Greetings to all SODBP members. As I write this children across the country are headed back to school. In my area the school district for many of my patients is in fiscal crises. Large numbers of school nurses and school psychologists have been laid off and I wonder how my patients with disabilities and chronic conditions will do in this environment of even more limited resources. An internet search makes it apparent that this is an issue across the country and reinforces for me the importance of advocacy in allowing us to help children and families with special health care needs.

The 2012 Section on Developmental and Behavioral Pediatrics (SODBP) strategic plan set as one goal for our Section improving the advocacy skills of our members. In approaching this goal the tremendous resources of the American Academy of Pediatrics... continued on page 2
Notes from the Chair  continued from page 1

Pediatrics (AAP) have been a huge asset for us. In the past year we have offered scholarships allowing 4 of our members to attend AAP Department of Federal Affairs (DOFA) advocacy trainings and you will hear about the experience of one of them in this newsletter. Due to the success of this program we are partnering with the DOFA to offer a developmental-behavioral specific advocacy training early in 2014. We hope to develop a group of section members interested in the developmental and behavioral challenges of children who have the knowledge and skills to advocate for policy and systems changes that will improve functional outcomes for these children.

Another major arm of the strategic plan is the development of educational programing related to the developmental and behavioral issues in pediatrics. Drs Weitzman and Wegner have led a major effort in conjunction with the Committee on the Psychosocial Aspects of Child and Family Health and the Council on Early Childhood to develop a clinical report that will serve as an excellent resource for those considering adding behavioral screening to the services offered in their practice. In addition, we are working with the Mental Health Leadership Work Group to develop a curriculum for pediatric residents on an approach to behavioral and emotional challenges in primary care. Under the strong leadership of Dr Bob Voigt we sponsored a large number of presentations that were accepted for the 2013 AAP National Conference and Exhibition and we collaborated with the Council on Children with Disabilities (COCWD) in developing an exciting program on mental health and psychopharmacology in children with disabilities.

I am happy to report that this collaboration with the COCWD is one of multiple successful collaborations that have been greatly facilitated by Dr Ken Norwood who has served as the liaison for the COCWD to SODBP and Dr Carolyn Bridgemohan who has served as our liaison to COCWD. Dr Norwood was recently elected chair of the COCWD. We congratulate him and will miss him at our meetings, but are tremendously appreciative of his contributions. We welcome and look forward to working with Dr Susan Levy who will replace Dr Norwood as the liaison to SODBP.

In the midst of all these exciting activities, it is with sadness that I note the passing of 2 of the founding members of our field, Drs Stan Friedman and Morris Green. As we see the growth of developmental-behavioral pediatrics as a subspecialty and the increasing emphasis on the management of developmental and behavioral problems in primary care we must acknowledge the huge contributions of these truly visionary leaders.

Please continue to encourage your colleagues, fellows, and residents interested in developmental and behavioral challenges for children to join the section and to promote affiliate membership to those that you work with in related fields such as nursing, occupational therapy, physical therapy, psychology, psychiatry, speech language pathology, and social work. In addition the vitality of the SODBP is dependent on the active involvement of our members and the SODBP continues to work on ways to engage members in our activities. Thank you to all who provided feedback on the SODBP Communications Survey. This information will be used to guide the efforts related to communication vehicles with the SODBP membership.

We are continuing to have roundtable discussions at the section business meeting and we have an excellent discussion board led by Dr Damon Korb and SODBP Web site, DPeds.org (https://www2.aap.org/sections/dbpeds/membersonly.asp) that is continuing to develop under the leadership of Dr Stephen Contompasis. Dr Contompasis has elicited a team that will help in keeping the Web site up-to-date and practical for our members. The assistant Web site editors are Patricia Callaway Daniel, MD, PhD; Elisa I Muniz, MD; Cathy Jo Scheiner, MD; Kimberly LaShun Stringer, MD; and Ludwig Erik von Hahn, MD. Finally, thank you to Dr Michael Reiff for producing another stimulating newsletter.

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

Best Regards,

Nathan Blum, MD
blum@email.chop.edu
Editor’s Note

This issue of the newsletter highlights the publication of the Diagnostic and Statistical Manual of Mental Disorders (DSM)-5 from the American Psychiatric Association, and particularly the diagnoses of attention deficit/hyperactivity disorder (ADHD) and autism spectrum disorder (ASD) – highly relevant to both primary care and developmental-behavioral pediatrics. This affords a good opportunity to reflect of our use of the DSM as primary care and developmental-behavioral pediatricians.

Phillips et.al. have compared practitioners to baseball umpires and posed 5 different ways of approaching these criteria:

1. **Umpire 1** - There are balls and strikes and I call them as they are.
2. **Umpire 2** - There are balls and strikes and I call them as I see them.
3. **Umpire 3** - There are no balls and no strikes until I call them.
4. **Umpire 4** - There are balls and strikes and I call them as I use them.
5. **Umpire 5** - Don’t call them at all because the game is not fair.

I’ll comment on these 5 approaches as they may influence our work as primary care or developmental-behavioral pediatricians.

Practice guidelines appear to favor Umpire 1, in that they largely require that a child or adolescent meet DSM guidelines as a requirement for diagnosis. This approach assumes that the diagnoses are real, and categorical – that one either “has” the diagnosis or not. One problem with this approach is that there are no biological markers to confirm or rule out these diagnoses, and we know that the routes to “meeting the criteria” are quite heterogeneous. We are much more likely to take this “realist” approach when we are have laboratory tests that can verify these diagnoses.

Umpire 2 appears to recognize that there can be different interpretations of whether an individual meets any individual criteria for a given diagnosis. An example from the ASD criteria might be “deficits in developing, maintaining and understanding relationships.” This could certainly apply (out of context) to a child with ADHD, but more because of impulsivity rather than lack of social cognition. This seems like a thoughtful and balanced approach: consider whether a child meets DSM criteria, but consider how individual circumstances shape our clinical impressions. This approach recognizes that there is real suffering and pathology, but leaves some doubt about whether this particular diagnostic scheme adequately sorts it out.

The third umpire seems to believe that the DSM criteria do not represent “real” disorders, and that one’s clinical sense of the situation should override the DSM criteria. This approach can lead to a wide variation in diagnostic formulations depending on the experience and expertise of the individual clinician.

The fourth umpire is a pragmatist. This umpire is looking at the practical uses of these diagnoses and success rather than the accuracy of the diagnosis. Clinicians using this approach would be more concerned about the effects of one label versus another.

Umpire 5 would just abandon this diagnostic approach. I think that considering this approach opens up some useful discussion. For example, an alternate approach, because of the lack of biological verification of these diagnoses, is to look at areas of functioning that significantly interfere with a child’s developmental progress or optimal engagement in the family, with friends, with learning, at school or work, and in the broader community. This is a concept that is embedded in the International Classification of Functioning, Disability and Health. This manual describes a systematic approach for a broad range of functional consequences of disorders such as ASD and ADHD, including effects on body function and structures, activities of daily living, and participation in social and community activities. In the end, isn’t this really what we hope to achieve for children and families? – full and optimal engagement. However, this is an approach that would not be reimbursed by insurers, and would not presently serve as a gateway to medication, behavioral, or psychosocial treatments.

I urge us to think about and create a dialogue around these issues as practitioners as we attempt to remain staunch advocates for children and their families, and for our fields of practice.

*continued on page 4*
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I would invite readers to make this an ongoing discussion on the DBPeds discussion board http://www2.aap.org/sections/dbpeds/

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ADHD in DSM-5: Few Changes in Diagnostic Criteria

By Martin Stein, MD, FAAP

The recently published DSM-5 by the American Psychiatric Association includes several changes that are important to pediatricians and their patients. Modifications in Autistic Spectrum Disorders and Anxiety Disorders are the major changes that affect the diagnosis of conditions in childhood and adolescents. Although the changes in Attention-Deficit/Hyperactivity Disorder (ADHD) are modest in comparison, there are a few changes that merit comment.

The conceptual framework for the diagnosis of ADHD has maintained stability in comparison to the DSM IV. The 3 subtypes of ADHD remain the same: 1) Predominantly inattentive presentation, 2) Predominantly hyperactive/impulsive presentation, and 3) Combined presentation. The 9 symptoms in both the hyperactive/impulsive and inattentive domain and the requirement for at least 6 symptoms in either or both domains are stable diagnostic criteria.

The DSM-5 criteria for ADHD recognize that, although ADHD begins in childhood, it persists into adolescence and adult life in a significant number of individuals. Based on studies that have shown that a lower threshold of symptoms in adults was sufficient for a reliable diagnosis, the DSM-5 criteria for ADHD requires only 5 symptoms in either the hyperactive/impulsive or inattentive domain for individuals over 17 years of age. The authors of the DSM-5 concluded that research supports the idea that DSM-IV criteria are applicable to adults as well as children.

A major addition to the DSM-5 is the inclusion of clinical examples of behaviors for each symptom. Examples of specific behaviors for selected core symptoms are:

Often difficulty organizing tasks and activities (eg, difficulty managing sequential tasks; difficulty keeping materials and belongings in order; messy, disorganized work; has poor time management; fails to meet deadlines)

Often forgetful in daily activities (eg, doing chores, running errands; for older adolescents and adults; returning calls, paying bills, keeping appointments)

Often “on the go,” acting as if “driven by a motor” (eg, is unable to be uncomfortable being still for extended time, as in restaurants, meetings; may be experienced by others as being restless or difficult to keep up with)

Often interrupts or intrudes on others (eg, butts into conversations, games, or activities; may start using other people’s things without asking or receiving permission’ for adolescents and adults; may intrude into or take over what others are doing)

I suspect that these descriptors will be useful for pediatric residents and primary care clinicians beginning their practice as a way to define with greater clarity the meaning of each symptom. As seen in the examples above, descriptions of core behaviors as they emerge in older age groups are included as clinical guides. In addition, the key word “often” introduces each behavior. This important modifier was also in the DSM-IV as it recognizes that many individuals without ADHD have some of these behaviors occasionally. Not all hyperactive and inattentive children, adolescents, and adults have ADHD!

Several criteria from past iterations of the DSM persist with some changes:

*The age of onset of symptoms was raised from 7 years to 12 years for 2 reasons: some behaviors of ADHD are not prominent until educational and social demands are greater; and research shows that children identified at 7 years or later had a similar course, severity, outcome, and treatment response.

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ADHD in DSM-5: Few Changes in Diagnostic Criteria continued from page 4

*Symptoms that define ADHD must be present in 2 or more settings. This criterion was strengthened by requiring several symptoms and extending the examples to include home, work, school, with friends or relatives, in other activities.

*The requirement for documentation of impairment (a critical part of the diagnosis) took on a new language: from clear evidence of clinically significant impairment in social, academic, or occupational functioning to clear evidence that symptoms interfere with or reduce the quality of social, academic, or occupational functioning. A new section on functional consequences of ADHD clarifies potential areas of impairment. Another added section on risk and prognostic factors emphasizes the role of temperament, environment, and genetics when considering a diagnosis of ADHD.

*The DSM-IV listed severity as only mild, moderate or severe without clear definitions. The DSM-5 provides guidance in defining severity:

Mild: Few, if any symptoms in excess of those required to make the diagnosis are present and symptoms result in no more than minor impairments in social or occupational functioning. Moderate: Symptoms of functional impairment between “mild” and “severe” are present. Severe: Many symptoms in excess of those required to make the diagnosis, or several symptoms that are particularly severe, are present, or the symptoms result in marked impairment in social or occupational functioning.

The sections on Differential Diagnosis and Comorbidity are written with greater clarity. More attention to the importance of screening for common co-existing conditions would have been important for pediatricians. A new childhood diagnosis, disruptive mood dysregulation disorder (DMDD), is included in the differential diagnosis section. Anxiety, oppositional behaviors, depression, learning disabilities, environmental stressors, and DMDD should be a part of every ADHD evaluation. The sections on culture-related and gender-related diagnostic issues are important considerations.

ADHD is now included in the classification of Neurodevelopmental Disorders. This large category also comprises intellectual disabilities, communication disorders, autistic spectrum disorder, specific learning disorder, and motor disorders. An important change in the DSM-5 is recognition that ADHD may co-occur in patients with autistic spectrum disorder.

Since the publication of the Preschool ADHD Treatment Study (PATS), ADHD in younger children has received greater attention. It is also addressed in the 2nd edition of the AAP Clinical Practice Guideline for the Diagnosis, Evaluation and Treatment of ADHD. I was surprised that the discussion of ADHD in preschool children in the DSM-5 is limited to, “Many parents first observe excessive motor activity when the child is a toddler, but symptoms are difficult to distinguish from highly variable normative behaviors before age 4 years.” (italics not in DSM-IV) The recognition that ADHD behaviors in preschool-age children are challenging to differentiate when they are observed in a developmentally normal, high energy child with impulsivity and a limited attention span is important. The new iteration of DSM would have been strengthened with more guidance for clinicians who see preschool-age children.

Comment

When ADHD is a consideration in a child or teenager, the interview with the patient and parent (as well as parent and teacher questionnaires) must be attentive to impairments that are the result of ADHD behaviors. The new section on Functional Consequences is an improvement. However, considering the importance of functional impairment when making an accurate diagnosis of ADHD, a guide to assist clinicians in documenting impairment would have been useful—eg, key questions to ask in the patient interview, parent interview, and from teacher reports. I believe that this is important because inadequate documentation of impairment is among the most frequently seen omission when ADHD is over-diagnosed.

Some clinicians and researchers have proposed splitting the predominately inattentive type of ADHD from the predominantly hyperactive/impulsive and combines types. They point out that separating the inattentive type (perhaps naming it ADD) may be helpful to clinicians and be more effective in research. The DSM-5 has maintained the 3 presentation subtypes found in prior editions.

In the introduction section of DSM-5, the authors point out that “The current edition...builds on the goal of its predecessors of providing guidelines for diagnoses that can inform treatment and management decisions.” It is not a manual that provides instruction in the process of obtaining a patient history, in general, or specific behaviors characteristic of a diagnosis category, in particular. The section on ADHD illustrates this limitation of the manual.

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ADHD in DSM-5: Few Changes in Diagnostic Criteria continued from page 5

There are scarce comments about effective ways to use a clinical interview and parent/teacher questionnaires in order to acquire information. There is no guidance on the integration of these 2 methods of documentation. One example is the application of a parent’s responses on a questionnaire as a way to guide the interview with the parent and the child. Another example is to request a teacher narrative that describes classroom behaviors and educational performance as a supplement to a teacher questionnaire. For many years, I have asked a parent to request from the teacher “a paragraph or 2″ about their child (“Tell me about ____’s behavior in the classroom.” “Tell me about his/her learning style.”) Other questions may yield different information, but I have found these questions to be useful as a way to understand a child’s world beyond individual symptoms. In addition, most teachers appreciate being asked to document their impressions of the child. It seems to reflect a heightened level of respect for their work as teachers compared to a check list.

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About the author:

Martin Stein, MD, FAAP is a recipient of the C. Anderson Aldrich Award from the AAP for his contributions in the field of child development. He continues to have an active practice and teaches in both general pediatrics and developmental-behavioral pediatrics at the University of California San Diego and the Rady Children’s Hospital San Diego in the Division of Academic General Pediatrics, Child Developmental and Community Health.

Transition to DSM-5 Criteria for Autism Spectrum Disorders: Opportunities and Challenges for Clinicians, Families, Service Systems, and Researchers

By Carolyn Bridgemohan, MD, FAAP

The evolution to new and updated diagnostic criteria for autism spectrum disorders has been both long awaited and fraught with anticipatory fears, strong opinions, and general confusion. For the diagnosis of autism spectrum disorder (ASD), the DSM-5 criteria will bring relief for many of the problems we faced using the DSM-IV. However, there will also be challenges in adaptation and implementation of these new criteria in clinical, educational, and research settings.

The DSM-IV diagnostic criteria for pervasive developmental disorders (PDD) created a system for categorizing atypical behaviors, expanded the criteria to account for children with milder phenotypes, and brought some standardization to the diagnostic process. However, the system was not without flaws. Problems included a lack of clarity with some diagnoses [ie, PDD-Not Otherwise Specified (NOS)] and multiple related diagnostic terms that created confusion for families, clinicians, and care systems. This lack of clarity led to idiosyncratic patterns of diagnosis and service delivery. In fact many families would receive different diagnoses for the same child. Eligibility for school and state services varied by region and even between neighboring communities. Certain diagnoses were interpreted as more desirable or less severe and this led to over use of PDD and Asperger’s.

Clinicians recognized the lack of precision with the DSM-IV criteria in their own practices as a single patient might “fit” different diagnoses over time or even from one day to the next. There was also recognition over time that certain symptoms seemed to track more with autism than others. Some children who technically met criteria for PDD, for example, clearly had more language problems than social or behavioral impairments.

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The multiple diagnoses within PPD also created problems for epidemiologic tracking and research studies. It was not clear if data from one source could be compared with another due to lack of diagnostic validity and precision. Even within studies utilizing rigorous diagnostic ascertainment, application of DSM-IV criteria was not standardized or reproducible among expert diagnosticians (Lord et al, 2011).

However, despite the problems with DSM-IV, experienced clinicians internalized the list of symptoms and the terminology. School districts and states developed systems for identification and service delivery. Public awareness of autism increased dramatically and changed both the experience of, and resources available to, families receiving a new diagnosis. Adjusting all of these systems to the new DSM-5 criteria will also be challenging but must happen.

The major changes from DSM-IV to DSM-5 criteria include:

- Change from multiple diagnostic categories to one – autism spectrum disorder
- Shift from 3 major symptom categories (social, language, and behavior) to 2 (social communication and restrictive repetitive behavior)
- Shift from 12 to 7 symptoms
- Requirement for all 3 social communication and 2 of 4 restrictive repetitive behavior symptoms
- Inclusion of specifiers (eg, with or without intellectual disability, with or without language impairment)
- Inclusion of severity rating indicating level of support needed

Clinicians need to learn these new criteria and be able to apply them in a seamless manner. Currently, experienced clinicians will unconsciously consider the PDD diagnostic criteria as they obtain a history from caregivers and informally observe a child. Standardized assessments such as the Autism Diagnostic Observation Scale (ADOS) 2 facilitate more direct consideration of the criteria. This won’t happen immediately with the DSM-5 criteria. Clinicians first need to understand how elicited and observed symptoms track to the criteria and then apply the criteria to make a diagnosis. Many symptoms previously grouped under language are now credited under the social (poor conversation skills) or behavioral (echolalia or scripted language) domains. In addition, qualifiers are listed. Clinicians also need to learn how to apply the severity rating based on level of support. The DSM-5 manual provides case examples and descriptions to help clarify the qualifying symptoms and severity levels. However, even with multiple examples the current criteria cannot explain every possible presentation. The volume of text in the DSM-5 section on ASD is a testament to the continued limitations of standardizing this behavioral diagnosis.

“The primary impact is learning to use the new criteria with fidelity and consistency across our clinicians, particularly the severity levels. I think the dimensional descriptions for the criteria are much better than the more categorical descriptions in DSM-IV, and I think will aid in consistency of diagnostic agreement across clinicians. One issue that has come up clinically is the requirement for meeting at least 2 of the restrictive and repetitive behavior (RRB) criteria for very young children who meet the social communication criteria but may not as clearly meet RRB. I think this requires us to take focused histories, particularly if some of the behavioral criteria are not observed during the ADOS-2 or clinic observations,” explains Robin Hansen, MD, Professor of Pediatrics and Director of the Center for Excellence in Developmental Disabilities, M.I.N.D. Institute, University of California Davis.

Clinicians also need to determine how and when to apply DSM-5 diagnostic coding for billing purposes. For mental health clinicians, use of DSM-5 is required. However, other medical providers are expected to use ICD codes. Given the current discrepancy between DSM and ICD, physicians are left with the position of providing a written diagnosis that may differ from the billing diagnosis. Electronic medical records will also need to be updated with the new codes. Medical providers will need to determine how and when to update diagnoses in their systems. (Note: The recommendation at this time is to use ICD-9 code 299.00 for autism spectrum disorders. However, ICD-10 is coming! At that time, diagnoses codes will change dramatically. We will offer educational updates over the next year so that all are prepared and comfortable with the ICD-9 to ICD-10 cross-walk.)

Families and individuals with ASD will need to figure out where they fit in this new landscape. Individuals with a diagnosis of Asperger’s, for example, may feel a strong sense of identity with this diagnostic label and understandably resist a new identity. Parents who have a child with PDD-NOS may be worried that their child will not meet the new criteria for autism spectrum disorder. The DSM-5 is very clear, however, that individuals previously diagnosed with autistic disorder, PDD-NOS, or Asperger’s under DSM-IV will by default qualify for diagnosis of ASD. In addition, symptoms that were present in the past but have disappeared as a result of developmental improvement can be considered in making the diagnosis. This should allay some fears about diagnostic and eligibility shifts.

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For educational and state systems, the new criteria will impact eligibility determination. The potential legal implications of the change in diagnostic criteria are very well outlined in 2 papers available through the Autistic Self Advocacy Network Web site (Kaplan and Ne’eman 2012; Ne’eman and Kaplan 2012).

Shifting to a unified diagnosis of ASD will likely improve access to services (under IDEA and SSI) and accommodations (under Section 504 and ADA) for individuals who previously were diagnosed with PDD or Asperger’s because previously the educational category autism was interpreted to include all PDD in some settings and regions but only autistic disorder in others. However, the implications for individuals who meet criteria for Social Communication (Pragmatic) disorder rather than ASD are not clear. Although these individuals will require many of the same services and accommodations as individuals with ASD, they may not be able to meet eligibility criteria.

For researchers, there are several considerations related to the transition from DSM-IV to DSM-5. Researchers using medical record review will need to determine how to capture and accurately categorize potential subjects. It will likely be months or years before clinicians consistently apply the DSM-5 criteria in a reproducible manner. For retrospective studies, there will likely be a transition period where both DSM-IV and DSM-5 criteria are accepted. This may muddy interpretation of results as well as comparison to prior studies. For established studies, methodology will need to be updated to incorporate subjects diagnosed under the new criteria. These changes will also create opportunity, however, for research comparing validity of the 2 systems. In longitudinal studies where subjects were diagnosed with DSM-IV criteria, for example, the DSM-5 can be queried at follow up visits. In addition the DSM-5 system with specifiers and severity ratings provides more phenotypic data that will be useful for characterizing research subjects and monitoring outcomes.

Dr. Hansen explains, “The systematic reporting of additional characteristics (intellectual impairment, language impairment, other medical, genetic, environmental factors, other neurodevelopmental or behavioral disorders) helps to describe the heterogeneity of ASD better than the subgroups of PDD in DSM-IV.”

Charles Nelson, PhD, Professor of Pediatrics and Neuroscience at Harvard Medical School and Director of the Laboratories of Cognitive Neuroscience at Boston Children’s Hospital comments, “I think the biggest implication for research, moving forward, is whether kids who meet DSM-5 criteria are the same kids who would have met DSM-IV criteria. If we hope to examine similarities/differences in studies over time (eg, whether a particular finding replicates), then we face the conundrum of whether the samples are the same. There are a few implications of the changes made in DSM-5 for research. For example, there has been a tremendous amount of work on Asperger’s syndrome (AS), including genetics. Now that AS doesn’t formally exist, what should we do with the countless studies that examined AS? For example, how shall we interpret findings purporting to identify genes associated with AS if AS no longer exists?”

Dr. Nelson adds, “I think one very positive change is the greater emphasis placed on social communication impairments, which does a better job of capturing the essence of autism than DSM-IV did. But, with this change in emphasis, one wonders whether prevalence figures, so widely reported the past few years, will need to shift.”

In sum, the DSM-5 criteria bring many improvements to the field – a single clear diagnostic term rather than multiple confusing terms; a dimensional rather than categorical system; the use of modifiers and severity rating to better delineate phenotypes across the spectrum. The adaptations needed as we move forward include the ability of clinicians to understand and use the new criteria in a standardized manner, the adjustment of families and individuals to the new diagnostic terminology and the integration of care systems to allow appropriate services and eligibility determination. In addition, researchers will need to figure out how to integrate this new system into the prior evidence base and future studies. Clinicians, researchers, educators, legislators, and families will need to work together to inform research with new clinical knowledge, translate research knowledge into clinical practice, and guide policy and eligibility decisions.

References

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Imagine an experiment in which each of the different criteria or classificatory schemes for autism over the last century is printed on a separate sheet of paper. The subject is asked to organize them in chronological order. I have tried this with my students, and no one has gotten it right—largely because they look in vain for a sequence that will reflect advances in scientific thought.

But the changes in autism diagnosis over the years have not been advances but rather adaptations. Collapsing the PDDs into one category, ASD, allows the schools and psychologists the diagnosis they need to provide appropriate services to people across the spectrum (since there is only one category, “autism,” in the public school systems). Moreover, the dimensional rather than categorical definition of autism allows providers to conceptualize the many changes that occur in children with autism, sometimes over a short period of time, without having to worry about whether the diagnosis is still warranted.

Perhaps most importantly, we no longer need Asperger’s. It was desirable as a less stigmatizing word for autism at a time when there was great stigma – indeed, many parents kept their children’s autism diagnoses a secret but were willing to adopt Asperger’s. The reality is that, under the DSM-IV criteria, most everyone with Asperger’s also fit the profile of autistic disorder; the best diagnostic instruments, when employed by the best diagnosticians, could not clearly distinguish between Asperger’s and autistic disorder; and the concept took on the meaning of “high functioning” autism, despite the fact that people with Asperger’s are often just as socially impaired, if not more so, than people with “autistic disorder.”

The unsung achievement in autism over of the last 2 decades occurred not in science, but in the decline of stigma, and society’s ability to understand and appreciate people with special needs. Asperger’s played an important role in this development. The concept helped create an awareness of the spectrum, and a new openness to talking about children with ASD. Asperger’s may endure as a cultural identity, but as a clinical diagnosis it needs only our gratitude for a job well done.

Unfortunately, this social achievement has been obscured because, over the past several years, leading psychiatrists have dwelled on their concern—even embarrassment—that, in comparison to other areas of medicine, their field has made little progress. Professional presentations often begin with statements about the decrease in deaths from leukemia and other cancers, AIDS, and ischemic heart disease, and are followed by statistics about the high prevalence of major mental illnesses. From an anthropological perspective, these are false comparisons, because all diseases are constructs, even those based on lab tests. They are created by consensus at particular historical periods and are not always better than previous constructs (consider, for example, the ambiguous and often arbitrary determination of what counts as hypertension, and whether hypertension counts as a “disease”).

So, what if we consider autism not as a disease but as a framework for treatment, support, and services? This is a simple and pragmatic clinical view based on the idea that diagnoses provide a socially acceptable vocabulary for understanding behavior. Leave the debates about the relationship between scientific data and psychiatric nosology to the researchers, and give the diagnosis that will be most beneficial to the child. It seems to me that the DSM-5 criteria are well-suited to this goal—at least for the moment.
Managing Encopresis in the Pediatric Setting

By Edward R. Christophersen, PhD, FAAP (Hon) and Matthew Wassom, PhD
Children’s Mercy Hospitals and Clinics, Kansas City, Missouri

Encopresis is defined as a child over the age of 4 repeatedly passing feces into inappropriate places (such as clothing or the floor) at least once per month over a 3-month period. Encopresis can be primary, in which case the child has never been toilet trained, and secondary, in which case the child was toilet trained and accident free for a period of at least 6 months. Because constipation has been implicated in about 90% of cases of encopresis, most of the empirical work has focused on children with a history of constipation.

Prevalence and Significance of Encopresis

Christophersen and Friman (2010) estimate the prevalence of encopresis to range from approximately 4% of 4-year olds to 1.6% of 10 year olds, with boys being affected 3 to 6 times more often than girls. Encopresis and constipation have been reported to account for 3% of pediatric referrals (Loening-Baucke, 1993) and 30% of referrals to pediatric gastroenterologists (Culbert & Banez, 2007). Har and Croffie (2010) reported that there are no correlations between encopresis and socioeconomic status, the child’s position in the family, parental age, or family size. Population based studies on the prevalence of encopresis in children, beyond American populations, have been scarce. Van den Berg et al. (2006) reported no evidence that the rate of constipation occurs any less in non-Western societies.

Encopresis can lead to significant impairment in multiple areas. Parents have rated the child’s lack of self-esteem as the most important consequence of constipation and encopresis while emerging evidence shows that these children may exhibit more emotional and behavioral difficulties than other children, perhaps as a result of the condition. Despite the commonality of this condition, encopresis has been referred to as the “hidden disease” and parents of children with encopresis often think that they are the only family who has a child with this problem (Christophersen & Friman, 2010). There has been very little discussion about encopresis in the popular press.

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Etiology of Encopresis

Har & Croffie (2010) stated in their review that 90% of all cases of encopresis are functional in nature, with no obvious medical cause for the constipation. There may be some predisposing factors present that promote tendency toward constipation such as genetics towards slow motility, change in diet or poor diet, or dehydration. The most common condition that must be distinguished from functional constipation in infancy is Hirschsprung’s disease.

There is support that stool-withholding behavior is a major cause for the development and persistence of constipation and encopresis. However, it is felt that stool withholding and anxiety about defecation are preceded by large, hard, and painful difficult to pass stools (Blum, Taubman, Nemeth, 2004). Because of this relationship between initial difficult stools, withholding behavior, and then subsequent increased problems with constipation, this condition is often thought of as a self-perpetuating condition. Long-term fecal retention due to stool withholding eventually may lead to chronic presence of a fecal mass and cause changes in the functioning of the rectum and lower GI system. Therefore, the maintenance of encopresis can be thought of as both a physical problem and a learned behavior problem that requires both medical and behavioral intervention.

There has been some limited research on the role that child temperament may play in the further maintenance of stool toileting refusal and thus encopresis. Taubman (1997) found that there was a trend toward children with stool withholding being rated by their parents as having a more difficult temperament. Burket and colleagues (2006) showed constipated children aged 2-7 years were rated by their parents to be more stubborn in general and regarding toileting behaviors.

Evidence Based Assessment

Initial assessment of the child with encopresis should include a thorough medical history and a physical examination by the physician. It is important to fully evaluate the presence or history of constipation to determine treatment course, as treating encopresis in children with constipation will differ from treating encopresis when there is no history of constipation. A working group composed of gastroenterologists and pediatricians published the Rome III criteria for functional constipation which should be used as a guideline in this evaluation (Rasquin, Di Lorenzo, Forbes, Guiraldes, Hyams, et al., 2006) (See Table 1 for Rome III criteria).

<table>
<thead>
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<th>Table 1: Rome III criteria for functional constipation</th>
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<td>Must include 2 or more of the following in a child with a developmental age of at least 4 years:</td>
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<tr>
<td>• Two or fewer defecations in the toilet per week</td>
</tr>
<tr>
<td>• At least 1 episode of fecal incontinence per week</td>
</tr>
<tr>
<td>• History of retentive posturing or excessive volitional stool retention</td>
</tr>
<tr>
<td>• History of painful or hard bowel movement</td>
</tr>
<tr>
<td>• Presence of a large fecal mass in the rectum</td>
</tr>
<tr>
<td>• History of large diameter stools that may obstruct the toilet</td>
</tr>
<tr>
<td>*Criteria fulfilled at least once per week for at least 2-months before diagnosis</td>
</tr>
</tbody>
</table>

It is important for the history to include a review of the child’s toilet training as well as their response to the training. Examination of the perineum and perianal area is essential and digital rectal examination, while rarely actually performed in practice, is also recommended. Some physicians also order a kidney, ureter, and bladder (KUB) x-ray to determine the extent of the fecal mass, which can also sometimes be used to help educate the family. Lastly, physicians should consider a brief screening of other behavioral concerns. A useful behavioral screening measure that can be implemented quickly in the physician office is the Pediatric Symptom Checklist (PSC) (Jellinek, & Murphy, 1988).

Evidence Based Treatment

The medical-behavioral treatment approach is recommended for children with encopresis associated with functional constipation (Christophersen & Friman, 2010). This includes 4 major treatment components: 1) education about the condition, 2) disimpaction of constipation, 3) maintaining regular bowel movements, and 4) behavior strategies to improve toileting habits and behaviors. The
Medical-Behavioral Treatment Approach

The education component usually involves making sure that the family understands the role that constipation plays in the etiology of encopresis including a developmentally appropriate discussion of the anatomy and physiology of the lower GI tract and defecation. It is important to alter negative attributions of the parents about the cause or origin of the soiling accidents. Many parents of constipated children with encopresis think that the child is soiling on purpose or is being lazy or defiant. Parents should be educated that the encopresis or loss of feces in the underwear is involuntary and the result of overflow incontinence, deconditioning and altered functioning of the rectum, and learned withholding behavior. In our clinic we use Levine’s (1982) schematic representation of the colon of a child with encopresis. The clinician uses the schematic to explain how constipation leads to the increased diameter of the colon and rectum as well as the decreased sensitivity to pressure in the colon. Parents are coached to maintain a consistent, positive, and supportive attitude in all aspects of treatment. It is important to include the child in this education and we often discuss being a team with the child to help this problem go away.

The second treatment component that can be discussed and carried out after providing the education is the treatment of the child’s current constipation and/or impaction. It is important to again provide detailed education about why a “clean-out” is essential in the success of treatment and prepare parents for the process. It should be clarified with the child that this means taking medicine and having a lot of stool out. Disimpaction or “clean-out” typically involves medication (either oral or rectal - there are no published studies comparing the 2 routes of administration). The NASPGHN Clinical Practice Guidelines (2006) discuss the various medications and dosing for relief of constipation, which may involve enemas, suppositories, or oral medication (such as polyethylene glycol 3350 powder). Absent adequate management and monitoring of the child’s constipation, the likelihood of significant progress is significantly reduced.

The third component is the maintenance of regular and consistent bowel functioning and making sure that the child does not get constipated again. Christophersen and VanScoyoc (2013) recommend including management of the diet (with increased consumption of dietary fiber and reduction in the intake of dairy products when indicated, and increased water consumption). Maintenance may also include the use of stool softeners and laxatives to prevent accumulation of stool and allow the rectum to return to normal functioning. The 2 most common agents are polyethylene glycol and lactulose, which draw fluid into the large intestine. Again, NASPGHN Clinical Practice Guidelines (2006) give recommendations for specific medical regimens for maintenance treatment of constipation.

The fourth component of treatment that occurs concurrently with maintenance medical treatment is behavioral strategies that promote healthy bowel habits and routines. One helpful approach discussed in the literature and used in our clinic is to work with parents (and include the older child in the process) to closely monitor bowel output for a period of time to ensure that medication and diet adjustments can be made when necessary. We routinely ask the parent(s) and child to complete a Bowel Symptom Rating Sheet (SRS) on a daily basis (See Table 2). This bowel symptom rating sheet helps track bowel movement details such as frequency of stools in the toilet, soiling accidents, size or volume of stools out, and consistency or appearance of stools out. Often children who are having slow and insidious onset of constipation can be managed by calculating estimates of weekly stool volumes and working towards consistency each week. In addition, the SRS can track medication doses given, amount of dietary fiber, amount of water intake, and other goals which provides the opportunity to quickly and efficiently review not only the patient’s progress, but also their level of adherence to the treatment regimen. At the same time, the parent/child completing the SRS is reminded daily what the components of the treatment regimen are and this can be a motivating intervention.

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Behavioral interventions should include scheduled and rewarded toilet sits. Scheduled toilet sits can occur 20-30 minutes after meals to take advantage of the gastrocolic reflex and because pairing with meals is easier to build into the family routine. Scheduled toilet sitting improves healthy toilet behavior and responsibility and also helps with reconditioning the rectum by keeping the rectum empty as much as possible. The time on the toilet should be unrushed and positive and may include special activities that are only available while on the toilet (special books, toys, or handheld electronics). Toilet sits should generally last 5-10 minutes but some children need to gradual work their way up to longer sits if there is initial resistance. The key to toilet sits is that the child has to learn to relax during these sits and hopefully concentrate on the sensations from their lower abdomen.

Positive reinforcement systems should be used for toilet sitting and other successive goals towards appropriate toileting behavior. Reward systems for toilet sitting compliance can include toilet sit sticker charts, calendars, and also earning tokens/chips/points that can be used for purchase of incentives or privileges. Typically, we recommend rewarding the patient for cooperation with the components of the treatment regimen (and not just for proper elimination in the toilet which is rarely achieved early in the treatment program). Often times there needs to be a progression of successive steps towards toileting that may include focus on general compliance, completion of the bowel symptom rating sheet with parents, medication adherence, scheduled toilet sit compliance, changes in diet and water intake, compliance with a clean up routine, bowel movements in the toilet, and periods of cleanliness or time without soiling.

A specific example of a positive reinforcement system that is relatively easy to implement is “reward menus”. We ask the parent(s) to identify 5-6 activities (that don’t involve travel or money) that their child enjoys, most of which involve one-on-one participation with the parent(s). Examples include playing catch, playing on a swing set, going for bicycle rides, favorite board game or videogame. With younger patients, we will ask the parents to put pictures of the various rewards that they have identified on a sheet of paper that is posted in the bathroom as a frequent reminder to the patient of the rewards that are available. We generally recommend to parents that the rewards must be consumed the day they are earned, not saved for the weekend or a better time because we want immediate reinforcement for a behavior that needs to occur daily.

Other behavioral interventions often need to be implemented in individual patients to address barriers to treatment success. In many cases, these children would benefit from referral to a behavior specialist. For example, some families need guidance in improving
the child’s general compliance with instructions. This may include providing guidance on positive attending and describing desired behaviors, consistent limit setting, and using immediate and consistent consequences for noncompliance. Other children may have significant fears of the toilet or full toilet refusal and need a more gradual approach or “systematic desensitization” to toilet sitting. Some children may need more specific behavioral guidance and training for effective defecatory pushing and evacuation of stools. A particular intervention that was found to be effective, using random controlled assignment to alternative treatments, was “enhanced toilet training”, which teaches children appropriate defecation pushing and works on correcting paradoxical contraction and learned withholding behaviors (Borowitz, Cox, Sutphen, & Kovatchev, 2002).


References

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I tried to keep up with Mungala’s pace, an energetic 17-year-old transgender who grew up working in the commercial sex industry. In the middle of the slum, we finally reached the clinic where he would be getting his operation. The filthy equipment, unsanitary room, and unlicensed physician shocked me. This defining moment, while spending the summer in India when I was in high school working on a service project, ignited my desire to become a physician. I wanted to empower underserved individuals like Mungala by helping them receive access to adequate medical care.

A few years later, after graduating from college, I decided to take a gap year and work in India before starting medical school. If I wanted to work in global health, I thought, shouldn’t I have some more experience before starting medical school? It may give me greater context, technical knowledge about global health, and field experience.

However, the previous sentence does not fully express how much I observed, learned, and grew during this past year in India.

I fortunately received the William J. Clinton Fellowship from the American India Foundation to work at the Non-governmental organization (NGO) Ummeed Child Development Center for 10 months. Located in Mumbai, India, Ummeed serves families with children with developmental disorders and disabilities. Their clinic provides weekly therapies to children and counseling to parents. I remember Sonya, sitting quietly in the room with a therapist, while I observed this session through a one-way mirror. Sonya’s child with autism waited outside with his father. The therapist calmly explained to Sonya that children like her son do better with routines; a daily schedule can reduce the occurrence of unexpected events that can upset children with autism. Sonya, along with her husband, understood. However, her in-laws did not. They neither accepted the notion that their grandchild had a developmental disorder nor provided support ensuring daily routines.

As these family members all lived together, a common Indian tradition, they gave me my first glimpse into how a family’s custom can influence a child’s care.

Another mother, Arthi, had a young child with hearing impairment and developmental delays. Her husband’s unemployment and alcoholism pushed her to become the permanent family breadwinner and caregiver for their child. After 6 years, Arthi became overwhelmed with all of her responsibilities, and was depressed when she came to the center. Eventually, she started meeting with a mental health counselor. With time and diligent effort, she rebuilt her self-esteem and confidence, ultimately to new heights. Her relationship with her son improved, she attended college, got a full-time job, and found her own methods for working with her son within her family’s dynamic. Arthi showed me that empowering parents equips them to overcome their unique troubles. I learnt that working with families has the greatest influence on their child’s development.

In college, I had heard and read similar anecdotes about how community, familial, or religious dynamics of a region can affect medical care. But witnessing this first-hand, in the case of Sonya and Arthi, gave me a deeper, personal, and more genuine understanding for why we need to account for these dynamics when providing care. Written anecdotes, in comparison to field exposure, rarely provide the depth one must comprehend first before knowing how to best help a family.

Before coming to India, I did have one concrete goal in mind. I knew that entering a field such as global health without having a large network or a role model would be unsettling for me. Fortunately, through my experience, I met a diverse group of people equally invested in global health, including my colleagues working at Ummeed to countless others I met through the fellowship.
At Ummeed, knowledgeable individuals mentored me on my 2 research projects. I was part of a team that conducted an evidence-based study on a pilot reading intervention for children with disabilities. I also helped do an impact assessment on Ummeed’s Mental Health training program, a program that builds capacity for organizations working with children with disability and children at risk. My roles included analyzing the qualitative and quantitative data and documenting the findings. The guidance my mentors gave me, supplemented with their honest and supportive feedback on how I could improve, showed me how my work would directly benefit Ummeed’s current practices. In effect, this cultivated my interest in global health research and in medical writing.

I decided to explore medical writing further. A friend of mine whom I met through the fellowship, Anusha, became an ally. We wrote an article together for an Indian newspaper on the importance of the mental well being of caregivers, which served as awareness building and advocacy for both Ummeed and for Anusha’s organization. This gap year gave me the time and flexibility to develop my interest in medical writing further before entering medical school.

My experiences over the past year surpassed my expectations for what I thought I was going to get out of this fellowship. Working at Ummeed introduced me to a number of intricate factors that must be acknowledged when working in a community. Meeting extraordinary families with their unique stories helped me create a stronger connection with those I hope to work with in my future. These families also provided a context to recall as I begin my medical education. Finally, individuals like Sonya and Arthi reminded me that the developmental classes I took in college were not just case studies and theoretical analysis, but had real people that stood behind them. In preparing for my career, and also for my personal growth, taking a gap year was one of the best decisions I have ever made.

About the author:

Ambar Mehta graduated from the Massachusetts Institute of Technology in 2012. He worked in India at Ummeed Child Development Center on a William J. Clinton Fellowship from the American India Foundation. He currently attends Johns Hopkins University School of Medicine, class of 2017.

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**Assistive Technology for Communication Problems**

*By Larry Desch, MD, FAAP*

**Overview**

Children and adults who have various types of disabilities can often be helped to be more functional in their day-to-day living activities by the use of adaptive, augmentative, or assistive technology. Although definitions for these have differed in various settings, over the past decade some apparent consensus has developed.

Assistive technology, the more general term, refers to a device or system which can help alleviate the impact of a disability, lessening the functional limitations. Adaptive technology is that which specifically substitutes for the loss of functioning from a disability. Finally, augmentative devices are those that “augment” an area of functioning that is deficient, sometimes severely, but for which there is some residual ability. An example would be the use of a microcomputer-powered speech-generating communication device (SGD) device for a child with severe dysarthria. In this last situation, the child’s speech may be understood by family members but the augmentative communication device would be needed as an “alternative” when the child wanted to communicate with others. The most common context for the use of the term ‘augmentative’ is in the field of speech and language (eg, augmentative/alternative communication [AAC] devices).

Children who have moderate to severe physical impairments involving the extremities always have some type of communication disability. These communication problems may mainly involve text production (written or typed), but many of these children also
have some vocal communication problems. Those children and adults who have an autism spectrum disorder (ASD) frequently also have significant communication delays. The rest of this article presents an overview of the evaluation for and use of AAC.

Communication Disabilities (including that seen in ASD): The World of AAC

Many types of communication devices can be used by a child who is unable to use speech as an effective means of communication. Symbols rather than words are often used in the development of communication techniques used by children who do not speak, such as those who have ASD. The use of symbols is especially helpful if the individual does not know how to read prior to using a communication device. Those children who have significant intellectual disabilities, for example, may continue to use pictures or symbols as their main method of communication even as adults.

Low-tech answers to communication problems might include various lists of words or pictures that a child could point to in order to get the message across. Low-tech communication boards can be constructed by putting pictures, words or symbols on a flat surface, and can be used in face-to-face communication by pointing. Visual systems (eg, Picture Exchange Communication System) are often used with children who have ASD.

A battery-operated scanning communication device (simplest being a light that can be turned on to indicate yes/no) is an example of a mid-tech device. These have been successfully used by children who have isolated speech and language disorders as well as ASD. Other mid-tech devices that can be used by these groups include portable voice-output storage devices, which require direct selection (using a switch or a keypad) and hold only a few minutes of prerecorded sentences or phrases (eg, “I want to eat now”). However, all low-tech and mid-tech devices have 2 faults: 1) they represent a very slow and/or very limited method of communication, and 2) they cannot be used for long-distance communication.

Many high-tech electronic communication aids, often incorporating the use of symbols that may substitute for groups of words, are becoming more commercially available to children with disabilities. For individuals with severe physical and communicative disabilities, these high-tech aids commonly use the methods of scanning (eg, lights might move across a screen of letters and one switch is used to select) or encoding (eg, 2 or 3 switches could be used to call up phrase or sentences). Systems that allow direct selection (eg, using a keyboard) are used with those children who have better control of movements (which would be most children who have an ASD).

Single-function speech generating devices (SGD) (ie, limited ONLY to communication) have been found to be quite helpful to both children and adults with severe communication disorders over the past decades, but their use has been curtailed by their high cost and somewhat by their limited flexibility. A growing number of companies have recently addressed this cost factor by using less expensive commercial laptop microcomputers as the core part of a communication system. Rather than being used only for person-to-person communications, these adapted laptops can be used for all types of communication—letter writing, telecommunications, and electronic mail—and other personal uses such as for environmental control, as safety and security systems, or for just playing computer games.

The past few years have seen the explosion of use of the popular tablet computer on which input is usually accomplished by touch screen or is pen-based. These commercial devices can often be modified into an AAC device by adding the appropriate software to provide the best display and input method and, usually, voice-output. Good hand/eye skills are needed to access tablets, thus limiting the use of these devices to those persons without such problems (eg, ASD, childhood verbal apraxia). These tablet applications are increasing at an exponential rate: at the time of writing this, on the App Store of the iTunes Store ™, there were over 180 iPad™ apps found by searching “AAC speech”.

The main advantages of using a commercial laptop/tablet over that of most dedicated communication aids are the greater flexibility and lower cost of the commercial device. These devices are often initially designed for the possible use by persons who have disabilities, an example of “universal design”. However, a major barrier to using laptops or tablets as communication aids, if the intended user has significant physical impairments, is the custom-made interfacing needed (ie, switch controls) usually much easier to do with dedicated AAC devices.

Issues Regarding Assessment

Every child with a disability is different in his or her abilities and needs, and the process of selecting any assistive device nearly

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always requires extensive planning, evaluation and monitoring by an experienced team of professionals. This team approach is needed to properly evaluate both the functioning of the child and the device in order to ensure that the device can be used effectively and will not interfere with other parts of the child’s overall treatment, educational, or vocational plan. Depending on the type of assistive device to be prescribed, this team might include such individuals as speech-language therapists, physical therapists, occupational therapists, rehabilitation engineers, pediatricians, neurologists, physiatrists, special educators, computer specialists, and others who, by their training or experience, are appropriate. Obviously, whenever AAC is being considered, a qualified speech/language therapist, experienced in AAC, must be part of the team.

An important aspect of the assessment for AAC systems is to always consider the entire spectrum of assistive technology that may be useful. The best approach is always to begin with the low-tech devices and then, if needed, to assess mid-tech devices and, finally, high-tech devices. If a low-tech solution solves a particular problem, then it is seldom appropriate to go any further in the processes of assessment and monitoring of use. For example, if a child who has ASD is doing well using a low-tech picture-based system and is not getting frustrated from a small “vocabulary” then changing to something more complex, such as a tablet, may be more of a distraction rather than something that will improve function.

As complete an evaluation as possible of the functional limitations (including environmental) of the person should be done prior to actually ordering equipment so that devices that are inappropriate are not inadvertently acquired. The ultimate goal for using any assistive device is to achieve the highest possible functioning.

Training and Monitoring

The physicians or therapists who prescribe or recommend AAC must also accept responsibility for seeing that the child receives proper training and monitoring (usually by a speech/language therapist). Training is probably the most crucial factor in ensuring that a child who has disabilities becomes comfortable with and properly uses any assistive device, including AAC.

Monitoring Using Single-Subject Designs

Despite the limited data from controlled studies that have addressed the indications for and effectiveness of assistive devices, including AAC, there are, however, methods that pediatricians and therapists can use that will, at the very least, lead to more evidence-based and appropriate use of assistive devices. The best available method to determine the usefulness of such interventions is the careful implementation of what has been called a “single-subject research design” (eg, Zhan & Ottenbacher, Disability Rehabilitation, January, 2001). This type of study, also called an “N of 1 trial” or “single-patient trial,” essentially involves the determination of baseline abilities by an evaluation test or technique, followed by one or more interventions. The effectiveness of each intervention also is determined by the same evaluation test or technique. In the best of such studies, the evaluations are done by blinded evaluators; however, this is not critical. Although statistical techniques could be used, a careful, unbiased, “visual analysis” of the data collected during a single-subject evaluation process can be a very effective way of analyzing results.

Funding Issues

Despite the frequent funding for AAC by both school systems and medical insurance companies, there continues to be debate as to whether AAC devices are “medically” or “educationally” necessary. Unfortunately, if a school system purchases an AAC device the child is usually prevented from taking the device home to use. The federal “Tech Act” and its amendments have tried to solve this problem in part by legally allowing Medicaid funding to be used by the schools to purchase assistive devices (Assistive Technology Act of 2004, PL 108-364). The “Tech Act” further requires that schools allow any such devices purchased, even with only partial Medicaid funding, to be taken home by the children for “educationally related” purposes.

Some AAC devices, especially dedicated SGD devices, are gradually being seen as medically necessary in much the same way that a wheelchair can be determined to be a medical necessity. Most private and governmental medical coverage agencies have been willing for years to pay for the purchase of wheelchairs and gradually are beginning to fund assistive devices, including AAC, as durable medical equipment (DME).

Pediatricians are often called upon to send “medical necessity” letters and prescriptions to funding sources in order to help obtain funding for assistive devices. In most cases, this correspondence should be written only after conferring with several different therapists who have evaluated the child to obtain as much information as possible about his or her current abilities. Complete information, in this sense, does not mean a report of the physical examination findings or treatment, but rather a presentation of the

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findings that would be of most interest to the funding agency. It might be best to imagine oneself as the reviewer of the funding program, and include only information that the reviewer would be specifically looking for, such as the child’s current abilities and expected outcome from using the devices. Many funding agencies need to be properly, but gently, instructed about the potential of these devices to improve functioning and independence for children with disabilities.

**Recommendations for Pediatricians** (Adapted from Desch & Gaebler-Spira, 2008)

1. Pediatricians should provide early referral for evaluations of toddlers and young children with communication disabilities.
2. If use of an AAC system is appropriate, the pediatrician should help arrange for complete evaluations, training, and monitoring by professionals (eg, speech-language pathologists) and acquisition of devices.
3. Pediatricians should advocate for the appropriate funding of AAC evaluations, devices, and training services for children with communication disabilities at the local, state, and federal levels.
4. Pediatricians should provide guidance, information, and support for families of children who have communication impairments and act as advocates and care coordinators for these children to ensure that AAC systems are improving their functional abilities.
5. Those pediatricians who follow children who have communication disabilities should assist parents in discussions with school and child care personnel to ensure that any communication system or device that is being used in these settings can also be provided for use in the home and other family settings.

**RESOURCES**

1. National Assistive Technology Technical Assistance Partnership (NATTAP), [www.resna.org/taproject](http://www.resna.org/taproject)
2. RESNA Catalyst Project, [www.resnaprojects.org](http://www.resnaprojects.org)
4. American Speech-Language-Hearing Association, 10801 Rockville Pike, Rockville, MD 20852; [www.asha.org](http://www.asha.org); 301-897-5700

**About the author:**

Larry Desch, MD, FAAP directs both the clinical and educational aspects of developmental pediatrics at Hope Children’s Hospital, a major teaching affiliate of the University of Illinois College of Medicine, Department of Pediatrics. Over the years, Dr Desch has also assisted various state agencies that deal with children with a wide spectrum of disabilities and has served on a number of advisory boards and committees for children with disabilities of state chapters of the AAP.

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**Please Visit Our Section Web site**

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

Recent highlights include:

- Access to our SODB Discussion Board where members can connect on questions and discussions related to ADHD, developmental delays, screening, and more.
- Information about the 2013 National Conference and Exhibition
- Information about the 2014 DB:PREP Course
- The Fetal Alcohol Spectrum Disorders Toolkit
- Access to the LD Navigator
ASHA Connections:
Speech and Language Development and Disorders:
When to Refer The Earlier, the Better!

By Diane Paul, PhD, CCC-SLP, Ann-Mari Pierotti, MA, CCC-SLP, and Leigh Deussing, MEd, CCC-SLP
American Speech-Language-Hearing Association

Children with speech and language disorders have problems understanding, talking, reading, and writing. Speech and language disorders can have a significant effect on a child’s behavior, school performance, and social interactions. Early identification and intervention are critical. The earlier the disorder is identified and treated, the better the outcomes, regardless of the cause. With early intervention, affected children can become more successful with communication, literacy, academics, and interpersonal relationships. The type of treatment prescribed depends on the nature and severity of the disorder and the identified strengths and needs of the individual child.

Speech and Language Development
Speech and language skills develop in a predictable way. For example, children use their first word around their first birthday, but they understand words months earlier. Children start to use about 50 single words before they start putting words together, which occurs around 18 months. Certain sounds (p, b, m) emerge earlier than others that involve more complex motor patterns (l, r, s). However, each child is unique and develops speech and language skills at an individual rate. A chart with developmental milestones for communication is available at www.asha.org/public/speech/development/chart.htm.

Learning Two Languages
Language developmental milestones are universal across all languages. Bilingual children develop speech and language skills in the same way as those who speak only one language, although it may take somewhat longer for bilingual children to develop their skills. It is common for bilingual children to mix languages, even in the same sentence. There is no optimal way to help a child become bilingual, such as waiting for the child to reach a certain age to introduce a second language or having one parent speak to the child in the second language only. Researchers all agree that a critical message for families is to provide a rich model of language for their children and that learning multiple languages does not cause speech or language problems.

Experts indicate that parents should communicate with their children in the language they are most comfortable using. Children having problems with both languages should be referred to a speech-language pathologist (SLP). It is important for families to understand that, even if a child is diagnosed with a speech or language disorder, he or she is capable of learning more than one language.

Causes of Speech and Language Disorders
Speech and language disorders in children can result from genetic conditions (eg, Down syndrome or Fragile X syndrome), developmental disabilities (eg, autism spectrum disorder, cerebral palsy, intellectual disabilities), diseases (cytomegalovirus or meningitis), toxins (eg, fetal alcohol syndrome), reduction of sensory input (eg, hearing loss, chronic ear infections), craniofacial anomalies, and brain injury. Often, the specific cause for a speech or language disorder is unknown. A family history of a speech or language disorder is a risk factor.

Signs of Speech and Language Disorders
Children may have mild to severe speech disorders, language disorders, or both. Speech disorders encompass difficulties with sound production (articulation problems, apraxia of speech), fluency (stuttering or cluttering), voice quality, and resonance.

Language refers to the way words are combined and used to communicate thoughts and ideas. Language comprises the processes of understanding, speaking, reading, and writing. Components of language include semantics (word meaning, vocabulary), syntax and morphology (word order and grammar), and pragmatics (use of language in its social context). Language disorders involve problems with any of these components of language and may occur with understanding (receptive language) and/or using (expressive language) spoken or written words or other symbol systems (eg, sign language). Because oral language is the foundation for written language, oral language problems often result in difficulties reading, spelling, and writing. Children with social (pragmatic) communication disorders typically don’t have problems with vocabulary or grammar, but have difficulties with verbal and nonverbal communication in social interactions. Social communication includes communicating for different purposes (eg, requesting, commenting), modifying communication to accommodate the listener or setting, having meaningful conversations, continued on page 21
telling stories in sequence, and understanding nonliteral meanings of words and phrases (eg, understanding and using humor, idioms, metaphors). Social communication norms can vary significantly within and across cultures.

Signs that signal the need for referral to an SLP may be that a child
• doesn’t smile or interact with others (birth–3 months),
• doesn’t babble (4–7 months),
• makes only a few sounds or gestures (eg, pointing; 7–12 months),
• says few words (12–18 months),
• doesn’t understand what others say (7 months–2 years),
• doesn’t put words together (18 months–2 years),
• has speech that is unintelligible to unfamiliar listeners (2–3 years),
• struggles to say sounds or words (2½–3 years).

Because of the value of early detection and early intervention, pediatricians are strongly encouraged to refer a child to an SLP as soon as the child shows signs of a speech or language problem; a delay in treatment will only compound the consequences of a communication disorder. Families may have the hope and misconception that a late or missed milestone is indicative of a condition or phase that a child will outgrow. Some children spontaneously recover from early speech and language delays. For example, stuttering typically begins in children around 2-3 years when they are learning increasingly complex language skills. The majority of children become fluent speakers as language skills develop. However, some fluency problems persist. SLPs can work with parents and children and differentiate developmental fluency problems from those that will likely persist. Pediatricians can alert families to early communication warning signs and make a referral to an SLP. It’s also important to convey that it’s never too late, because SLPs can also help older children with communication problems.

Ways Speech-Language Pathologists Help
SLPs diagnose and treat children and adults with all speech, language, and social communication impairments. In addition, SLPs work with people of all ages who have dysphagia (feeding and swallowing disorders) or cognitive communication disorders (eg, problems with memory, attention, problem solving, organization). For speech and language evaluations, the SLP talks with the family about the child’s medical and developmental history, observes the child interacting with different people, and also may administer speech and language tests to see how the individual child’s speech and language skills compare with those of other children in the same age group. Speech and language intervention offers needed support for families and direct treatment for children. Through early intervention, the family receives counseling and resources and can develop skills to facilitate effective communication for their child. SLPs help children develop speech and language skills in natural settings during interactions with regular communication partners. Depending on a child’s communication needs, the SLP may provide direct services on an individual or small-group basis and may train others to implement the targeted communication goals. For children who are learning more than one language, evaluation and intervention is provided in the language(s) most relevant to the individual child and family.

Children with severe speech or language problems—who cannot be understood or who have no speech—need augmentative and alternative communication (AAC) systems. AAC can supplement existing speech or replace speech that is not functional. SLPs conduct evaluations and recommend AAC systems tailored to the needs of the individual. AAC devices include low tech aids, such as picture and symbol communication boards, and electronic aids, such as tablets and speech generating devices. Research shows that the use of AAC systems does not impede the development of speech.

For more information about speech and language development, go to www.asha.org/public/speech/development/. Visit www.asha.org/public/speech/disorders/ChildSandL.htm for detailed information about various speech and language disorders and medical and developmental conditions. To make a referral to a speech-language pathologist in your local area, go to ProSearch at www.asha.org/findpro/. Speech Referral Guidelines for Pediatrics is available at www.asha.org/public/speech/speech-referral/.
AAP Department of Federal Affairs Update
Psychotropic Medications and Access to Care

In December 2012, the Government Accountability Office (GAO) released a report examining the relationship between psychotropic drugs and the long-term development of children in foster care. The report found that children in foster care were more likely to be prescribed psychotropic medications, and multiple medications, than have access to non-pharmaceutical treatment options. The GAO concluded that many children, particularly those in the foster care system and on Medicaid, are not receiving appropriate mental health services. The report recommends steps to improve access and increase oversight of prescriptions of psychotropic medications and best practices for integrating mental health into primary care settings. AAP members gave input to GAO as they were developing the report and AAP will continue following this issue as we continue to advocate for appropriate screening, early intervention, and services for children’s mental health. Officials in the Department of Health and Human Services’ Office of the Inspector General have launched an investigation into the use of antipsychotic drugs for those 18 and younger who receive Medicaid. The investigation will also use medical records to determine the extent to which the atypical antipsychotic drug claims were for off-label uses and for indications not listed in one or more of the approved drug compendia.

AAP Endorses Garrett Lee Smith
On July 18, 2013, Representative Bill Cassidy (R-LA) and Representative Danny Davis (D-IL) introduced the Garrett Lee Smith Memorial Act (GLSMA) Reauthorization (H.R. 2734).

The GLSMA, signed into law by President George W. Bush in 2004, authorizes grant money to states, Indian tribes, colleges and universities to develop suicide prevention and intervention programs. Reauthorization of the GLSMA would continue commitment to important youth and college suicide prevention programs.

The legislation supports grants that provide appropriate information, training, and technical assistance concerning cost-effective intervention programs, suicide risk factors, and outcomes and best practices in suicide prevention. The program also authorizes continued on page 23
competitive grants awarded to states and tribes/tribal organizations to develop and implement early intervention and prevention strategies for youth. Competitive grants authorized under the GLSMA also provide colleges and universities with the resources necessary to engage in educational and outreach activities to prevent youth suicide.

The AAP joined The Mental Health Liaison Group (MHLG), a DC-based advocacy coalition, in sending a letter to Rep. Cassidy and Rep. Davis endorsing the legislation and praising the work made possible by this grant program. AAP staff will continue to monitor this legislation as it moves forward.

Supplemental Security Income Program
In June 2012, the GAO released its final report on the Supplemental Security Income (SSI) children’s program. Entitled Better Management Oversight Needed for Children’s Benefits, the report finds that applications and awards based on mental impairments have risen in the past decade, demonstrates that the use of a medication does not make an applicant more likely to receive benefits for a mental health disability, and makes recommendations on improving the SSI program. The AAP was generally pleased with the outcome of the report. It suggests a number of reasons why the number of children applying for and receiving SSI benefits due to mental impairments has increased, including an increase in poverty and better diagnosis of some mental health impairments. The AAP is closely monitoring congressional interest in the SSI children’s program and works regularly with a DC-based coalition, the SSI Coalition for Children and Families, of which AAP is a member.

Senate Passes Mental Health Amendment
On Wednesday, April 10, the Senate Health, Education, Labor and Pensions (HELP) Committee approved S. 689, the Mental Health Awareness and Improvement Act.

S. 689 reauthorizes and improves programs related to awareness, prevention, and early identification of mental health conditions. Further, the legislation promotes linkages to appropriate services for children and youth. Additionally, the legislation would reauthorize the Garrett Lee Smith Memorial Act, an important program for the prevention of youth suicide.

This legislation was offered as an amendment to the Senate’s larger legislative package (S. 649) to curtail gun violence in the wake of the tragic shooting at Sandy Hook Elementary School in Newtown, Connecticut. The amendment was agreed to in the Senate by a vote of 95-2, but the Senate failed to pass the larger gun legislation. AAP has been actively supporting S. 689 and recently circulated a support letter among groups advocating for children’s mental health to the bills’ authors Senator Tom Harkin and Senator Lamar Alexander.

Administration to Issue Final Regulations on Mental Health Parity Act
On January 16, President Obama unveiled a set of recommendations, attached at the end of this document, for how the administration and Congress can work to prevent gun violence in the wake of the tragic shootings in Newtown, Connecticut.

Included in these recommendations is a commitment that the administration will issue final regulations on the Mental Health Parity and Addiction Equity Act of 2008. This law, signed on October 3, 2008 but never fully implemented, requires employers with more than 50 workers to offer mental health coverage that is on par with medical benefits.

AAP Leaders Attend White House Conference on Mental Health
On Monday, June 3, AAP President-Elect James Perrin, MD, FAAP, and AAP Immediate Past President Robert Block, MD, FAAP, joined the President Barack Obama, Vice President Joseph Biden, administration officials and other advocates for a National Conference on Mental Health at the White House.

The conference marks the launch of a national dialogue intended to reduce the stigma associated with mental health and encourage individuals with mental health challenges to seek treatment. To aid with this mission, the White House launched a new website, www.mentalhealth.gov.

As a key partner in the White House’s event, the AAP added new mental health resources to its Web site www.aap.org/mentalhealth and aggregated comprehensive information on children’s mental health for parents and pediatricians. The AAP also developed a federal advocacy page on mental health to highlight federal policy priorities that would improve early identification and treatment for mental health disorders in children.
New AAP Resources on Health Reform Implementation
Starting on October 1, 2013, as part of Affordable Care Act implementation, a 6-month open enrollment period begins for individuals and families to sign up for health insurance in the new marketplaces (formerly known as exchanges) in every state. The marketplaces will allow millions of people to compare options and choose which type of insurance plan will work best for their family. The AAP has developed new, state-specific resources to help pediatricians and parents understand how to navigate the new health insurance marketplace and find the most appropriate health insurance plan for their families and employees:

- On www.aap.org/ACAmarketplace, there is an interactive map with state-specific, printable flyers for pediatricians to share with parents about what open enrollment means for them and how to navigate the marketplace. Please feel free to share these with parents in your offices and clinics. On www.healthychildren.org/ACAmarketplace, parents will find even more information about open enrollment, including basic information about health insurance.

- The Affordable Care Act also provides health insurance coverage options for small business owners, including many pediatric practices. AAP developed a new fact sheet to help pediatrician small business owners understand their options for covering their employees. State-specific versions and additional resources can also be found on www.aap.org/ACAmarketplace.

AAP Submits Comments to FDA on New Drug Shortages Task Force
On March 13 the AAP submitted comments to a Food and Drug Administration (FDA) notice establishing a Drug Shortages Task Force. The formation of this task force is required by a provision of the Food and Drug Administration Safety and Innovation Act (FDASIA), signed into law on July 9, 2012.

The FDA seeks comments from stakeholders to aid the Drug Shortages Task Force to develop and implement a strategic plan for enhancing the FDA’s response to preventing and mitigating drug shortages. Pediatricians throughout the country experience firsthand the risk that drug shortages, discontinuances, or interruptions in the pediatric drug supply cause to patients.

The AAP’s comments, developed with input received from pediatricians across the Academy, urge the FDA to consider an approach that identifies the root causes of drug shortages in an attempt to prevent future ones, while also communicating with providers, pharmacies, and medical societies when drug shortages appear to be inevitable.

AAP Supports Senate Efforts to Pass Pharmaceutical Compounding Legislation
Prior to the August recess, the Senate attempted to pass legislation, S. 959, the Pharmaceutical Quality, Security, and Accountability Act, that would give the Food and Drug Administration (FDA) additional tools to ensure the safety of compounded products. In the wake of the fungal meningitis outbreak caused by contaminated steroid injections, which sickened 749 and caused the deaths of 61 people in 21 states, Congress has been working to advance legislation giving the FDA authority over certain types of pharmaceutical compounding.

The AAP, along with the Children’s Hospital Association (CHA), has been working closely with congressional staff to ensure the legislation strikes the appropriate balance between safety and access to compounded products for children. In light of ongoing drug shortages, the AAP has been particularly concerned that efforts around compounding not exacerbate the drug shortage situation.

Recently, the AAP and CHA sent a joint letter to Senate Health, Education, Labor, and Pensions (HELP) Committee Chairman Tom Harkin (D-Iowa) and Ranking Member Lamar Alexander (R-Tenn.) thanking them for the pharmaceutical compounding provisions of S. 959. Recently, the Washington Post editorialized about the need for the senate bill, and the GAO released a report concluding that Congress should consider clarifying FDA’s authority to oversee drug compounding.

AAP Advocates to Protect Children from Gun Violence
Since the tragic shootings at Sandy Hook Elementary School in Newtown, CT that took the lives of 20 students and 6 educators, the Academy has been engaged in a thoughtful, organization-wide response and call to action to assure the future safety and protection of our nation’s children.

Academy leadership and staff are working closely with partner organizations to raise the voice of the nation’s pediatricians on Capitol Hill and among state legislatures to ensure that appropriate legislation is developed to promote children’s safety. For a comprehensive overview of the Academy’s federal advocacy efforts on this issue, please visit our Web site.
Ways to become involved in federal advocacy

Sign up to be part of the AAP Department of Federal Affairs Key Contact program. As a Key Contact, you will receive weekly legislative updates on child health policies advancing at the federal level, as well as targeted requests for action when bills or issues require pediatrician advocacy. To sign up, please e-mail the AAP Department of Federal Affairs at kids1st@aap.org.

Attend an advocacy training in Washington, DC. The AAP Washington office hosts frequent federal advocacy trainings and conferences in the nation’s capital throughout the year. During the trainings, pediatricians from across the country learn about federal policy priorities advancing in Congress and attend meetings on Capitol Hill with federal legislators and congressional staff. Save the date: On February 27, 2014, SODBP will host a training in Washington.

Become a “tweetiatrician.” AAP has increased the frequency with which it uses social media to advocate at the local, state, and federal level. To follow AAP’s advocacy and other child health activities on Twitter, use #putkids1st and follow @AmerAcadPeds, @AAPNews, @AAPPres, @AAPPerrin and @DrBobBlock on Twitter. For Facebook, go to www.facebook.com/ameracadpeds and www.facebook.com/aapfederalaffairs.

Editor’s Note

Advocacy: A Current Priority of the Section on Developmental and Behavioral Pediatrics

In 2012-2013, the SODBP Executive Committee undertook a process for the development of a strategic plan. You might recall a survey being sent to all SODBP members about the role and activities of the section as well as the future of the field of developmental and behavioral pediatrics. With that information, along with some key informant interviews, the SODBP Executive Committee developed a strategic plan which is now posted on www.dbpeds.org.

One of the focus areas within the strategic plan is to develop, promote, and enhance advocacy skills among SODBP members. To accomplish this, the section enhanced its relationship with the AAP Department of Federal Affairs (DOFA). You might notice that DOFA updates focused on topics related to the field of developmental and behavioral pediatrics have been included in past newsletters. And of course, who could forget the successful collaboration between the SODBP and DOFA around the CMS ruling on 96110?!

In addition, the SODBP Executive Committee allocated funding for 4 scholarships to support member participation in AAP federal advocacy trainings. Eric Weil, MD, FAAP, from Baton Rouge, LA, was the first to attend a training. The scholarship supported travel and lodging costs. In return, the Section asked recipients to share their experiences through a newsletter article, a presentation at their institution or practice setting, or another avenue.

We hope that Dr Weil’s summary of his experience will encourage others to get involved. To facilitate additional opportunities, the Section has arranged for a developmental-behavioral specific advocacy training on February 27, 2014 with the DOFA. Be on the lookout for future articles describing how these experiences have translated to supporting the optimal development for children.
Reflections on Advocacy Experience

By Eric Weil, MD, FAAP

On February 4th of this year, thanks to a scholarship from the SODBP, I had the opportunity to participate in an Advocacy Training program in Washington, DC.

As an introvert, going to DC to advocate for children was in itself a bit out of my normal comfort zone. However, this experience meant much more to me than just a chance to step into the shoes of an extrovert. Rather, it was in a sense my reaching an adult “developmental milestone.” To give you some background, on October 23, 2008 I went from taking care of patients to becoming a patient. While at clinic that afternoon, I suddenly lost consciousness after having a hemorrhagic stroke due to a ruptured Arteriovenous Malformation. A helicopter ride later, I was in the neurointensive care unit, unable to speak and unable to move my right side. And so began my long journey, with multiple “detours” along the way, back from being a patient to being a pediatrician again (but this time as a pediatrician with a new understanding of the power of one’s voice).

As I said to the AAP Department of Federal Affairs (DOFA), “the goal for me [back in October 2008] was survival. As I made it through that initial critical window, the next big goal for me was to learn how to walk and talk again. Now, just over 4 years later to be able to use my re-discovered voice to help advocate for those children without a voice [was] such an incredible and rewarding experience that I never thought I would have.”

With the recent events at Sandy Hook Elementary, the focus of our February 4th advocacy was gun safety as well as the importance of good mental health care. The topic of gun safety was broad in itself and ranged from such things as raising awareness for how to safely store guns when they are not being used to somewhat more controversial topics like universal background checks to even more controversial topics like controlling access to guns by means of increased regulation of the sale and distribution of guns and limiting what type of guns could be bought and sold.

Regarding mental health, topics such as ways to improve access to mental health care (eg, through the school systems and other community agencies) and obtaining mental health parity (ie, requiring insurance companies to provide benefits for mental health care at the same level that they provide coverage for the care of other medical conditions) were discussed.

In the morning of the advocacy training day, we were brought up to speed on some of the more recent AAP reports and recommendations to the federal government about gun control and mental health access. Then, we rehearsed in small groups (facilitated by the DOFA staff) what a visit might be like with a Congress person and/or a congressional staffer. Then, it was off to Congress we went….

I should take a step back here and tell you a few things that I learned about meeting with Congress:

1. Every Congress person and Senator has staff members which are assigned to help handle various topics/issues.
2. In addition to the staffers that are in charge of the various issues/topics, there are also staff members that help to schedule visits with the particular member of Congress. If one is interested in meeting with a representative/senator and/or with someone from his or her staff, the scheduler is who one should try to speak with directly. I know it sounds obvious, but sometimes the offices can become really hectic and when the front desk person answers the phone, one right off the bat asks to speak to the scheduler or for directions on how to contact the scheduler, it makes for a much more efficient process.
3. Most of the time when constituents try to meet with a particular member of Congress, he or she will end up meeting with a member of their staff who is in charge of the particular area to be discussed. First of all, often (but now always) it can be more productive to meet with the staffers (and to develop a working relationship with them) (as compared to meeting directly with the Senator or a Congress person). The staffers often are very familiar with the particular topic that they are assigned, the legislation related to that topic, and they help to collect and consolidate input from constituents about that topic.
4. When trying to schedule a visit with a staffer, please know that it may take a while to get it scheduled, that sometimes many phone calls are needed to make it happen, and that due to the nature of the unpredictability of DC politics, sometimes last minute

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changes need to be made.

5. Finally, as I learned by experience, sometimes even after many, many attempts to set up a meeting with a political official’s office, sometimes it may just not be able to happen. It does not mean that you have failed.

While I was in DC I met with a staffer from democratic Senator Landrieu’s office as well as with republican Congressman Cassidy and 2 of his staff. Despite their political differences, much common ground could be found, especially focusing on mental health care and on ways to make it harder for children to accidentally shoot a gun that they might find in a house. Issues like background checks and other regulations on the exchanges of guns created more disagreement.

This political disagreement became apparent on a larger scale when, despite that fact that most people in this country support strengthening background checks for those getting guns, on April 17, 2013, there was a set back to our goal of helping to increase gun safety. The Senate voted 54-46 to block the expansion of background checks on gun purchases. The particular amendment voted down on that day was the bipartisan sponsored bill proposed by Senators Manchin and Toomey. It would have required background checks to take place for gun sales both at gun shows as well as those sold online.

As this was the first piece of legislation that I had ever advocated for in DC, this vote had an especially significant psychological impact on me. However, at that point, I had to make a decision. On the one hand, I could have said that it was not worth advocating anymore because despite all of the efforts that we had put forth, nothing changed. This train of thought would be similar to that of a student who fails a test after studying for it and then erroneously concludes that studying was a waste of time because he still did poorly on the test. The other more productive response to this bump in the advocacy road would be to become even more motivated and energized to try to find different ways to improve gun safety.

Later that night after hearing about the failed amendment, I sent myself an email reminder with the following phrase, “I know what it feels like not to be heard.” (Of note, because of my poor typing skills on my phone, the word “heard” came out as “heated,” but I knew what I meant the next morning). This message was to remind me of the frustrations that I endured when I was physically unable to talk for the first few days after the stroke, and functionally unable to communicate efficiently for many months after the stroke, despite my knowing the idea that I wanted to convey. Like Gabrielle Giffords, I have become even more motivated to take advantage of my re-discovered voice to communicate on behalf of those with less ability to do so.

With privilege comes responsibility. I received the privilege of a lifetime to survive my hemorrhagic stroke in October 2008 and to then go on to have such a great recovery. Now, I feel it is my responsibility to take advantage of all that I have learned during this recovery.

All of us as providers advocate on a daily basis for our patients. We also have a lot of medical knowledge and experience that political officials are seeking to guide them as they navigate many areas where law and health care intersect. Whether you want to write letters, send emails, make phone calls, meet with your local politicians, sign on to a petition, join an advisory committee, etc, I strongly encourage you to realize your potential as an advocate.

About the author:

Eric Weil, MD, FAAP, trained and initially practiced as a general pediatrician. However, after recovering from a series of life changing health events that helped to only further increase his interest in the field of Developmental and Behavioral Pediatrics and provided him with many new insights, in 2011 he started practicing at a developmental-behavioral pediatrics clinic caring primarily for children with ADHD, learning difficulties, and the related co-morbidities such as sleep disturbances, anxiety, depression, low self-esteem, etc.
Dear Coding Counselor:

After your last coding column, I am suffering PTSD after reading the brief description of mapping ICD-9-CM codes for ADHD onto the ICD-10-CM set for attention deficit disorder! Can you continue your discussion with more diagnoses? What in the world are GEMs??

Signed,

Still Reeling in Wheeling, WV

Dear Still Reeling:

Don’t have a breakdown – let’s discuss a few more general conditions! The National Health Interview Survey sponsored by the US Department of Health and Human Services collects data from US parents/guardians every 8-10 years on the number of conditions impairing chronic functioning in US children less than 18 years of age. In the 30 year period from the 1979-1981 Survey to the 2008-2009 Survey, mental health (and developmental) conditions displaced physical health illnesses as the top 5 disabilities. In descending order, the top 5 conditions in 1979-1981 were: Diseases of the respiratory system; Impairment of speech, special sense, and intelligence; Mental or nervous system disorders; Diseases of the eye and ear; Specified deformity of the limbs, trunk, or back. In the 2008-2009 Survey, the top 5 chronically impairing diagnoses, also in descending order, were: Speech problems; Learning disability; Attention deficit/hyperactivity disorder; Other emotional, mental and behavioral problems; Other developmental problems. Moreover, respondents provided data indicating 8% of US children in that Survey had an activity-limiting disability (Halfon N, Houtrow A, Larson K, et al, 2012).

So, let’s use these top 5 conditions reported in the 2008-2009 Survey to continue our ICD-9-CM to ICD-10-CM mapping discussion (“General Equivalence Mappings aka GEMs”). In 2014, National Center for Health Statistics (NCHS/CDC) will release these public domain diagnosis code reference mappings of the International Classification of Diseases 10th Revision Clinical Modification (ICD-10-CM) and the International Classification of Diseases 9th Revision (ICD-9-CM) Volumes 1 & 2.

The purpose of the GEMs is to create a useful, practical, code to code translation reference dictionary for both code sets, and to offer acceptable translation alternatives wherever possible. For each code set, it endeavors to answer this question: “Taking the complete meaning of a code (defined as: all correctly coded conditions or procedures that would be classified to a code based on the code title, all associated tabular instructional notes, and all index references that refer to a code) as a single unit, what are the most appropriate translation(s) to the other code set?"

Shown below are the mappings from ICD-9-CM to ICD-10-CM for our top 5 conditions:

<table>
<thead>
<tr>
<th>Title ICD-9-CM</th>
<th>ICD-9-CM</th>
<th>Title ICD-10-CM</th>
<th>ICD-10-CM</th>
</tr>
</thead>
<tbody>
<tr>
<td>Developmental Speech or Language Disorder</td>
<td>315.3</td>
<td>Specific developmental disorders of speech and language</td>
<td>F80</td>
</tr>
<tr>
<td>Specific Delays in Development (aka Learning Disability)</td>
<td>315</td>
<td>Specific Learning disorder, With impairment in reading</td>
<td>F81.0</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Specific Learning disorder, With impairment in mathematics</td>
<td>F81.2</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Specific Learning disorder, With impairment in written expression</td>
<td>F81.81</td>
</tr>
<tr>
<td>Hyperkinetic Syndromes of Childhood</td>
<td>314</td>
<td>Attention-Deficit/Hyperactivity Disorder, predominately inattentive presentation</td>
<td>F90.0</td>
</tr>
<tr>
<td>Special Symptoms of Syndromes, not elsewhere classified (Other emotional/behavioral problems)</td>
<td>300.9</td>
<td>Other specified mental disorder</td>
<td>F99</td>
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<td></td>
<td></td>
<td>Other unspecified mental disorder</td>
<td>F99</td>
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<tr>
<td>Other Specified Delays in Development</td>
<td>315.8</td>
<td>Other specified neurodevelopmental disorder</td>
<td>F88</td>
</tr>
<tr>
<td>Unspecified Delay in Development</td>
<td>315.9</td>
<td>Unspecified neurodevelopmental disorder</td>
<td>F89</td>
</tr>
</tbody>
</table>

For more information about GEMs, here are some Web sites you might find helpful:

www.cms.gov/Medicare/Coding/ICD10/.../GEMs-CrosswalksBasicFAQ.p...
http://www.icd10codesearch.com/training.php
http://www.icd10data.com/Convert

Keep checking our SODBP newsletter in 2014 and we'll continue this discussion!