinate mental health services for children in our 3 offices in November 2005. Columbia Pediatrics has 10 pediatricians and two pediatric nurse practitioners in three offices, serving south central middle Tennessee. The practice serves children on TNCARE, commercial insurance and all others. Centerstone has placed a full time coordinator, a social worker, and a case manager in our office. With this program and developmental/behavioral screenings, the number of referrals for mental health services has increased dramatically. Children are being seen much quicker by Centerstone, coordination of care is much improved, and communication is very good. Children and parents are very satisfied and care is much improved. We hope to expand this project to other practices in Tennessee.

For more information about the TNAAP Chapter, please visit us at: www.tnaap.org

Submitted by Patricia C. Davis, MD; COCWD Liaison to Tennessee

National Conference and Exhibition

Special Session Focuses on Disaster Preparedness
Georgia World Congress Center, Room B308/B309

A special pre-NCE session will be held on Friday, October 6, from 1:00 p.m. to 6:30 p.m. titled "Pediatric Issues for the 21st Century: Disaster Preparedness, Response & Recovery for Children & Pediatricians." This session will bring together three pediatricians and key industry professionals who have first-hand knowledge of dealing with disasters and advice for other pediatric health care professionals on how to prepare for mass disasters.

For additional information, please visit www.aap.org/peds-21.

AMERICAN ACADEMY OF PEDIATRICS
PEDS 21 PEDIATRICS FOR THE 21st CENTURY SYMPOSIUM SERIES

2006 Arnold J. Capute Award Winner

Mark L. Batshaw, MD, FAAP

We congratulate Mark L. Batshaw, MD, FAAP, the 2006 recipient of the Arnold J. Capute Award! This award will be presented to Dr. Batshaw during the COCWD program (Saturday, October 7th at 9:15 am) at the 2006 AAP National Conference and Exhibition (NCE) in Atlanta. The program will be held in the Georgia World Congress Center (Room A401).

Dr. Batshaw received his B.A. from the University of Pennsylvania and M.D. from the University of Chicago. He completed a pediatric residency at the Hospital for Sick Children in Toronto and his fellowship in Neurodevelopmental Disabilities at Johns Hopkins and the Kennedy Institute in Baltimore where he remained on faculty. In 1988 he moved to Philadelphia to become Physician-in-Chief of Children's Seashore House at the University of Pennsylvania. In 1998 Dr. Batshaw was appointed Chief Academic Officer at Children's National Medical Center in Washington, DC; he is also Associate Dean for Academic Affairs at George Washington University School of Medicine and Health Sciences. Dr. Batshaw has written over 150 scientific articles as well as a number of books, included the classic textbook *Children with Disabilities*, now in its 5th edition.

On behalf of the Council on Children with Disabilities, we congratulate Dr. Batshaw and thank him for his continued dedication and service to the pediatric community. We look forward to seeing many COCWD members at the COCWD program – to share this special day with Dr. Batshaw.

For more information about the COCWD program and other education sessions sponsored by the COCWD at the NCE, please visit: http://www.medicalhomeinfo.org/about/CSOCWDed.html.

Frederick B. Palmer, MD, FAAP
Chairperson, 2006 Capute Award Committee

The COCWD is proud to sponsor the following sessions at the AAP National Conference and Exhibition.

We invite all of our members to attend!

Saturday, October 7

H110 Council on Children With Disabilities Program
8:00am-12:00pm
Topic: Advancing our Understanding of the Etiology of Developmental Disabilities

- **Advances in Neuroimaging for the Child with Disabilities**
  Alexander H. Hoon Jr, MD, MPH, FAAP
- **Arnold J. Capute Award Presentation**
- **Advancing our Understanding of the Etiology of Birth Defects and Developmental Disabilities**
  Sonja A. Rasmussen, MD, MS, FAAP
- **Council Business Meeting**

(WE INVITE ALL COCWD MEMBERS TO ATTEND)

Seminars

S130 Care Coordination for Children & Youth w/Special Health Care Needs: Providing It & Getting Paid For It
10:00am-12:00pm
W. Carl Cooley, MD, FAAP & Peter Rappo, MD, FAAP

S132 Early Identification and Evaluation of Autism
10:00am-12:00pm
Marshalyn Yeargin-Allsopp, MD, FAAP & Catherine Rice, PhD

S163 Coming Home to America: Working With Families in the First Year After International Adoption
1:30pm-3:30pm
Elaine Schulte, MD, MPH, FAAP & John Stirling, MD

S166 Care Coordination for Children & Youth w/Special Health Care Needs: Providing It & Getting Paid for It
1:30pm-3:30pm
Repeat of S130

S167 Tailoring Treatment in Autism
1:30pm-3:30pm
Susan L. Hyman, MD, FAAP & Susan E. Levy, MD, FAAP

S190 Early Identification and Evaluation of Autism
4:00pm-6:00pm
Repeat of S132

For more info on COCWD sessions: click here

For more information on the NCE: www.aap.org/nce

Sunday, October 8

Seminars

S233 Early Recognition of Neuromuscular Diseases
10:00am-12:00pm
Katherine D. Mathews, MD

S240 Tailoring Treatment in Autism
10:00am-12:00pm
Repeat of S167

Meet-the-Expert Discussions

X249 Strategies to Improve Communication & Co-management Practices Between Specialty Physicians & Community-based PCPs in the Medical Home
12:15pm-1:15pm
W. Carl Cooley, MD, FAAP

X250 Everything You Need to Know About Early Intervention But Were Afraid to Ask—How Pediatricians Can Interface Effectively With Early Intervention
12:15pm-1:15pm
Paul H. Lipkin, MD, FAAP

Workshops

W299 Developmental Surveillance and Screening: Walking and Talking Through the New Algorithm
4:00pm-6:00pm
Paul H. Lipkin, MD, FAAP & Michelle Macias, MD, FAAP

Monday, October 9

Workshops

W343 Developmental Surveillance and Screening: Walking and Talking Through the New Algorithm
10:00am-12:00pm
Repeat of W299

Seminars

S363 Occupant Restraint for Children With Special Health Care Needs
1:30pm-3:30pm
Marilyn Bull, MD, FAAP

Selected Short Subjects

F375 Identifying and Dealing with Early School Problems
5:00pm-5:50pm
Damon Korb, MD, FAAP

Tuesday, October 10

Selected Short Subjects

F439 Identifying and Dealing with Early School Problems
1:30pm-2:20pm
Repeat of F375

New Resources

What Does Normal Mean?

A Documentary Film Exploring the World of Students with Disabilities

The 60-minute documentary film "What Does Normal Mean?" follows seven students with disabilities through an academic year as they attend regular classes with their friends. Three award-winning documentary filmmakers visited elementary, middle, and high schools in urban and rural communities in New Mexico. The film-makers and the producers, two of whom have sons with disabilities, created a film that illustrates how inclusion can succeed and learning environments improve when school administrators, teachers, families, and disabled students and their friends work together.

The stars of "What Does Normal Mean?" are Rudy Via, Brandon Via, Tara Matzick, Kade Goss, Phillip Contreras, Rebecca Salazar, and Seda McLuckie. Among them, they are blind, have severe dyslexia, cerebral palsy, down syndrome, anacephaly, seizure disorders, a neuromuscular disease, and medical fragility. They are cowboys, artists, track stars, honor roll students, public speakers. In some ways, the students are extraordinary. But in most ways, they are just like other kids.

COST:
$50 for individuals and family-run organizations plus shipping and handling
$100 for schools, agencies, institutions, businesses plus shipping and handling

TO ORDER COPIES OF THE FILM:
Contact Lacey Keene (lkeene@familyvoices.org) or Eric Ulibarri (eulibarri@familyvoices.org) at Family Voices or call: 888/835-5669. Or order online at: http://www.familyvoices.org/whatdoesnormalmean.htm

A Toolkit on Child Development: Learn the Signs. Act Early.

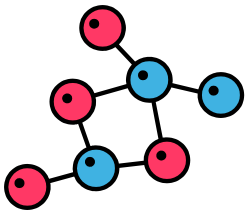
The Centers for Disease Control and Prevention (CDC) has launched an awareness campaign to educate parents, health care professionals, and child care providers about childhood development, including early warning signs of developmental disorders. The earlier a child with a developmental delay receives appropriate assessment and intervention, the better the outcome can be.

To help prepare the health care community for the anticipated increase in questions and requests for information from parents, CDC has developed a Provider Resource Kit. This kit contains materials designed to help you communicate with parents about child development, including a series of fact sheets on child development and developmental screening and informational cards for parents listing developmental milestones by age. Materials in this kit are printed in Spanish on the reverse side.

CDC has tools available on the campaign's Web site to help chapter leaders publicize the campaign to their constituents. You can request samples of the kits, along with fliers about how to order the free campaign materials for distribution to members. You can download a presentation complete with speaker's notes, for workshops and general sessions at chapter meetings. You can also download all of the materials for free and find links to additional information and resources.

To learn more about the campaign or to order a free kit, visit www.cdc.gov/actearly.

For more information on the campaign or to discuss ways your chapter can get involved, please contact Julia Whitney at 404-498-3864 or actearly@cdc.gov



Pediatric Medical Cost Model

An updated and enhanced Pediatric Medical Cost Model that allows practices to calculate the cost of providing care to children became available on the AAP Web site July 1. Commissioned by the Academy and developed by the actuarial firm of Reden & Anders Inc., the model can be used to estimate state and locale-specific costs for each medical service recommended in the newly updated AAP Scope of Benefit Policy Statement. Two previous versions of the model have supported chapter and other AAP efforts in public and private payer advocacy. The current release has been further enhanced to provide pediatric practices a versatile tool in contract negotiations.

If you have questions, please contact Suk-fong Tang in the Department of Practice at 800/433-9016, extension 7622, or by e-mail at stang@aap.org. Additional information about the model is available at: www.aap.org/research/pedmedcostmodel.cfm.

Newborn Screening Resource

A new resource can provide pediatricians with additional details on many of the conditions detected by expanded newborn screening. Health professionals also can use the information to help communicate with family members.

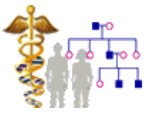
Called ACTion (ACT) sheets, the resource from the American College of Medical Genetics and the Maternal and Child Health Bureau/Health Resources and Services Administration has been endorsed by the Academy. A work group of experts developed the material.

The first page of the ACT sheet offers basic and clinical information with recommendations for follow-up after a report of an abnormality is received. The second page lists Web sites to help identify subspecialists for consultation and referral, along with other resources. To view a complete set of ACT sheets, go to www.acmg.net/resources/policies/ACT/condition-analyte-links.htm. One ACT sheet was included in the August issue of *AAP News*.

NATIONAL ACADEMY for STATE HEALTH POLICY

Resource Guide for Developmental Screening in Primary Care Practices

New on the National Academy for State Health Policy (NASHP) Web site is an office resource guide designed to help primary care practices integrate developmental screening into their workflow. The guide was developed by the Office of Research, Demonstrations, and Rural Health, North Carolina Department of Health and Human Services, as the result of two demonstration programs in integrating developmental screening and surveillance. The programs were conducted under NASHP's Assuring Better Child Health and Development (ABCD) project, supported by The Commonwealth Fund. To access these materials, visit the office resource guide.



Genetics Home Reference
Your Guide to Understanding Genetic Conditions

Genetics Resource for Providers and Families

The Genetics Home Reference is the National Library of Medicine's web site for consumer information about genetic conditions and the genes or chromosomes responsible for those conditions. Viewers of the site can find genetic condition summaries, gene summaries, chromosome summaries, a handbook to understanding genetics, and a glossary. The Genetics Home Reference also features tools and resources for patients and families, educators, health professionals and more. The Genetics Home Reference can be found at http://www.ghr.nlm.nih.gov/.

CACSHCNEWS

e-Newsletter with a Focus on Children with Special Health Care Needs in California

Download the Inaugural Issue (July 2006)

CaCSHCNews is produced quarterly by a consortium whose members work toward the common goal of improving systems of care for children with special health care needs (CSHCN) in California: California Children's Medical Services Branch (CACMS)

- Los Angeles Partnership for Special Needs Children (LAPSNC)
- Family Voices of California (FVCA)
- Children's Regional Integrated Services System (CRISS) Program
- USC University Center for Excellence in Developmental Disabilities (UCEDD) at Children's Hospital Los Angeles

This group coalesced through a series of planning efforts directed toward the development of a statewide strategic plan for CSHCN in CA. Such efforts include the California Children's Medical Services Branch Needs Assessment, the federal (MCHB-HRSA) Champions for Progress Initiative, and an MCHB-HRSA state implementation grant, Integrated Community Systems for CSHCN.

CaCSHCNews evolved out of the desire to communicate news and outcomes of these efforts to stakeholders across the state, in addition to creating a centralized source for information on both state and national issues concerning children with special needs in CA. It is hoped that this newsletter will become the "be all and end all" periodic news source for providers serving California children/youth with special needs.

To download your copy of the inaugural issue, please visit www.uscucedd.org. To receive a copy via email and for subscription, send an email to ycasillas@chla.usc.edu with *CaCSHCNews* in the subject line.

For more information about this newsletter and associated projects, please contact Kathryn Smith, RN, MN (kasmith@chla.usc.edu). If you would like to contribute news items, please contact Nikki Garro (ngarro@ucla.edu).

COMMUNITY PEDIATRICS TRAINING INITIATIVE

A program of the American Academy of Pediatrics

Pilot CATCH Residency Training Grants

The Community Pediatrics Training Initiative (CPTI) is partnering with CATCH to pilot a new grants program targeting pediatric residency training programs. The mission of this program is to provide support to residency programs to build sustainable opportunities for residents to gain experience working on community-based child health initiatives that increase access to medical homes or specific health services not otherwise available. Grants of up to $10,000 will be awarded on a competitive basis to residency programs which submit proposals to plan and implement community-based child health initiatives as part of the training curriculum over a 16-month period. The new application will be available this fall. For more info, visit: http://www.aap.org/commpeds/cpti/Opportunities.htm.

Campaign for Children's Health Care

Petition circulating on children's health care

The AAP is participating in the Campaign for Children's Health Care in coalition with dozens of other organizations. The Campaign's goal is to make high-quality, comprehensive, affordable health insurance coverage for the nation's 9 million uninsured children a national priority.

The Academy is asking its pediatricians to sign and circulate (to colleagues, family and friends) the Campaign's online petition. It calls for the president and Congress to immediately address the problem of uninsured children. Please go to: http://ga3.org/campaign/petition_main?source=aap. Signatures will be collected through spring 2007 when the Campaign partners will present the signed petition to Congress to show the depth of public support on the issue.

The Campaign Web site, www.childrenshealthcampaign.org provides an overview of other future events and activities. AAP members can contact Marjorie Tharp, AAP Dept. of Federal Affairs, 800/336-5475x3003 or mtharp@aap.org, with any questions.

Coming Fall 2006

practice management online
Helping You Help Children

A Centralized, Online Practice Management Resource for Pediatricians

http://practice.aap.org/

Practice Management Online is a resource that supports pediatricians in running a practice that is fiscally sound and efficient and provides quality health care to children and families. This resource will be a virtual home for pediatricians seeking information on practice management. This new resource will be launched at the 2006 National Conference & Exhibition in Atlanta, GA.

Practice Management Online will address 4 key areas.

- **Practice Basics**—How to start, join, or enhance a practice
- **Finance and Payment**—Helping pediatricians get paid for what they do
- **Office Operations**—Helping pediatricians run their offices as smoothly as possible
- **Patient Management**—Helping pediatricians get recognized for the quality health care they provide to children

Resources on starting a practice, hiring new partners, working with staff, coding and billing, increasing efficiency, scheduling techniques, medical liability, electronic health records, and more are provided on this new Web site. Practice Management Online will provide easy access to theoretical background as well as practical tools that have been used by pediatricians around the country.

The project is a collaborative effort between the Department of Practice and Department of Marketing and Publications within the AAP. Materials have been shared from groups such as the Section on Administration and Practice Management, Section on Telephone Care, Committee on Medical Liability and Risk Management, Council on Clinical Information Technology, and Immunizations Task Force, to name a few.

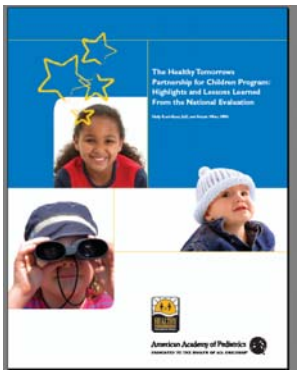
Practice Management Online will be accessible through the Member Center of the AAP Web site or directly at practice.aap.org and will provide a simple and clear search function and brief, descriptive annotations for each document to make it easy for pediatricians to find the information they need.

A demonstration of the new *Practice Management Online* Web site will be available at the AAP Resource Center in the exhibit hall at the 2006 NCE. Make sure to visit and see this amazing new resource for pediatric practices.

Practice Management Online
Helping You Help Children

***Practice Management Online* is made possible through the unrestricted support of our members and friends with their annual contributions to the AAP Friends of Children Fund.**

NEW! The Healthy Tomorrows Partnership for Children Program: Highlights and Lessons Learned From the National Evaluation



The Healthy Tomorrows Partnership for Children (HTPCP) is pleased to announce the release of a new report outlining major findings from the HTPCP National Evaluation conducted by the American Academy of Pediatrics (AAP). Implementation of community-based health initiatives continues to be a hot topic among HTPCP grantees and AAP members in general. To assist pediatricians with implementation and evaluation of these initiatives, the report features lessons learned for the following:

- Developing your community-based program
- Evaluating your community-based program
- Sustaining your community-based program

In addition to the lessons learned, the report highlights three successful HTPCP initiatives, including their accomplishments, evaluation approaches and program sustainability strategies. These lessons are designed to provide guidance to pediatricians and other child health professionals as they engage in community-based project work.

HTPCP is a cooperative agreement program between the federal Maternal and Child Health Bureau and the AAP. The program aims to stimulate the development of health programs in areas where unmet child health needs exist. HTPCP projects are 5-year grants that receive $50,000 per year to implement direct health service projects with pediatrician leadership and involvement.

To view the report online, visit www.aap.org/commpeds/htpcp/EvalSummary.html. For more information or to request a copy of the report, contact Karla Palmer at 800/433-9016, ext 4279, or kpalmer@aap.org.

National Center on Birth Defects and Developmental Disabilities
Early Hearing Detection and Intervention Program (EHDI)

EHDI Posters for Your Office -- FREE!

With the inception of the AAP Early Hearing Detection and Intervention Program (EHDI) program in 2001, the primary focus was on advocacy efforts to ensure that all children were screened for hearing loss prior to hospital discharge. Now 38 states have passed legislation mandating newborn hearing screening prior to hospital discharge. Although the specific nature of the legislation passed in states varies, these measures have made a significant impact. The percentage of babies screened for hearing loss at birth has risen to an all time high of almost 90% – a 65% increase in the past five years. However, most state programs are still addressing high referral rates and inadequate follow-up.

According to the National EHDI goals, the current recommended practice is based on a 1-3-6 approach. All infants are screened for hearing loss before 1 month of age preferably before hospital discharge; those who do not pass the initial hearing screening are rescreened and sent for audiologic evaluation and diagnosis before 3 months of age, and children with confirmed hearing loss should be enrolled in early intervention before 6 months of age.

In an effort to further educate pediatricians, other pediatric primary care providers and parents about EHDI issues, the AAP is offering you posters on this topic to display in your office/clinic setting. The posters serve as an important reminder for your colleagues and patients' parents of the importance of early hearing screening, diagnosis, and intervention.

To order a copy of the posters, contact Jennifer Gascon in the AAP Department of Community, Chapter and State Affairs, at jgascon@aap.org. Please provide your exact mailing address with your request. There is no charge for the posters.

Upcoming Conferences

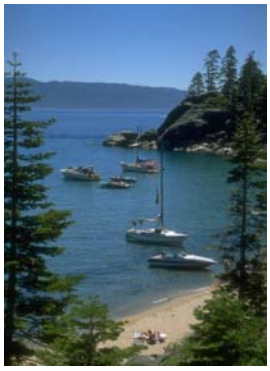
Make your plans now to attend the

2006 Annual TASH Conference

November 8—11, 2006
Baltimore, Maryland

A new generation of TASH members are stepping up to continue the unrestrained progress that has resulted due to the leadership of TASH members for more than 30 years. The TASH conference is the largest and most progressive conference in the United States that focuses on strategies for achieving full inclusion for people with disabilities. This year's TASH conference will feature over 400 breakout sessions, exhibits, roundtable discussions, poster sessions and much more. www.tash.org/2006tash

TASH is an international membership association leading the way to inclusive communities through research, education, and advocacy. TASH members are people with disabilities, family members, fellow citizens, advocates, and professionals working together to create change and build capacity so that all people, no matter their perceived level of disability, are included in all aspects of society.



Developmental Disabilities Over the Lifespan

October 20-21, 2006
Embassy Suites Lake Tahoe

NEEDS ASSESSMENT

Individuals diagnosed with developmental disabilities continue to be underserved by healthcare providers and other caregivers. This training is an ongoing effort to improve the care of this group. The program will feature a wide array of topics reflecting the reality that there are a variety of disciplines involved in providing care to this population. Primary care providers will gain information about issues facing this population, and they will be able to implement recommendations and strategies that will improve the care they provide for developmentally disabled patients and their families. This program is designed for physicians, nurses, psychologists and social workers as well as parents and other caregivers.

EDUCATIONAL OBJECTIVES

At the end of the program, participants should be able to:

- Identify Early Start issues and suggestions for addressing them
- Describe treatment implications of known genetic disorders
- Identify developmental disabilities associated with drugs and alcohol
- Describe some of the complex issues involved in dual diagnosis
- Recognize patterns of some genetic abilities and the implications for school functioning
- Identify some of the complex issues involved in competency and the right to decide
- Identify sexuality issues and recommendations for ways to handle them
- Identify some gender-specific health issues and how to address them

For more information: http://cme.ucdavis.edu; Cheryl Nelson cheryl.nelson@ucdmc.ucdavis.edu; www.embassytahoe.com

Living With Spina Bifida Conference

October 21, 2006
Best Western Washington Gateway Hotel
Rockville, MD

Presented by: Chesapeake-Potomac Spina Bifida Association, Inc.
Sponsored by: Office for Genetics and Children with Special Health Care Needs of the Maryland Department of Health and Mental Hygiene and Spina Bifida Association of America

About the Conference: Participants will learn about the neurological, orthopedic, and psychosocial conditions that can develop in individuals with spina bifida at each stage of life; learn about current best practices for the prevention and treatment of secondary conditions of spina bifida; share resources and experiences.

Designed for: primary care and specialty physicians, nurses, occupational therapists, physical therapists, and social workers. MedChi designates this activity for a maximum of 6 AMA PRA Category 1 Credit(s).

Registration: $50 fee includes breakfast, lunch, breaks, session materials, and a copy of *Living with Spina Bifida*. To register, contact Chesapeake-Potomac Spina Bifida Association, Inc. at 888/733-0988. www.chesapeakespinabifida.org

Developmental Disabilities Over the Lifespan

October 21, 2006
South Lake Tahoe, California

Topics To Be Covered: **Early start; Treatment implications of genetic disorders; Substance abuse and developmental disabilities; Sexuality; Dual diagnosis and developmental disabilities; and, Competency and the right to decide. There will also be a parent panel and a panel of experts addressing issues related to developmental disabilities over the lifespan.**

Jointly Sponsored by: UC Davis Health System The M.I.N.D. Institute AND Office of Continuing Medical Education and The California Department of Developmental Services

For additional information, please contact John R. Brown, PhD at 916/703-0228 or email john.brown@ucdmc.ucdavis.edu. Brochure providing details regarding the program will be available soon at www.ucdmc.ucdavis.edu/cme/conferences/

CDC'S 2006 NATIONAL HEALTH PROMOTION CONFERENCE

Innovations in Health Promotion: New Avenues for Collaboration

The 2006 National Health Promotion Conference is the first joint conference presented by CDC's Coordinating Center for Health Promotion (CoCHP) and its constituent groups: the National Center for Chronic Disease Prevention and Health Promotion (NCCDPHP), the National Center on Birth Defects and Developmental Disabilities (NCBDDD), and the Office of Genomics and Disease Prevention (OGDP). With a conference theme of *Innovations in Health Promotion: New Avenues for Collaboration*, the conference will provide an unprecedented opportunity to create new partnerships and strengthen existing ones to move forward with a national health promotion and wellness agenda.

Conference Date and Location

Tuesday, September 12—Thursday, September 14, 2006
Hilton Atlanta; Atlanta, Georgia

Conference Goals

CDC's 2006 National Health Promotion Conference goals are:

- Laying the foundation for a national health promotion agenda—moving from disease specific agendas to the broadest concepts and practices of wellness and health promotion;
- Providing a platform for ongoing innovation in the collaborative science and implementation of birth defects, disabilities, genomics and chronic disease prevention practices;
- Facilitating the creation of new partnerships and strengthening existing relationships.

Conference Tracks

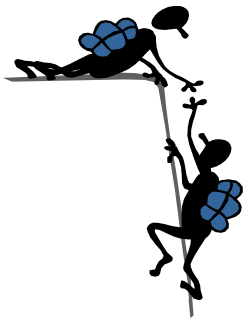
- Nontraditional partnerships
- Innovative approaches to public health practice
- Translating science and evaluating results
- Health policy and communications
- Implementing best practices at the local level
- Emerging issues and hot topics in public health

Visit the conference website for more information including online registration.

AUCD is pleased to announce another exciting fellowship opportunity under its Cooperative Agreement with the National Center on Birth Defects and Developmental Disabilities (NCBDDD) at CDC, the NCBDDD/AUCD Fellowship in Behavioral Science and Health Education. AUCD is seeking a faculty, staff, current trainee or recent graduate (within the last two years) candidate from the UCEDD, LEND, and DDRC network passionate about addressing the issues and needs of children with autism. The Fellow will have an intensive experience working primarily with an audience of health care professionals for the "*Learn the Signs, Act Early*" Campaign team. The Fellow will assist and in some instances will direct the health care professional outreach for the team, and will be involved in a wide range of activities, partnerships and assessments for this project. This is anticipated to be a two-year fellowship (one year, renewable). Applicants with medical professional degrees are highly desired. Other qualified applicants will be considered as well.

Applications can be submitted immediately online! To get additional information on this announcement go to: http://www.aucd.org; to find out more about the "Learn the Signs, Act Early Campaign" go to http://www.cdc.gov/ncbddd/autism/actearly/ and to apply online go to: http://www.aucd.org/apply. Consideration of candidates will begin in early October of 2006, and will continue until the search is successfully concluded. Start date for the fellowship is negotiable with a start date as soon as possible in 2006.

To obtain additional information, please contact Sue Lin via email at slin@aucd.org or by phone at 301/588-8252



Get in the Know!

Quick! In 3 seconds, give me the name of a supervisor at your local Early Intervention program. How about the phone number to a local Parent-to-Parent support group? Where might you find assistance in writing letters to support the need for school-based speech therapy? Many of you may know the answers to these questions, but if you're struggling, don't worry about where to go to find this information. You only need to know one phone number – your local PTI: Parent Training and Information center.

In order to help the pediatricians at Boys Town Pediatrics become great medical homes, I knew I'd need to know about community resources in Omaha. Well, coming from Chicago, I knew absolutely nothing about the services available here, so I made my first order of business to visit the Nebraska PTI. From the moment I walked through their doors, I received the royal treatment! Not only did they welcome me into their library of information on resources and services in Nebraska, but they also provided me with the names and phone numbers of key individuals who could grant me direct access to many of the child and family programs in the state. The PTI staff even offered to provide training on community resources to all of the Boys Town Pediatrics staff – free of charge!

Oftentimes pediatricians can become overwhelmed with all of the aspects of providing a medical home. It's important to remember that you don't need to do it alone. Professional parents at your local PTI are experts at navigating the health and educational systems. They know the best resources to offer parents, who to call to get things done, and better than that, they really want to partner with pediatricians. So, before you find yourself with another family, scratching your head about who to call about transition planning, make an appointment to meet the staff at your local PTI. They're the people you should know to get your practice "in the know."

Amy Gibson, MS, RN (gibsona@boystown.org)

For more information on your local PTI, visit http://www.taalliance.org/ , click on "Find your parent center."

CDC Finds 13 Month Delay between Evaluation and Autism Diagnosis in Children

Children with autism spectrum disorders (ASDs) may experience a 13-month delay before they are diagnosed. A new study, published in the May autism supplement of the Journal of Developmental and Behavioral Pediatrics, found that children diagnosed in metropolitan Atlanta were initially evaluated at an average of 4 years of age but were not diagnosed with an ASD until an average of 5 years 1 month. Instead, most children were first diagnosed with other conditions, such as language delay or general developmental delay.

"Although this study draws upon data from the metro Atlanta area, it serves as an important indicator of the nationwide challenges of diagnosing autism, particularly more mild cases," said Dr. José Cordero, director of CDC's National Center on Birth Defects and Developmental Disabilities. "The real public health challenge is to educate doctors on the signs of autism and to encourage use of standardized diagnostic instruments that better identify symptoms relevant to ASD and help distinguish ASD from other developmental delays or disorders."

According to the study, 13-month delay in ASD diagnosis existed for both boys and girls and across racial/ethnic classification. While children with more severe symptoms of autism were evaluated and diagnosed almost two years earlier than children with milder symptoms, they were not evaluated until an average of 3½ years old and were not diagnosed with an ASD until an average of 4½ years old. Previous research indicates that parents of children with an ASD report that they began to have concerns about their child's development between 1 and 2 years of age.

Seventy-six percent of the children were identified at medical facilities such as hospitals and clinics, and 24 percent were identified at schools. The study's researchers found that 70 percent of health care professionals did not use a standardized diagnostic instrument when assigning the first ASD diagnosis.

ASDs are lifelong neuro-developmental disorders characterized by early onset of social, communication, and behavioral problems that are present before 3 years of age. Early identification of ASDs leads to earlier entry into intervention programs that can help improve developmental outcomes. Therefore, it is important for parents and healthcare professionals to recognize early symptoms of ASDs so that children can receive appropriate services. It is also important that children with identified delays be administered routine developmental and autism-specific screenings. CDC designed the "Learn the Signs, Act Early" campaign to educate both parents and professionals on the early signs of autism and other developmental disorders. For more information, visit **www.cdc.gov/actearly**.

NATIONAL CENTER ON BIRTH DEFECTS AND DEVELOPMENTAL DISABILITIES

Learn the Signs. Act Early.

To obtain a full copy of the article, visit the Journal of Developmental and Behavioral Pediatrics' Web site at **www.jrnldbp.com**.

Understanding Autism Spectrum Disorders

The 44-page booklet, developed by the Academy's Autism Expert Panel (Co-chaired by COCWD members Drs Chris Johnson and Susan Hyman), was written to answer the questions of parents of children who have ASD or used as a resource for health care professionals to provide to parents upon their child's diagnosis. The booklet defines ASD, discusses the clinical features, and describes the full range of interventions (both traditional and complementary/alternative) commonly used with children with ASD over the lifespan. The booklet also addresses special concerns in the teen and adult years as well as financial and legal planning. Finally, a list of recommended books and web sites is provided.

Additional information and resources about ASDs can be found on the AAP National Center of Medical Home Initiatives for Children with Special Needs Web site at: www.medicalhomeinfo.org/health/autism.html.

Exceptional Parent Magazine Position on the Use of Restraints and Aversives in Children with Developmental Disabilities
by Rick Rader, MD, Editor-in-Chief & Joe Valenzano, Publisher

Over the past few years, EP Global Communications, Inc. and its flagship publication, Exceptional Parent Magazine [EP], have become increasingly alarmed by the proliferating use of physical restraint, seclusion, and aversive practices to address the needs of children whose intellectual or other disabilities lead to behavioral challenges. The escalating use of physical restraint, seclusion and aversives has contributed to the death or serious injury to schoolchildren throughout America. The need for vigilance is increasing because more and more schools are employing police officers and others who then use tasers and other devices to subdue children who already are at risk. EP has adopted the following position statement declaring its opposition to this escalating practice.

Exceptional Parent Magazine joins with the national organizations that have united to form the Alliance to Prevent Restraint Aversive Interventions and Seclusion [APRAIS see www.aprais.org]to declare the vision that all children should grow up free from the use of restraint, seclusion and aversive practices to respond to or control their behavior and from the fear that these practices will be used on themselves, their siblings or their friends. EP declares that it is unequivocally opposed to the inappropriate use of restraint and to the use of overly restrictive and aversive procedures under any circumstance and calls for the use of all such procedures to end immediately.

EP is concerned that in this world of ever-dwindling resources, educational and care providing personnel look to restraint, seclusion and aversive intervention because they are understaffed or for staff convenience. Others justify these practices as a means to punish bad behavior. Still others use these practices because they are unaware of alternative, more positive approaches to behavior challenges.

The clear trend and best practice to address behavior challenges is through the use of positive behavior support. Positive behavior support accepts that behavior is communication and seeks to understand and explain why the behavior is occurring. Positive behavior support plans are then created and implemented to help educate the child and provide the child with safe and positive environments within which to address the behavior.

EP has implemented a policy of rejecting advertisements, sponsorships or support from any group, organization, school, camp, residential facility or association that employs the use of aversive tactics including physical restraint and seclusion and aversive devices.

EP invites other organizations and individuals to join it in advancing behavior approaches that reject the use of physical restraint, seclusion, and aversive interventions. We thank you for the opportunity to share this with the American Academy of Pediatrics committee and appreciate the forthcoming revision of "Assessment of Maltreatment of Children with Disabilities". If we all work together we can eliminate these unsafe practices and better protect and provide for our children in a nurturing and caring environment.

For more information, contact: Exceptional Parent Magazine; 800/E-PARENT; www.eparent.com; Tricia Luker at 248/542-4128 or tluker@eparent.com; Joe Valenzano at Jvalenzano@eparent.com or Rick Rader, MD at habctrmd@aol.com

Learning Disabilities: What Parents Need to Know

This brochure assists parents in understanding and recognizing the early warning signs of learning disabilities; describes common learning disabilities; gives options for finding assistance for children who may have a learning disability; and lists resources for additional information.

Click here to order online. For all AAP publications, visit the online bookstore: www.aap.org/bst

Transition Program for Adolescents and Young Adults With CHD

During 2007, the Ahmanson/UCLA Adult Congenital Heart Disease Center (ACHDC) in Los Angeles, CA will launch its transition program for adolescent and young adult patients. The goal of this program is to further reduce the complications experienced by patients with congenital heart disease (CHD) over their lifespan. The staff at Ahamanson/UCLA plans to implement the program in two phases, starting first by offering education programs for parents of pre-teens and teenagers and following up this spring when they start scheduling a monthly clinic session designed specifically for patients 12-18 years of age.

After its 1980 opening, when it became the first center in the United States to formalize services for the rapidly growing population adult congenital heart disease patients, Ahmanson/UCLA founder and first Director, Joseph K. Perloff, MD immediately began to identify the problems faced by patients who arrived for the first appointment in their mid to late twenties. Often this was a decade after their last visit to cardiologist. His concerns were shared by Mary Canobbio, RN, MN, FAAN, then the center's first advanced practice nurse and since 2002, Administrative Coordinator for Programs, Research and Development. She reports that adult patients commonly presented with a very limited understanding of their cardiac lesion, previous surgeries or knowledge on how to minimize long-term complications. "I met too many of our young female patients when they were referred to UCLA's High Risk Obstetric Service." Canobbio states.

When current Director, John Child, MD asked Canobbio to take an active role in program development he gave full support to the design and opening of a transition program that would serve as a "step in between" Pediatric and Adult Cardiology Clinics. In response to their own experience and the input of a large referral base comprised of both academic and community based Pediatric Cardiologists, Ahmanson/UCLA plans to introduce the parents to the transition process before inviting the patients to begin. As their children approach the teen years, the parents often have questions about insurability, genetics, women's health including family planning, education/vocation choices and adolescent behavior. By offering education sessions for parents, the staff believes they can help them be better prepared to answer the questions their children will ask. With an estimated 30-50,000 CHD patients reaching adulthood each year, the answers to important questions have often changed from when the families first learned about their child's lesion in infancy.

Although the national goal of improving transition services made it easier to arrange time and space for a once monthly clinic for those patients whose parents and Pediatric Cardiologists feel they would be better served by a program and staff committed to the unique needs of adolescents, Canobbio reports that funding is an issue. With the addition of a Pediatric Cardiologist to the Ahmanson/UCLA Center staff, they are ready to move forward, but they will do so with a skeleton staff at the outset. To their advantage, they do have established working relationships with consultants at both the Mattel Children's Hospital and UCLA Medical Center.
Contact information: Mary Canobbio, RN, MN, FAAN (mcanobbi@sonnet.ucla.edu); www.achdc.med.ucla.edu

For more information on
Medical Home and Transitions
Visit: medicalhomeinfo.org/health/trans.html

Welcome to the COCWD!!

From May 1 to August 22, 2006, 16 pediatricians have joined (or rejoined) the Council on Children with Disabilities – hailing from 14 states. We welcome them and look forward to their active participation in the future!

Alabama
LaDonna Maria Crews MD (Mobile)

California
Amy Joy Houtrow MD, MPH (San Francisco)
Howard Leiter Wolfinger Jr. MD (San Diego)

Connecticut
Sobhy Ghabrial, MD (Manchester)

Florida
Nina S. Sanchez MD (Miami)

Kansas
Kathryn Anne Ellerbeck MD (Fairway)

Maryland
Lindsey K. Grossman MD (Baltimore)

Minnesota
Sherilyn Whateley Driscoll MD (Rochester)

New York
Jaishree Capoor MD (New York)
Meg Allyn Krilov MD (Brooklyn)

Ohio
Farah Aspi Wadia-Brink MD (Shaker Heights)

Rhode Island
Joseph J. Hallett MD (Pawtucket)

Tennessee
Karen Lowry Summar MD (Brentwood)

Texas
Nhung Thi-Vien Tran MD (San Antonio)

Utah
Joseph M. Johnson MD (Orem)

Virginia
Rachel D. St. John MD (Arlington)

Council on Children With Disabilities Executive Committee

(current as of 8/25/06)

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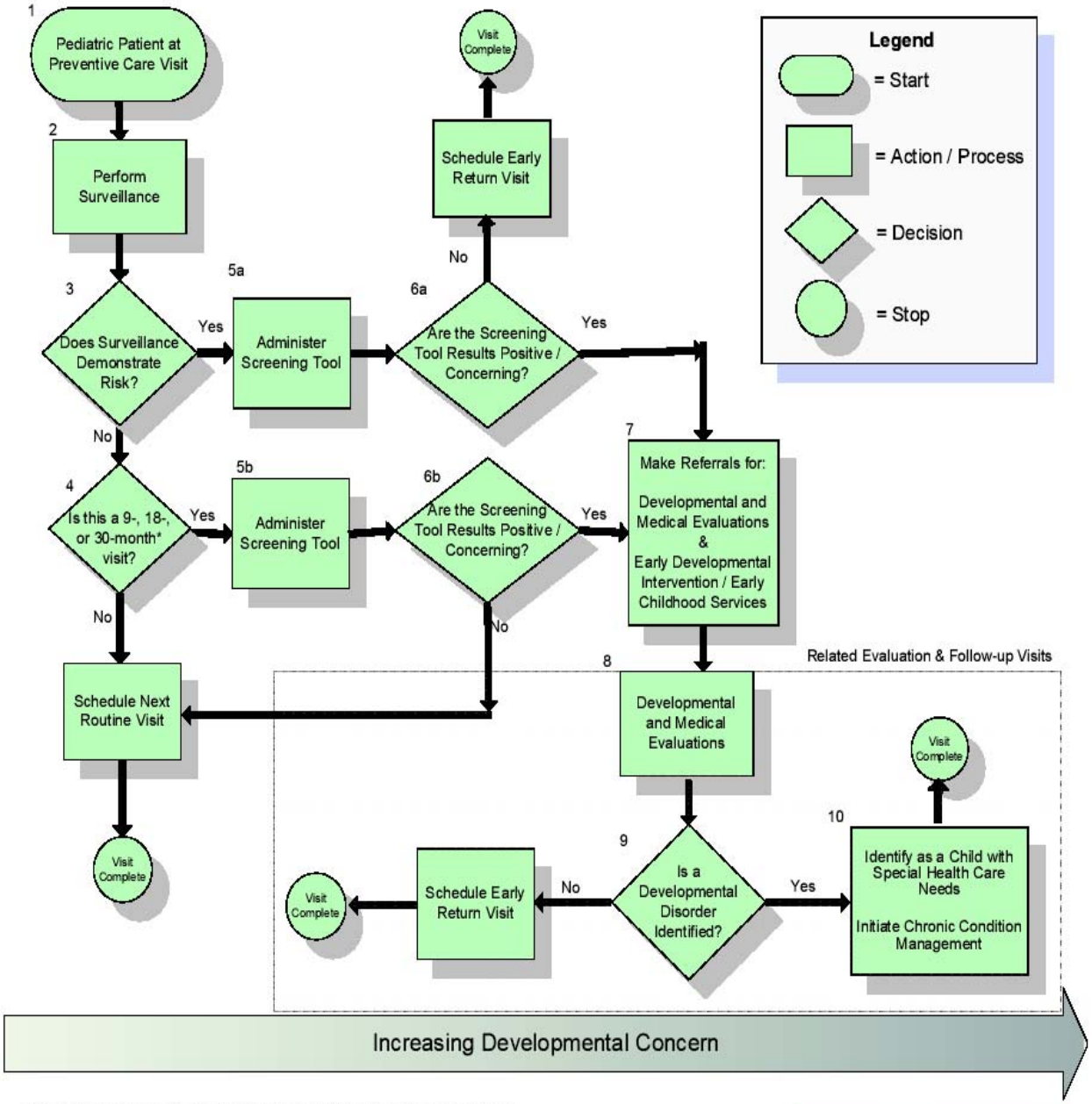
mdelmonte@aap.org

Do We Have Your Correct Contact Information?
Have you moved recently; changed phone or fax numbers? Do we have your most current board certification info & practice demographics? The contact & demographic info we collect on each member is kept confidential and secure. This data enables us to customize our messages to you & provides aggregate stats on our members. Please help us make informed decisions by keeping your personal info updated. Log on to the AAP Member Center, click on "Update my Personal Profile" in the right column, then update all data fields as necessary.

American Academy of Pediatrics
DEDICATED TO THE HEALTH OF ALL CHILDREN™

Developmental Surveillance and Screening Algorithm Within a Pediatric Preventive Care Visit



*Because the 30-month visit is not yet a part of the preventive care system and is often not reimbursable by third-party payers at this time, developmental screening can be performed at 24 months of age.

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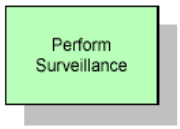
Developmental and Screening Algorithm Within a Pediatric Preventive Care Visit

1. Developmental concerns should be included as one of several health topics addressed at each pediatric preventive care visit throughout the first 5 years of life.[5]

2. ***Developmental Surveillance*** is a flexible, longitudinal, continuous, and cumulative process whereby knowledgeable health care professionals identify children who may have developmental problems. There are 5 components of development surveillance: eliciting and attending to the parents' concerns about their child's development, documenting and maintaining a developmental history, making accurate observations of the child, identifying the risk and protective factors, and maintaining an accurate record and documenting the process and findings.



3. The concerns of both parents and child health professionals should be included in determining whether surveillance suggests the child may be at risk of developmental delay. If either parents or the child health professional express concern about the child's development, a developmental screening to address the concern specifically should be conducted.

4. All children should receive developmental screening using a standardized test. In the absence of established risk factors or parental or provider concerns, a general developmental screen is recommended at the 9-, 18-, and 30-month* visits. Additionally, autism-specific screening is recommended for all children at the 18-month visit.
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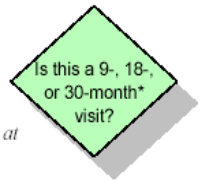
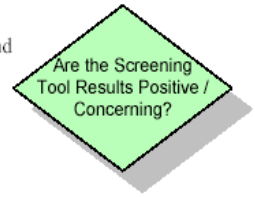
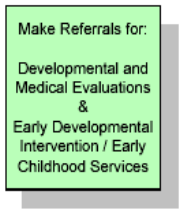


5a & 5b. ***Developmental screening*** is the administration of a brief standardized tool aiding the identification of children at risk of a developmental disorder. Developmental screening that targets the area of concern is indicated whenever a problem is identified during developmental surveillance.

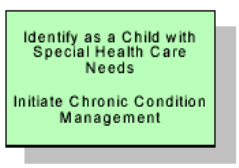
6a & 6b. When the results of the periodic screening tool are normal, the child health professional can inform the parents and continue with other aspects of the preventive visit. When a screening tool is administered as a result of concerns about development, an early return visit to provide additional developmental surveillance should be scheduled, even if the screening tool results do not indicate a risk of delay.





7-8. If screening results are concerning, the child should be scheduled for developmental and medical evaluations. ***Developmental evaluation*** is aimed at identifying the specific developmental disorder or disorders affecting the child. In addition to the developmental evaluation, a ***medical diagnostic evaluation*** to identify an underlying etiology should be undertaken. ***Early Developmental Intervention/Early Childhood Services*** can be particularly valuable when a child is first identified to be at high risk of delayed development, because these programs often provide evaluation services and can offer other services to the child and family even before an evaluation is complete.[24] Establishing an effective and efficient partnership with early childhood professionals is an important component of successful care coordination for children.[39]

9. If a developmental disorder is identified, the child should be identified as a child with special health care needs and chronic condition management should be initiated (see No. 10 below). If a developmental disorder is not identified through medical and developmental evaluation, the child should be scheduled for an early return visit for further surveillance. More frequent visits, with particular attention paid to areas of concern, will allow the child to be promptly referred for further evaluation if any further evidence of delayed development or a specific disorder emerges.



10. When a child is discovered to have a significant developmental disorder, that child becomes a child with special health care needs, even if that child does not have a specific disease etiology identified. Such a child should be identified by the medical home for appropriate chronic condition management and regular monitoring and entered into the practice's children and youth with special health care needs registry.[40]