From the President

Autism Awareness

By Phyllis J. Sloyer, RN, PhD, PAHM, FAAP

This issue of Pulse is devoted to autism and autism spectrum disorders (ASD). For many of us, this has become our most recent sentinel issue. Even before the passage of the federal Combating Autism Act of 2006, I noticed billboards in my state alerting everyone that one in 150 children had autism. The increasing awareness of ASD led to the enactment of health insurance mandates in some states while in others the focus was on the “potential causes” of autism and concern that the condition was linked to immunizations. I believe the most striking aspect of ASD is a reaffirmation of the need for solid public health approaches in partnership with our health care providers.

We understand the need for focused outreach to identify children as early as possible who may have ASD. It is one of our core functions. We also understand the need to train and work with our child health care provider partners in implementing evidenced-based screening and assessment of the condition. Certainly, we have a responsibility to provide the evidence around the effectiveness of immunizations and the possible effects of allowing immunization exemptions. Finally, we work with communities in the development of a system of services and interventions that are appropriate for children with ASD. Frankly, the elements of that system...
are not uniquely different than any system of services and central to it is a comprehensive medical home.

AMCHP will play a key role as a state public health coordinating center for autism. The association will be working with our state programs in assuring that children and youth with ASD receive early and appropriate screening, diagnosis and intervention. It is a wonderful opportunity for us to demonstrate our extraordinary capability at using our resources to promote quality and a comprehensive system of services.

By Mike R. Fraser, PhD

Autism Spectrum Disorder (ASD) brings together many maternal and child health issues including health policy and politics, healthcare financing and access, public health science and evidence-based decision making, family and professional partnerships, and the need for increased support for both research and practice at the state and local levels. There are so many unknowns when it comes to ASD that it is difficult to feel like there is anything we can do to address this growing issue and yet because of the prevalence of ASD it is essential that we act to address the challenges autism poses for our families and friends, our neighbors and communities.

Since I joined AMCHP almost two years ago, I have been struck by the number of stories I hear from families living with autistic family members. These stories are difficult: they involve the sacrifice and the struggle that caregivers face daily in their experience caring for a son, daughter, cousin, grandchild or other family member living with ASD. These stories are inspiring: they celebrate the resiliency and resolve which parents, friends, and others living and working with autistic individuals bring to their daily lives and the many small victories and blessings that they observe every single day. These stories are also a call for action: with so much that is not known about ASD, including its cause and how to best treat it, we have to continue to invest in research as well as programs and services for families impacted by ASD in states and communities.

While there is much we do not know about autism we do know that early diagnosis and intervention can lead to improved outcomes for children and youth with ASD. That is why this month’s focus on Autism Awareness is so important – the more parents and health professionals do early on in a child’s life to
From the CEO CONT.

Autism Spectrum Disorder

screen for developmental delay the more opportunities there are to intervene, link to services, and develop systems to address the complex needs of individuals with ASD and their families. The “Learn the Signs. Act Early.” campaign promoted by the Centers for Disease Control and Prevention (CDC) is a good example of a public health program that raises awareness of ASD and other developmental disabilities and links families to resources and support at the local level. State maternal and child health programs have also developed autism awareness campaigns and initiatives to address autism within their states. AMCHP is currently engaged in working with six state MCH programs that are funded by the Maternal and Child Health Bureau (MCHB) to develop state plans for autism and we will be sharing the work of these states with all Title V programs through our MCHB-funded State Public Health Coordinating Center for Autism.

Recently I had the chance to meet a young man living with autism. Diagnosed early, his family and he obtained services and supports from many agencies including public health and education. And while each day presents its challenges, this young man is anticipating college, working and living independently. His success is attributable to his own resolve and his family’s perseverance, fortitude and unending optimism. His success is also attributable to the services that were available to him in his community including access to well-trained professionals, accessible and supportive caregivers, and systems designed to meet the needs of families. While there is much that individual families can do to support their loves ones with ASD, systems of care are also needed to assure that individuals living with autism and other developmental disabilities have access to quality services that are culturally competent and family-centered.

Autism Awareness month is an opportunity to better understand ASD but also to educate and inform ourselves and our neighbors about what more is needed to build on successful plans and practices for individuals and families living with ASD. As maternal and child health programs continue to meet the needs of women, children and families nationwide AMCHP will continue to work with its members and partners to share what works, learn from new research and science, and advocate for continued support for programs to address the many challenges ASD presents for families and communities. I would love to hear from you as this work moves forward and continue to get your input and thoughts on how AMCHP can support state maternal and child health programs’ autism initiatives in the future.

“AMCHP will continue to work with its members and partners to share what works, learn from new research and science, and advocate for continued support for programs to address the many challenges Autism Spectrum Disorder presents for families and communities.”
Feature
April is National Autism Awareness Month

By Marguerite Kirst Colston
Vice President, Marketing and Strategic Initiatives
Autism Society of America

Established in the 1970s by Autism Society of America (ASA) advocates to highlight the growing need for concern and awareness about autism, National Autism Awareness Month presents a special opportunity for everyone to educate the public about autism and issues within the autism community. With one in 150 Americans now being diagnosed, the need for services and supports are greater than ever, and this year ASA hopes to raise awareness of the many issues faced by families affected by autism.

Autism is a complex neurodevelopmental disability that typically appears during the first two years of life and affects a person’s ability to communicate and interact with others. Autism is defined by a certain set of behaviors and is a “spectrum disorder” that affects individuals differently and to varying degrees. There is no known single cause for autism, but increased awareness and funding can help families today.

The Autism Society of America, the nation’s leading grassroots autism organization, will be presenting a slew of awareness activities to celebrate National Autism Awareness Month this April. ASA’s goal is to present activities that create opportunities for people with autism and their families to be included in their communities, educate their friends, but most importantly, have fun.

1. **1Power4Autism.** ASA just launched 1Power4Autism, the first grassroots fundraising website for the autism community. It gives people an opportunity to “turn on their power” by starting an event online and the tools they need to mobilize friends and family. Learn more [here](#).

2. **Bounce for Autism.** After a successful first year, ASA and inflatable playground franchise Pump It Up are bouncing again with “Bounce for Autism” - a nationwide, community-based fundraising event that combines family fun with raising awareness and support for autism in locations that welcome children on the autism spectrum. Find a local event [here](#).

3. **The Horse Boy.** In *The Horse Boy*, Rupert Isaacson shares his inspiring story of how he and his wife learned to think of their son’s autism as an adventure rather than a curse, a beginning rather than an end. After seeing the progress his son Rowan makes when he’s around a neighbor’s horse, Isaacson convinces his wife to join him and their child on an adventure that combines horses with traditional shamanic healing in the untamed landscape of Mongolia. Though this kind of adventure is far from the norm, both ASA and the book aim to empower families to think creatively and openly when it comes to treatment. Little, Brown and Company is publishing *The Horse Boy* on April 14, 2009, and will be partnering with the Autism Society of America to raise awareness. Learn more [here](#).

4. **AMC Sensory Friendly Films.** Did you know that something that seems as simple as going to the movies is not an option for many families affected by autism? Autism often comes with sensory challenges, such as hypersensitivity to light or sound, and children or adults affected by autism may not understand the social boundaries of movie theatre etiquette, such as not talking during the film or sitting still through most of the show. In order to accommodate these special needs, AMC Entertainment has partnered with ASA to bring Sensory Friendly Films to families affected by autism: the movie auditoriums have their lights brought up and the sound turned down, families will be able to bring in their own gluten-free, casein-free snacks, and no previews or advertisements will be shown before the movie. Additionally, audience members are welcome to get up and dance, walk, shout or sing - in other words, AMC’s “Silence is Golden®” policy will not be enforced unless the safety of the audience is questioned. In honor of National
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**Feature cont.**

**National Autism Awareness Month**

Autism Awareness Month, AMC will be having a Sensory Friendly Show this month: Hannah Montana: The Movie on April 18. For a list of participating theatres, visit [here](#).

To learn more about the Autism Society of America, autism and National Autism Awareness Month, please visit [here](#).

**Interagency Committee Releases First Federal Strategic Plan for Autism Research**

*By Dr. Susan Daniels*

*Deputy Director, Office of Autism Research Coordination, National Institutes of Health, U.S. Department of Health and Human Services*

In March 2009, the Interagency Autism Coordinating Committee (IACC) released the first federal strategic plan for autism research. The document, called the [IACC Strategic Plan for Autism Spectrum Disorders (ASD) Research](#), advises the federal government on needs and priorities for autism biomedical and services research. The IACC strategic plan is organized around six critically important questions for people with ASD and their families regarding diagnosis, the biology of autism, risk factors, treatments and interventions, services and supports and issues faced by adolescents, adults and older adults with autism. Each question is followed by a brief discussion of what is currently known and what more is needed through research. The plan lays out a broad set of research objectives, including several objectives that address biomedical aspects of ASD, as well as objectives that address services research issues such as assessment of state-based services and supports programs and efficacy and cost-effectiveness of evidence-based services for people with ASD of all ages.

It is anticipated that findings relevant to biomedical research portions of the plan, in addition to impacting medical options, will also translate to refinements and improvements in services for people with ASD.

The IACC was first established by Congress under the [Children’s Health Act of 2000](#). The Services Subcommittee of the first IACC developed a [Roadmap for ASD Services Research](#) in 2005, which addressed a broad array of services issues, including screening, access to mental health, educational and social services, transition from child to adult services and financing of care. The IACC was reauthorized and reconstituted under the [Combating Autism Act (CAA) of 2006](#). The CAA requires that two-thirds of the committee be composed of representatives of federal agencies, while one-third must be composed of public members. Currently, IACC membership includes a person with ASD, several parents of children with ASD (two of whom are also leaders of national ASD advocacy groups - Autism Society of America and SafeMinds), and officials from the following federal agencies that address ASD research or services: Centers for Disease Control and Prevention (CDC), Department of Education, Centers for Medicare and Medicaid Services (CMS), HHS Office on Disability, Substance Abuse and Mental Health Services Administration (SAMHSA), Administration for Children and Families (ACF), Health Resources and Service Administration (HRSA), and five Institutes of the National Institutes of Health (NIH).

Under the CAA, the IACC is responsible for developing a strategic plan for ASD research, monitoring ASD research and annually updating the strategic plan. According to the requirements of the Federal Advisory Committee Act, all meetings of the IACC are public and all decisions made by the committee are advisory to the federal government.

Like the first IACC, the current IACC has a Services Subcommittee that is specifically focused on ASD services and supports. In August 2008, the Services Subcommittee issued a Request for Information (RFI) to obtain public input on areas of greatest interest and concern with regard to ASD services and supports. The subcommittee plans to use the information gained through the RFI to guide future discussions about how the IACC may best advise the federal government to
address current public needs in the area of services and supports for people with ASD across the lifespan.

In a fortuitous convergence of events, the IACC strategic plan was completed just prior to the passage of the American Reinvestment and Recovery Act of 2009 (Recovery Act), which provided increased funding to several federal agencies that support ASD research. In March 2009, the NIH released several new initiatives that will use Recovery Act funds to jumpstart implementation of the IACC strategic plan, including initiatives on access to and effectiveness of services for people with ASD and their families. In fiscal year 2008, the NIH autism research program had a budget of $118 million. In 2009 and 2010, more than $60 million in additional funding will be added as a result of the Recovery Act. Other federal agencies may also use Recovery Act funds to bolster autism-related biomedical research and support enhancements in services research and programs for people with ASD.

With the new framework provided by the IACC strategic plan to guide ASD research and the infusion of new funds to support the growth of ASD research to address critical biomedical and services needs, the federal government is well-poised to enhance and accelerate ASD research that will benefit people with ASD across the lifespan and the communities that support them. For more information about the IACC and its activities, please visit here.

It’s Time to Change How We View a Child’s Growth

By Georgina Peacock, MD, MPH, FAAP
CDC, National Center on Birth Defects and Developmental Disabilities

Research shows that children with developmental delays benefit considerably from early intervention services, yet half of these children are not identified until age five. While parents are very aware of changes in their young child’s physical development, such as height and weight, there are also important milestones children should reach in terms of how they play, learn, speak and act. Smiling for the first time, making eye contact, and pointing are just a few of these developmental milestones. A delay in any of these areas could be a sign of a developmental problem, even autism. The good news is that the earlier a delay is recognized the more you can do to help children reach their full potential.

To educate parents about developmental milestones and warning signs of a development delay, such as autism, and the importance of acting early, the Centers for Disease Control and Prevention (CDC) created the “Learn the Signs. Act Early.” campaign. The campaign offers free materials and resources including fact sheets, milestone checklists, growth charts, and flyers, in English and Spanish. To order or download materials, visit here.

If a child’s parent has concerns, they should consult a developmental pediatrician or other specialist and can contact the local early intervention agency (for children under 3) or public school (for children 3 and older). To find out who to speak to in your area, contact the National Dissemination Center for Children with Disabilities or call (800) 695-0285.

Another initiative of the “Learn the Signs. Act Early.” campaign is the Act Early Regional Summits convened in partnership with the Association of University Centers on Disabilities (AUCD). The Act Early Regional Summits are a forum to bring together stakeholders to address challenges and opportunities in early identification, diagnosis, and service provision and coordination for children with ASD and their families. Act Early Regional Summit participants are from entities such as state offices on health, early intervention, special education, developmental disabilities, and Head Start, as well as representatives of community service providers, state legislators, pediatric medical home providers, parents and advocacy organizations. Through the Combating Autism Act Initiative (CAAI) of 2006, the Maternal and Child Health Bureau (MCHB) at the Health Resources
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It’s Time to Change How We View a Child’s Growth

and Services Administration (HRSA) has joined with National Center on Birth Defects and Developmental Disabilities to sponsor these activities.

For more information about the “Learn the Signs. Act Early.” campaign contact Georgina Peacock, MD, MPH, FAAP.

Real Life Stories

A Mother’s Gift that Keeps on Giving: A Son Living With Autism

By Sophie Arao-Nguyen, Ph.D.
Executive Director, Family Voices, Inc.

It has been 15 and a half years since my son LJ got diagnosed with Language Disorder, then Pervasive Developmental Disorder Not Otherwise Specified (PDD NOS), then Autism, then now Asperger’s Syndrome. Back in 1993, autism was still an unknown diagnosis in most circles. I am thankful that at that time I lived in the Bay area where disability resources, advanced medical research and cutting edge technology were the norm.

Early intervention was key to LJ’s chances of living a regular life. Since LJ was of pre-school age, it was the school district’s assessment center that helped us get started. The path was not easy. When the school district’s solutions and LJ’s interests did not match, we had to hire a lawyer to make sure LJ’s chances of succeeding in the least restrictive environment would prevail. When the school district decided to settle with us, we got what we needed for LJ after which we started to team up and partner with the team composed of the case manager, principal, physical therapist, speech therapist, his teachers and his aide. My husband and I became active in school and assisted the school in getting parents together. We started a support group and parents of newly diagnosed kids were referred to our support group. I got invited to speak at teachers’ training.

Through our interaction with the Autism Research Institute in San Diego, we discovered that kids with autism were helped by giving them a megadose of Vitamin B6 and magnesium. That was the only supplement we gave LJ. Although he was prescribed some medications by a specialist in Tourette’s Syndrome, I chose not to start him on any medication. LJ was also lactose intolerant and allergic to food coloring. He would have a bloody nose each time he ingested anything with food coloring in it be it the Baby Johnson’s shampoo or M & Ms or over the counter medications that had food coloring in it. To date, LJ has learned to read the ingredients in shampoos, food, etc.

The only intervention we chose to use for LJ was the use of supplements, the presence of a one-on-one aide until fifth-grade, speech therapy, a lot of love and presence in his life. We noticed that LJ’s growth spurts coincided with the spring season.

By the time LJ went to middle school, he discovered choir. The choir teacher discovered LJ had perfect pitch. He was given the opportunity to sing some solos during choir recitals. He focused on choir for five years and during the last two years of high school, he decided to try his hand in drama. He loves drama too and it allowed him to refocus his verbal tics into something more productive.

He started voice lessons in high school and when we moved to New Mexico, we were able to find him a professional voice teacher who used to perform in Europe in her youth.

LJ has blossomed into a young man. He turned 18 recently and will graduate from high school in May. Little did I know that when LJ was born, I was destined to focus my life work on this mission of assisting
Real Life Stories CONT.
A Mother’s Gift that Keeps on Giving

children and youth with special health care needs. What I thought was a curse was actually my blessing and salvation. For LJ is truly the sunshine of our lives and many lives. He is well loved at school by his classmates and his teachers. He has made a lot of friends.

During Autism Awareness Month, I am thankful that much has happened in the autism world. LJ sang at AMCHPs Annual Conference and at the Family Voices gala. The face of autism shifted when people realized there is no one face of autism. It comes in different forms, size and shape as well as gifts. LJ is a gift. I will never exchange him for any other son without a disability!

To learn more about Family Voices, Inc. visit here.

Member to Member

In recognition of Autism Awareness Month, AMCHP asked the State Implementation Grantees funded through the Combating Autism Act Initiative, to answer the following question:

What is your team doing to raise awareness about autism in your state?

Alaska
Kristine Greene
Alaska Department of Health and Social Services

We have made a concerted effort to create a wide variety of activities around Autism Awareness Month, including:

1. To educate providers, Dr. Cowan will deliver educational presentations through Grand Rounds in five locations and seven general public informational presentations;

2. To entertain kids and families, we have organized Wii tournaments for children affected by autism, movie nights, autism night at bouncing bears (an inflatable gym), parents support group meetings, and a social club for siblings of children with autism;

3. To fundraise, we have planned three walks for autism to support the statewide parents support group, the Golden heart Chapter of Autism Speaks, Alaska and three book fairs to purchase books for autism libraries that distribute books to families in need; and

4. To raise awareness, we have scheduled radio shows, developed press releases, and organized families to tell their stories.

To learn more and to see a schedule of planned events, visit here.

The Autism Program (TAP) of Illinois
Carolyn Kopel
IMPACC Project Coordinator, The Hope School

Although TAP provides year-round awareness about Autism Spectrum Disorders, April is a very special month to help others understand the challenges, opportunities and achievements associated with Autism. TAP Service Network partners, with the help of local organizations, community members and public officials, offer diagnosis, treatment, support groups and resources to improve the lives of persons with an ASD and their families. Below are many of the events and activities TAP Service Network partners are coordinating to promote Autism Awareness.

- Central Illinois National Public Radio Purchased Service Announcements
  Due to a generous donation, six radio announcements will be aired on behalf of Autism Awareness month.

- Public Service Announcements – Capitol Radio Group
  A PSA will be aired throughout April promoting Autism Awareness and TAP services
Other Media Outlet Activities
Media will be presented with Share Your Story cards from participating families who have used TAP services to inspire others (including newspaper, radio and TV media)

April TAP Legislative Mailing
TAP’s April legislative mailing, sent to all members of the Illinois General Assembly, provided information on April as Autism Awareness Month and how to support funding to continue Autism programs and services

Consensus for Autism Family Connection initiative launch
An initiative by TAP to connect families with their local legislators in order to provide first-person accounts of the challenges, achievements of living with a child diagnosed with an ASD and the impact that funding has for Autism programs and services.

In addition, TAP has planned many Autism Awareness Month activities for children, families, and advocates. For more information about these activities, please visit here.

Missouri
Katie Dunn
Thompson Center at the University of Missouri

The State Implementation Grant team in Missouri has planned a full schedule of activities to recognize Autism Awareness Month. The events kicked off in late March with the Autism Intervention Conference hosted by the Thompson Center for Autism and Neurodevelopmental Disorders at the University of Missouri. This conference offered presentations by more than 60 speakers and included numerous workshops on topics related to State Implementation objectives, including screening for ASD, navigating the system of care, and transition to adulthood. During the same week, Dr. Daniel Coury, director of the HRSA Autism Intervention Research-Physical (AIR-P) initiative, delivered a free community education presentation about the Autism Treatment Network and strategies for improving the health care of individuals with ASD. The University of Missouri Thompson Center is a member of this national research network.

Additional Autism Awareness Month activities focus on the third week in April. On April 20th, the Thompson Center will sponsor the first event in its Exceptional Achievements Series. Hosted by Tim Page, a Pulitzer Prize winning music critic with Asperger’s syndrome, this series focuses on individuals who have overcome developmental challenges to make significant achievements. This year’s guest speaker is John Elder Robison, author of the best-selling memoir Look Me in the Eye: My Life with Asperger’s. The event also features a youth panel to discuss transition issues.

On April 21st, two autism advocacy groups (MO-FEAT and Autism Speaks-St. Louis Chapter) will host an Autism 101 Speaker Panel at Washington University in St. Louis. The event features a parent-professional educational meeting and an opportunity for families to ask questions of the experts. Finally, the It’s in the Cards dinner gala and auction takes place on April 23rd. This event helps raise awareness about autism spectrum disorders and the key role that the Thompson Center plays in making a difference in the lives of children and families affected by autism and other neurodevelopmental disorders. KMOX broadcaster Charlie Brennan will serve as the emcee and attendees will hear the inside scoop on the 2009 St. Louis Cardinals from manager Tony La Russa. Funds from the event benefit the Thompson Foundation, which supports the Missouri Autism Guidelines Initiative (MAGI) effort to establish best practice guidelines for autism in Missouri.

Utah
Rebecca Giles
Autism Program Manager, Utah Department of Health

The Utah ASD Implementation Project will be raising awareness about autism throughout the state over
the next three years. The Utah Department of Health and key partners will implement projects to train pediatricians, family practice physicians, dentists, early childhood educators, and early intervention specialists. The project will also increase access to information and community resources for providers and families. Utah Family Voices is expanding to recruit and train family advocates to provide families throughout the state with support coordination. The ASD page on the Medical Home’s website has been updated to better support and educate families and providers. Through these efforts, community providers will increase capacity for early recognition of signs of ASD to improve referral, diagnosis, and treatment.

2) Suggestions for what could be done: solicit a public library to engage in activities on autism awareness, develop email blasts, mass media announcements, messages on bulletin boards and electronic “reader boards”, create advertisements on public transit, taglines on council member emails, lobby displays, press releases, target radio and TV messages, post autism awareness materials at conferences in April, and make a website and list serve messages. It was noted that Autism Speaks has links that provide possible public awareness messages in different languages. A final strong suggestion was for grant staff to prepare advance information on the subject, with canned language that members of the council can disseminate.

Wisconsin
Amy Whitehead
Wisconsin Department of Health and Family Services
Wisconsin has several ongoing activities to increase awareness and education about ASD. The Regional Training Centers have been a particularly successful activity. Wisconsin has five Regional Centers for Children with Special Health Care Needs which provide training and outreach as part of the State Implementation Grant. The Northeast Region developed packets developed for primary care practice sites. These packets contain key fact sheets on early identification of children with ASD. Additionally, the packets also provide information on how the Regional Center can be a referral point for community services. These packets have been useful tools for the Regional Center staff who meet with primary care practice sites to advance the concepts of Medical Home and increase awareness on ASD.

As part of Washington State’s Autism Awareness: Partnership for Change grant activities we used an autism awareness exercise at one of our Combating Autism Advisory Council meetings to spread awareness throughout those agencies and organizations that are not autism specific in their work. This also worked as a “get to know who you are” exercise for the diverse membership of stakeholders with a resulting lively discussion on planned activities and other possible strategies for work. We developed two sets of useful information:

1) Planned community activities around Autism Awareness Month include: partnering with Barnes and Noble bookstore to hold a book fair and panel discussion on autism; mayor’s proclamation declaring April 2 as Autism Awareness Day; workshops coinciding with autism awareness month; a community event to highlight ‘a day in the life of a person with autism; campaign to get children into services while waiting for diagnostic outcomes. Definite Washington State Department of Health plans include agency brown bag lunch with presentation on Learn the Signs: Act Early and updates on autism grant activities, and display cases and tables with information in four buildings.
By Brent Ewig  
Director of Public Policy & Government Affairs, AMCHP

It’s springtime in Washington, and the debate about reforming our nation’s health system is about to take center stage. However, as this issue is focused on autism, it’s a perfect opportunity to highlight a few pieces of good news:

First, the recently passed FY 2009 omnibus appropriations bill included a $5.6 million increase for the Maternal and Child Bureau’s (MCHB) work authorized by The Combating Autism Act of 2006. As a refresher, this law authorized a program for early detection, education and intervention activities on autism and other developmental disorders. Today, the program supports activities to:

- provide information and education on autism spectrum disorder and other developmental disabilities to increase public awareness;
- promote research into the development and validation of reliable screening tools and interventions for autism spectrum disorder and other developmental disabilities and disseminate information;
- promote early screening of individuals at higher risk for autism spectrum disorder and other developmental disabilities as early as practicable, given evidence-based screening techniques and interventions;
- increase the number of individuals who are able to confirm or rule out a diagnosis of autism spectrum disorder and other developmental disabilities; and
- increase the number of individuals able to provide evidence-based interventions for individuals diagnosed with autism spectrum disorder or other developmental disabilities.

In FY 2008 Congress appropriated $36,354,000 to HRSA's MCHB for this program, of which approximately $20 million was moved from the Maternal and Child Health Block Grant training programs for Leadership Education in Neurodevelopmental and Related Disabilities (LEND) and Behavioral Pediatrics. The recently passed omnibus appropriations for FY 2009 increased this funding for the MCHB portion to $42 million.

These funds are being used to expand these programs, as well as support: grants to study interventions for autism and related developmental disabilities; demonstration grants to develop models of systems of services for children with autism and other disabilities; grants to disseminate current and accurate information to families and consumers on early identification, diagnosis and access to services; grants to disseminate screening intervention, and guideline information; and other technical assistance and evaluation.

Additionally, the president’s budget outline released last month announced planned investments to “support Americans with Autism Spectrum disorders (ASD).” The HHS budget outline noted that “the President is committed to expanding support for individuals, families, and communities affected by ASD.” His budget is expected to include $211 million in HHS for research into the causes of and treatments for ASD, screenings, public awareness, and support services.” While few additional details on that proposed funding are available at press time, we expect it will build upon the Combating Autism Act, and we’ll report more as details are released.

Health Reform Update

Congressional committees are gearing up now to write health reform legislation. On your behalf, the Association of Maternal & Child Health Programs is taking a lead role to advocate that the needs of women
and children are at the forefront of any reform package. We are joining with the Association of State and Territorial Health Officials (ASTHO) and other groups to spread the message loud and clear that the way to truly improve health and drive down health care costs is by strengthening our nation’s public health system. Guided by our member-developed and board-approved AMCHP Principles for Health Reform, we are actively reaching out to key staff now to share ideas about how to create and maintain an adequate and stable funding stream to support effective public health programs. Current expectations are that key committees in Congress could introduce health reform legislation as early as May, with a stated goal to complete action before their planned August recess. AMCHP will continue to advocate that reform include coverage for all with a strong benefits package, as well as inclusion of explicit provisions to strengthen our public health system. Stay tuned as it promises to be an interesting and perhaps historic summer in our nation’s capital.

Who’s New

Spotlight on New National Healthy Start Association Executive Director Stacey Cunningham

Our very own Stacey Cunningham, MSW, MPH was recently selected to be the next Executive Director of the National Healthy Start Association (NHSA) and lead the association’s efforts to reduce infant mortality and provide support to Healthy Start programs nationwide. After a national search, Stacey from among several qualified candidates was chosen for her passion, commitment and expertise in addressing the needs of women, children and families. NHSA President Cynthia Dean stated “We are so pleased to welcome Stacey to NHSA. She brings expertise, energy and enthusiasm to our work as well as a great dedication and commitment. Her experience with AMCHP will serve her well as she leads our association and its members forward.” Prior to joining NHSA, Stacey was the Associate Director for Women’s and Infant Health at AMCHP and worked with our Women’s Health, Preconception Health, Data and Assessment, and Infant Mortality programs. AMCHP is excited for Stacey and her new role but we are also sad to see her leave our team to which she contributed a great deal in the two years she was with us. Please join us in congratulating Stacey on her new leadership position. And she won’t be far away – NHSA is headquartered in the same office suite as AMCHP here in Washington, so it is just a short move down the hall!

Get Involved

Webcast on Perinatal and Infant Oral Health
MCHB will host a webcast on “Engaging Providers to Improve Perinatal and Infant Oral Health: Innovative Strategies” on April 16 from 2 to 3:30 p.m. (EST). This webcast will describe collaborative, early intervention activities to prevent oral disease between oral health grantees from MCHBs’ Alliance for Information on Maternal and Child Health grant programs. To register, visit here.

Webcast on Medical Homes for Children
MCHB will host this webcast on April 21 from 3 to 4:30 p.m. (EST). This webcast will highlight efforts to support the implementation of medical home across multiple stakeholder groups, including an overview of the medical home concept and an update on the activities of the American Academy of Pediatrics’ National Center for Medical Home Implementation. To register, visit here.

Webinar on Youth in an Online World
The Youth Intervention Programs Institute and the National Institute on Media and the Family will present a webinar on the opportunities, dangers and impacts for “Youth in an Online World” on April 21 from 10:30 a.m. to Noon (EST). To register, visit here.
Get Involved CONT.

Webcast on Cyberbullying
Bullying prevention experts will discuss Cyberbullying: Tools and Tips for Prevention and Intervention during a Stop Bullying Now! Campaign webcast on April 22 from 3 to 4:30 p.m. (EST). To register for the webcast, visit here. For more information about the webcast, contact Nicolle Grayson.

Upcoming AMCHP Board Meeting
The next AMCHP Board meeting will convene on Thursday, April 23, 2009 at 3 p.m. (EST) via teleconference. AMCHP Board meetings are open to the public and anyone interested in participating in the Board meeting is welcome to join the call. Please contact Nora Lam, Executive Assistant, for information about this upcoming meeting or call (202) 266-3038.

Public Comment on Draft Voluntary National Accreditation Standards
The Public Health Accreditation Board (PHAB) is developing and implementing a national voluntary accreditation program for state, local, territorial and tribal public health departments. The goal of the accreditation program is to improve and protect the health of every community by advancing the quality and performance of public health departments. The deadline for the comment period is April 27. To review a draft of the voluntary national accreditation standards, visit here.

Nominations for National MCH Epidemiology Awards
The Coalition for Excellence in MCH Epidemiology announces the ninth year of the National MCH Epidemiology Awards. The Coalition is recruiting nominees for the 2009 awards. Nominees are individuals, teams, institutions, and leaders of institutions who have made significant contributions to improving the health of women, children and families through epidemiology, applied research and the effective use of data. These awards recognize research, teaching, leadership and effective public health practice and recognize individuals and organizations at a community, state and national level. For more details on how to nominate and the awards criteria, visit here. Deadline for nominations will be June 1, 2009.

Data and Trends

CSHCN Performance Measures and More
The Data Resource Center website (DRC) provides easy access to the most recent findings for your state on the MCHB CSHCN Performance Measures. Also available are findings on over 100 other measures relevant to assessing needs and system performance for children, youth and families. Using the DRC website you can stratify findings from both the National Survey of Children With Special Health Care Needs (NS-CSHCN) 2001 and 2005/06 by numerous subgroups of children and youth in your state, such as race/ethnicity, income, insurance status and more by simply pointing and clicking. Substate data findings are also available in the state-by-state profile by geographic area. In addition, hundreds of child health measures are also available from the 2003 National Survey of Children’s Health (NSCH). And, coming in mid-May 2009, new measures will be available from the 2007 NSCH as well.

Autism, ASD and Other Developmental Disabilities
The 2005/06 NS-CSHCN contains national and state level data on autism and ASD. You can also find information on other behavioral conditions, emotional problems, Down Syndrome, and development delay. In the 2003 NSCH you can find additional national level data on developmental delay, behavior or conduct problems, ADHD and autism. The DRC website provides easy to download, user-generated state profiles, tables, graphs and all-state comparison sheets for you to copy and paste directly into your needs assessment. The DRC provides expert help and assistance by calling (503) 494-1930 or email.
Where in the U.S. is there an Autism Speaks Insurance Reform Initiative? The map below from Autism Votes provides a graphical representation of where each of the states stand with regard to their progress on creating an autism insurance reform law. Find this map online here.

**Autism Speaks 2009 State Initiatives**

![Autism Speaks 2009 State Initiatives Map](image_url)
Resources

Autism Awareness Month

AMCHP’s State Public Health Autism Resource Center (SPHARC)
The Association of Maternal & Child Health Programs has launched the State Public Health Autism Resource Center (SPHARC) in partnership with the Maternal and Child Health Bureau. Drawing on the experiences and successes of states and our partners, SPHARC coordinates and organizes public health resources around the diagnosis, care, and quality of life for families and children affected by Autism Spectrum Disorders and developmental disabilities. Visit SPHARC for guides, case studies, and information on how to develop a public health framework around autism in your own state or community.

Association of University Centers on Disabilities (AUCD)
The AUCD is a membership organization that supports and promotes a national network of university-based interdisciplinary programs consisting of the University Centers for Excellence in Developmental Disabilities (UCEDD), Leadership Education in Neurodevelopmental Disabilities (LEND) Programs, and the Intellectual and Developmental Disability Research Centers (IDDRC). These programs serve and are located in every U.S. state and territory and are all part of universities or medical centers. They serve as a bridge between the university and the community, bringing together the resources of both to achieve meaningful change.

Through its members, AUCD is a resource for local, state, national, and international agencies, organizations, and policy makers concerned about people living with developmental and other disabilities and their families. AUCD programs also train the next generation of leaders in disability-related research, training, service delivery, and policy advocacy to insure that this essential work continues.

Autism Internet Modules (AIM)
More school/community focused
The AIM project will develop a series of 60 modules by the time the project is complete on topics including assessment and identification, characteristics, evidence-based practices and interventions, transition to adulthood, and employment. Module authors include experts on ASD from across the nation. The AIM platform was designed and built by the Ohio Center for Autism and Low Incidence staff with components consistent with research on how adults learn. Information is presented at a universal reading level with activities providing support to those with introductory or advanced knowledge on ASD. These modules are available at no cost to any computer or digital telephone user.

Autism Society of America (ASA)
The Autism Society of America, the nation’s leading grassroots autism organization, exists to improve the lives of all affected by autism. They do this by increasing public awareness about the day-to-day issues faced by people on the spectrum, advocating for appropriate services for individuals across the lifespan, and providing the latest information regarding treatment, education, research and advocacy.

Autism Source (sponsored by ASA)
Is the ASA’s online referral database.

Autism Speaks
Autism Speaks is dedicated to funding global biomedical research into the causes, prevention, treatments, and cure for autism; to raising public awareness about autism and its effects on individuals, families, and society; and to bringing hope to all who deal with the hardships of this disorder.

Autism Speaks aims to bring the autism community together as one strong voice to urge the government and private sector to listen to our concerns and take action to address this urgent global health crisis. It is our firm belief that, working together, we will find the missing pieces of the puzzle.

Autism and Developmental Disabilities Monitoring (ADDM) Network
The ADDM Network is a group of programs funded by the CDC to determine the prevalence of the Autism Spectrum Disorders (ASDs) in U.S. communities.
Autism Awareness Month

The Autism Speaks 100 Day Kit is created specifically for newly diagnosed families, to make the best possible use of the 100 days following the diagnosis of autism.

Easter Seals
Easter Seals provides exceptional services, education, outreach, and advocacy so that people living with autism and other disabilities can live, learn, work and play in our communities.

State Autism Profiles
Easter Seals has prepared a state-of-the-state report of autism services in the 50 states, the District of Columbia and Puerto Rico. The profiles highlight the number of children with autism who have received the state’s special education services, state insurance coverage for autism if available, Medicaid services for specific individuals with autism, educational programs provided to students with autism or training that focused on autism, special education criteria, other state-led resources, and sponsors of autism legislation.

IAN - Interactive Autism Network (sponsored by Autism Speaks), is an innovative online project designed to accelerate the pace of autism research by linking researchers and families. Anyone impacted by an Autism Spectrum Disorder (ASD) can become part of IAN’s online community to stay informed about autism research, provide feedback, and make their voices heard. In addition, families of children with an ASD can share information in a secure online setting and become part of the nation’s largest online research effort.

Interagency Autism Coordinating Committee (IACC)
The Interagency Autism Coordinating Committee (IACC) coordinates all efforts within the Department of Health and Human Services (HHS) concerning autism spectrum disorder (ASD). Through its inclusion of both Federal and public members, the IACC helps to ensure that a wide range of ideas and perspectives are represented and discussed in a public forum.

The IACC mission is to (1) facilitate the efficient and effective exchange of information on ASD activities among the member agencies, (2) coordinate ASD-related activities, and (3) increase public understanding of the member agencies’ activities, programs, policies, and research by providing a public forum for discussions related to ASD research, screening, education, and interventions.

“Learn the Signs. Act Early.” Campaign
The Centers for Disease Control and Prevention’s (CDC) National Center on Birth Defects and Developmental Disabilities (NCBDDD), in collaboration with a number of national partners, launched a public awareness campaign called “Learn the Signs. Act Early.” The campaign aims to educate parents about childhood development, including early warning signs of autism and other developmental disorders, and encourages developmental screening and intervention.

“Learn the Signs. Act Early.” builds on familiar experiences of parents, such as monitoring their children’s physical growth, and expands to social and
emotional milestones such as how children speak, learn, act and play. Just as taking a first step is a developmental milestone, so is smiling, pointing and enjoying social play. While every child is different and develops at his or her own pace, there are still milestones that each child should reach within a certain range of time. The early identification of developmental concerns allows parents to seek intervention during the crucial period of early development.

Maternal and Child Health Bureau is part of the Health Resources and Services Administration, U.S. Department of Health and Human Services and is responsible for meeting the needs of the maternal and child health populations of the United States and its jurisdictions.

National Conference of State Legislatures
The National Conference of State Legislatures' Autism Legislation Database provides information about autism legislation introduced in the 50 states and the District of Columbia from the 2008 legislative session to present. The database can be searched by state, topic, keyword, status, year, bill number, or primary sponsor. Topics include awareness, education, financing, health and human services, infrastructure, insurance, professional training, and screening. New legislation will be added to the database as it is introduced.

National Medical Home Autism Initiative
The National Medical Home Autism Initiative, founded as a cooperative agreement by the federal Maternal Child Health Bureau, is a national technical assistance, resource and advocacy project designed to promote methods that will improve the capacity of the medical home and early intervention community to identify, appropriately serve and integrate children with autism into their communities.

The primary purpose of the project is to identify and demonstrate how principles of the medical home can be applied to achieve early identification and intervention for children with autism spectrum disorders.
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Save the Date!

AMCHP’s 2010 Annual Conference

March 6-10, 2010

Gaylord National Resort

(in the Washington, DC metropolitan area)