Greetings to all Section on Developmental and Behavioral Pediatrics (SODBP) members. The SODBP continues to be very busy and we hope that all of you have had the opportunity to benefit from some of our activities.

Increasing training related to advocacy has been a major focus of the SODBP leadership over the past 3 years. In February we hosted a developmental-behavioral pediatrics focused Advocacy Day at the AAP Department of Federal Affairs in Washington, DC that was attended by 25 section members who received advocacy training and then met with senators and representatives or their staff on Capitol Hill. Other articles in this and future newsletters will provide you more information about this tremendous experience and the topics covered. I am extremely pleased.
that the SODBP was recognized for these activities with a Section Advocacy Award at the AAP Annual Leadership Forum. Stay tuned for future SODBP advocacy training opportunities and note that the AAP Department of Federal Affairs does offer pediatric advocacy training opportunities throughout the year.

At the 2013 AAP National Conference we had a very successful joint program with the Council on Children with Disabilities (COCWD) on mental health problems in youth with neurodevelopmental disabilities. Special thanks to Dr. Bob Voigt (SODBP Program Chair) and Dr. Ken Norwood (COCWD Chair) for this great collaboration. Dr. Voigt has been hard at work planning our 2014 Section Program on the Pediatric Response to Disasters. We hope to see many of you at this program and at the Section Round Table Discussions which provide a tremendous opportunity for members to meet with each other and SODBP leaders for informal discussions about topics of mutual interest.

The SODBP and the Council on School Health have been involved in a very exciting collaboration with developmental pediatricians, government leaders, and school professionals in Shanghai, China on how the school and health systems can work together to better care for children with special health care needs. We participated in a conference in Shanghai (described elsewhere in this newsletter). At the 2014 National Conference, a reciprocal group of physicians from China will attend sessions and activities related to education and health system collaboration that will be open to all attendees. The afternoon portion of the SODBP program is included in these activities and will provide an opportunity to hear from experts from the both China and the United States. We hope that you will consider this session as you make your plans for the AAP National Conference.

Under the direction of Dr. Carol Weitzman, the SODBP worked with the Society for Developmental and Behavioral Pediatrics (SDBP) to offer the DB:PREP Board Review Course in Atlanta in January 2014. Despite some rather extreme weather related challenges (who would have expected that in January in Atlanta?) that did decrease attendance, the meeting was very positively reviewed by the over 150 people who were able to make it to the meeting. Those attending continue to be approximately half individuals in primary care and half individuals in subspecialty practice. The other planning group members include Jill Fussell, MD and James VanDecar, MD for the SODBP and Beth Ellen Davis, MD; Karen Miller, MD; and Beth Wildman, PhD for the SDBP.

Drs. Nerissa Bauer and Carolyn Bridgemohan have been serving on a subcommittee with representatives from the SDBP to revise the workforce survey last completed over 15 years ago. Please be on the lookout for this survey and we urge you to complete so that we can get an accurate picture of the activities of those caring for children and adolescents with developmental and behavioral concerns and be able to track trends in care provision and training.

The SODBP leadership continues to focus on ways to engage current members. Dr. Stephen Contompasis has been working on updating and enhancing the offerings on our Web site, DBPeds.org and although the Discussion Board has had a few technological glitches in the past year, the AAP is working to resolve these so that the Discussion Board, under the leadership of Dr. Damon Korb, can be a resource for robust discussion of topics related to developmental and behavioral aspects of pediatrics. In addition, I am pleased that Dr. Laura McGuinn has agreed to join Dr. Michael Reiff as an Editor for our outstanding newsletter. Thank you to Lisa Nalven, MD for serving as the contributing section editor for AAP Grand Rounds and to Drs Nancy Lanphear, Mary Pipan, and Yi Hui Liu for serving on the SODBP Nominations Committee.

We need you to help us recruit new members. Please let your colleagues know about the activities that SODBP is participating in and the opportunities that we offer for members. Think about psychologists, nurses, speech and language pathologists, occupational and physical therapists and others involved in developmental and behavioral care for children who can join SODBP as affiliate members and participate in SODBP activities like our advocacy trainings which have been attended by affiliate members.

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
How to Identify and Help Young Patients With Social Anxiety
(Or is My Patient Just Shy?)

By Susan M. VanScoyoc, PhD, ABPP and Edward R. Christophersen, PhD, ABPP

Parents of inhibited children may count on their provider’s opinion as to whether or not they should be concerned about their child’s discomfort with social interactions. In fact, over half of parents in a nationally representative study on adolescent mental health identified their teen as ‘shy.’ Often times the answer seems straightforward, such as when a preschooler expresses initial fear at joining peers at soccer practice, or when an adolescent is nervous to give speeches in class. Yet, for many children, what seems like behavioral inhibition or developmentally-appropriate angst is a more significant and distressing social anxiety disorder (SAD). Rates of childhood SAD range from 29% to 40% in clinical settings, making it one of the most frequently seen mood disorders in mental health care. Youth with SAD have fewer friends, receive fewer positive responses from peers, and experience higher rates of comorbid depression, anxiety, and substance use disorders than children without anxiety. They are not simply overly shy children, but individuals with a distinct psychiatric disorder resulting in significant impairment in their daily functioning. Left untreated (and over 30% of adults report having symptoms at least 10 years before they sought help), the course of SAD is typically chronic and unremitting. In short, children with SAD typically do not “outgrow” the disorder; poor coping skills reinforced by avoidance of social interactions perpetuate its persistence into adulthood. This article provides suggestions for assessing symptoms and impairment related to social anxiety, along with treatment recommendations for reducing distress related to social interactions.

Definition of Social Anxiety Disorder
Social anxiety disorder (SAD), also called social phobia, is defined in the DSM-5 as marked fear of interactional or performance situations that may involve scrutiny from others and has been present for at least 6 months. These situations must always elicit fear or anxiety and are typically avoided or endured with intense distress. In children, a diagnosis of SAD requires such anxiety related to peer interactions, not just those with adults. Examples of situations that children may fear are offered in Table 1. In such situations, the youngster fears negative evaluation, humiliation, or rejection based on his or her actions, with the fear being out of proportion to the actual threat. The child does not have to be aware of the excessive nature of the response. Clinical examples of how such fears may be expressed are also offered in Table 1. Many children with anxiety, including social anxiety, may present to providers with physiological complaints, especially recurring abdominal pain and headaches. They also experience behavioral avoidance and distorted cognitive evaluations that perpetuate their fears of social situations.

Table 1. Examples of Feared Social Situations and Expressions of Anxiety in Youth with SAD

<table>
<thead>
<tr>
<th>Feared Social Situations</th>
<th>Expressions of Anxiety</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Meeting unfamiliar peers or adults</td>
<td>Physiological: sweating, crying, clinging, flushing, lump in the throat, tense muscles, racing heart, headaches, stomachaches, nausea</td>
</tr>
<tr>
<td>• Starting or maintaining a conversation with a known or unknown person</td>
<td>Behavioral: excessive shrinking from contact with unfamiliar people, persistent reluctance to approach unfamiliar people, overcautious, clinging, crying, defiance, anger outbursts, avoidance of feared situations</td>
</tr>
<tr>
<td>• Initiating a social outing</td>
<td>Cognitive: Negative evaluations, interpret social situations as threatening, perform a ‘social autopsy’ on past social interactions (eg, “I won’t be able to think of enough to say”; “I will say something stupid”; “My classmates will think something is wrong with me”; “Everyone can tell how nervous I am”; “She will think I am boring”; “If I am quiet, he will think I am rude”; “We will get evicted if the neighbors think we are too loud”; “I am sure I just sounded stupid”; “Who says dumb things like that”).</td>
</tr>
<tr>
<td>• Joining an unfamiliar group activity such as an organized sport or school club</td>
<td></td>
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<tr>
<td>• Academic performance in front of others (reading aloud, writing on the board, speeches)</td>
<td></td>
</tr>
<tr>
<td>• Getting up in class to turn in a paper, sharpen a pencil, or use the restroom</td>
<td></td>
</tr>
<tr>
<td>• Recreational performance in front of others (sports, recitals)</td>
<td></td>
</tr>
<tr>
<td>• Eating or laughing in front of others</td>
<td></td>
</tr>
<tr>
<td>• Violating minor or serious rules</td>
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</tbody>
</table>
In addition to experiencing the symptoms of social anxiety summarized above, a child must also be impaired by these symptoms to a clinically significant degree in order for a diagnosis of a SAD to be supported. Impairment likely exists in peer relationships but may also be present in academic functioning, employment for teens, relationships with teachers, and overall family functioning. The child with social anxiety may have few friends, lack participation in any extracurricular activities or endure them with distress, experience many absences from school due to fears or somatic symptoms, report lower grades than desired due to poor participation or attendance, and endorse feelings of loneliness and depression. Family events may be altered to accommodate the child’s fears of unfamiliar family members or large crowds. Many older children can express distress about their discomfort with social interactions and perhaps a desire to interact more similarly to their peers. Overall, parents may note a general lack of development-appropriateness in their child’s level of independence and social interactions. If a parent is also socially anxious, she may not be as concerned about the child’s lack of participation in social events but likely still desires that the child participate in academic endeavors with less distress.

Screening for Social Anxiety

The American Academy of Child and Adolescent Psychiatry (AACAP) Practice Parameter for the Assessment and Treatment of Children and Adolescents with Anxiety Disorders\(^6\) recommended that all children be routinely screened for anxiety. For social anxiety, parents can provide valuable information on situations that are avoided, avoidance behaviors, statements of fear, and impairment related to social functioning at and away from home. Patients may be able to self-report on such information, and may also have insight into their negative cognitions and physiological discomfort when anticipating or facing a social situation. When screening for social anxiety, the provider is likely to gain the most useful information by administering a global screen for anxiety that also specifically measures for social anxiety. Two empirically-based, self-report examples of screening measures are the Screen for Child Related Anxiety Disorders (SCARED)\(^7\) and the Revised Children’s Manifest Anxiety Scale, Second Edition (RC-MAS 2).\(^8\) The SCARED Child version may be administered to children ages 8 and older and includes 41 questions assessing for social anxiety, as well as significant somatic symptoms, general worries, separation fears, and school avoidance. A parent version is also available. Both versions, including scoring information, are available at no cost at [http://www.psychiatry.pitt.edu/research/tools-research/assessment-instruments](http://www.psychiatry.pitt.edu/research/tools-research/assessment-instruments).

The RC-MAS 2\(^8\) is a 49-item measure for children ages 6 to 19 with subscale scores for physiological symptoms, general worry, and social anxiety. This tool also has a Defensiveness Scale and Inconsistent Responding Index, which can help identify children who may be answering in a socially desirable way. Children with social anxiety may have difficulty endorsing unfavorable symptoms, and thus such scales can help alert the provider to children who need more reassurance that their answers will not be viewed in a critical manner. The RC-MAS 2 is available for purchase at [www.mhs.com](http://www.mhs.com) in a hand-scored format.

The evaluation of social anxiety requires not only symptom presentation, but as noted above, information on distress and impairment as well. The child and parent should be asked about impairment related to peer relationships, family relationships, romantic relationships, school, and employment. Older children should be questioned about their level of distress related to social interactions as well. Patient questions for determining clinical significance of symptoms are offered in Table 2. Similar questions should be asked of caregivers.

**Table 2. Questions for Determining Impairment and Distress in Children with Social Anxiety**

<table>
<thead>
<tr>
<th>Questions for Children and Adolescents</th>
<th>Questions for Caregivers</th>
</tr>
</thead>
<tbody>
<tr>
<td>• How has your anxiety affected?</td>
<td>• Your ability to look for a job? Your ability to meet the interaction demands of your job?</td>
</tr>
<tr>
<td>• How you make friends? Join kids you know/don’t know? Willingness to try new social activities? Willingness to date?</td>
<td>• Your mood? How you feel about yourself?</td>
</tr>
<tr>
<td>• How you keep friends? How much you invite friends over/go with them places? How much time you spend with them alone? What kinds of activities you are willing to do with them?</td>
<td>• How bothered are you by your social worries? Do you tend to focus on what you did wrong in an interaction? Do you feel very different from your peers and how they interact with other kids?</td>
</tr>
<tr>
<td>• Your relationship with your parents? Siblings? Extended family? Family outings?</td>
<td>• How would your life be different if you weren’t so worried all the time about social situations?</td>
</tr>
<tr>
<td>• How much you participate in class? Ask the teacher for help in class or privately? Ask permission to leave class? Your grades? Your relationship with your teacher?</td>
<td></td>
</tr>
</tbody>
</table>

*continued on page 5*
What About Shyness?

In response to the typical and increasing social demands of childhood, youngsters may endorse symptoms of social anxiety related to one situation or another. Young children may become clingy, tearful, even defiant when faced with an unfamiliar peer group, and adolescents may report stomachaches and dread at the thought of giving an oral report in class. Are such children just shy? Are they experiencing developmentally-appropriate worry similar to their peers? Do they have a diagnosable SAD?

The essential feature for distinguishing shyness from a SAD is the level of distress and impairment the anxiety causes the patient and family. Children who are shy may ‘hang back’ from group situations but may eventually warm to the social demands and interact freely with 1 or 2 other peers. A child with SAD may not comfortably interact with peers or others well beyond preschool, creating impairment in functioning at and away from school. Providers should also be alert for children, especially teens, who appear to have mastered social situations from an outsider’s perspective, but report depression or distress related to how they feel about social interactions. Such teens are often high-achieving and appear confident but privately perform a ‘social autopsy’ on the smallest social interaction such as passing a peer in the hall. In short, parents of inhibited children should be made aware that being “shy” is not a disorder, but once significant impairment is noted it is likely time to intervene and improve their child’s social functioning and overall development.

Treatment for Social Anxiety Disorder

The successful management of SAD in children is typically multi-modal, often including education of immediate caregivers, consultation with school personnel, and cognitive-behavior therapy (CBT). CBT has strong empirical support and typically involves exposing the child to feared situations, cognitive restructuring, and social skills training. Perhaps one of the most dramatic examples of the efficacy of CBT for anxiety disorders, including SAD, is reported by Barrett, et al. who demonstrated that 52 clients (ages 14 - 21 years) who had completed treatment an average of over 6 years earlier, maintained their treatment gains 12 and 60 months later.

Key Components of CBT: One of the most important components of effective treatment for SAD is that of exposure to feared social situations. Graduated exposure therapy involves confronting the least anxiety provoking situation directly until it no longer triggers fear or negative self-evaluation, then advancing to the next least anxiety provoking situation, and so on. For example, a teen could be encouraged to meet a friend at a movie instead of driving together to reduce the amount of time needed to generate conversation. Such activities should be repeated until the child is relaxed before moving on to a slightly more difficult situation such as adding another peer to the same situation. A thoughtful approach to graduated exposure almost always works better than simply encouraging the child to pick up the phone and invite someone over to play. Also, most seasoned CBT therapists know that these strategies are more effective, at least initially, if the child can earn a tangible reward for practicing or participating in such exposure exercises. The child should be rewarded for participating in the exposure, and NOT for successful interaction. Older children and teens may be intrinsically rewarded by their decrease in distress and growing friendships but external rewards are also effective for these youngsters as well. In addition to exposure, children with SAD often also need to learn skills to reduce their negative thoughts, relax when they are faced with frightening social situations, and build confidence in their social skills. Patients and parents need to know that the child’s brain is sending ‘false alarms’ about the level of danger in social situations, and that avoiding or escaping fearful situations only makes the connection between distress and social interactions stronger.

Effective CBT treatment is available from mental health providers with training in this treatment modality. Given the nature of social anxiety, however, parents and children with this disorder may be reluctant to seek individual mental health help. The shortage of well-trained, mental health care providers readily available to treat anxiety is also a barrier to care in most communities. Furthermore, the provider may not be convinced that a referral for therapy is necessary given a low level of distress or impairment for the child and family. Thus, recommendations that can be discussed in the office with less impaired families or for those waiting for outside mental health care are provided in Table 3.

Medication: Many advances in the pharmacological treatment of childhood anxiety disorders have been made in the past decade, often guided by whether or not medication works as well as CBT. The AACAP Practice Guidelines suggested enough well-controlled research evidence was available to recommend the use of selective serotonin reuptake inhibitors (SSRI’s) as a short-term treatment option in certain cases, with no single SSRI working better than any others for childhood anxiety. Children who require acute symptom reduction, have interfering comorbid conditions, or who could benefit more fully from therapy should be further evaluated for the appropriateness of medication as an additional treatment option. Large, well-controlled studies comparing medication to CBT also offer some support for the use of SSRI’s for anxiety disorders, including SAD. Authors from the
How to Identify and Help Young Patients . . . continued from page 5

Child/Adolescent Anxiety Multimodal (CAMS) study\textsuperscript{11} reported that CBT and sertraline both work equally well for reducing anxiety symptoms in children with SAD and other anxiety disorders, with a combination of these 2 therapies demonstrating superior results. Other medication such as tricyclic antidepressants, benzodiazepines, and buspirone do not have enough evidence from well-controlled studies to be considered beneficial for treating anxiety symptoms in children.

Table 3. Office-based Strategies for Children who are Shy or with SAD

Know that your child (and you) can tolerate a little distress when it comes to social situations.

Do not punish or lecture your child for not talking or not participating in a social activity. Ask other well-meaning caregivers to avoid comments about your child's social fears.

Try not to rescue your child by telling others 'he is just shy.' Wait a few seconds for him to respond. If he doesn’t, simply state something like, 'he is working on being brave around other people.'

Keep exposing your child to new experiences. Some children do better when they can participate in a group activity like soccer vs. t-ball, which has increased individual attention. Private lessons provide your child the opportunity to gain comfort and skill level with 1 adult and may be preferable for some children.

Try to keep your child in a committed activity for as long as possible, but within reason. If your child is 3 and refusing to attend basketball practice, you can probably let her off the hook and try again in a few years. If your child is 7, ask her to meet at least some of her commitment. For example, ask that she attend practices and games and cheers on her team if she does not want to actually participate in the game.

If your child must leave a social situation due to high anxiety, try to calm him down even slightly before leaving. Encourage him to get a drink, take deep breaths, watch a funny video, or walk around until he feels calmer. This will help break the association between high anxiety and escape behaviors.

Consider teaching your child relaxation strategies such as deep breathing, guided imagery, and progressive muscle relaxation. Many media resources such as CD’s and apps for smart phones are available (see additional resources).

Problem solve with your older child about situations that he struggles with now but would like to master. Rate them 1-10 depending on how scary they sound to your child. Start with activities on the ‘1’ end of the scale and practice them until the rating drops to a 1 or 2. For example, if your child is afraid of raising her hand in class because her classmates will think she is dumb, have her practice raising her hand at home while you play school. Or ask the teacher to practice with her during 1:1 time. The teacher and your child could also pick a question she would like to answer and arrange for the teacher to call on her in class for that question only.

Involve school personnel when appropriate to modify their demands for social interaction. A preschool teacher could simply say, ‘you are here today in your green dress’ versus questioning your child about her weekend when she arrives at school. Teachers of older children can be asked to not call on them in class unless they raise their hand, to allow all children to ‘pass’ on reading out loud, and modifying participation requirements for more significant anxiety. These modifications may take a request from the provider to be pursued.

Additional Resources

1. Anxiety and Depression Association of America at www.adaa.org (includes podcasts for teens; CEU workshops are offered at their annual meetings)
2. Social Anxiety Institute at www.socialanxietyinstitute.org (includes fee-based, online CBT course-appropriate for motivated teen or adult)
3. Child Mind Institute at www.childmind.org (includes educational videos on selective mutism)
4. Kids Health at www.kidshealth.org (also provides information in Spanish)
5. Relaxation Apps for iOS such as MindShift, Smiling Mind, Mind Jar, and Super Stretch Yoga
6. Web sites with relaxation information and an iOS app such as stopbreaththink.org and kidshappyapps.com

continued on page 7
How to Identify and Help Young Patients . . . continued from page 6

References

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**Editor's note:** The article below is an excellent summary of DSM-5 Criteria for Communication disorders. One new addition, the diagnosis of Social (Pragmatic) Communication Disorder remains somewhat controversial. The Interagency Autism Coordinating Committee (IACC) Statement Regarding Scientific, Practice and Policy has recently commented on the new diagnosis category. Social Communication Disorder (SCD) which applies to individuals who exhibit persistent difficulty with the social use of verbal and nonverbal communication that cannot be explained by low cognitive ability. The IACC points out that the symptoms of SCD have significant overlap with those of the ASD social communication domain, but in the new DSM-5 the 2 disorders are considered to be unique and separate from each other. The distinction is clarified in the DSM-5 criteria, which note that ASD must be ruled out before a diagnosis of SCD can be considered. However, there is limited published information on SCD with a research basis primarily in the condition previously studied as Pragmatic Language Disorder (PLD). While SCD includes PLD, there is much to learn about the definition, measurement, scope, reliability, and validity of SCD as a diagnosed condition.

**ASHA Connections:**
**DSM-5 Diagnostic Criteria for Communication Disorders**
*By Diane Paul, PhD, CCC-SLP, CAE*
*American Speech-Language-Hearing Association*

The fifth edition of the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-5) was released by the American Psychiatric Association (APA) in May 2013. The DSM-5 provides diagnostic criteria for mental disorders and is widely used by professionals in clinical and community settings in the United States and other countries. Major changes were made in the area of neurodevelopmental disorders, including disorders of communication (Paul, 2013). The practice, research, training, and billing implications of these changes are starting to emerge. Clinicians and families have concerns about what the new diagnostic criteria mean in their day-to-day experience and practice (Paul & McCarty, 2014).

**Communication Disorders**

Diagnostic categories for communication disorders include Language Disorder, Speech Sound Disorder, Childhood-Onset Fluency Disorder (Stuttering), Social (Pragmatic) Communication Disorder, and Unspecified Communication Disorder. These categories represent a change from the DSM-IV categories of Expressive Language Disorder and Mixed Receptive-Expressive Language Disorder.

**Language Disorder**
The diagnostic criteria for Language Disorder include “persistent difficulties in the acquisition and use of language across modalities (ie, spoken, written, sign language, or other) due to deficits in comprehension or production and language abilities that are “substantially and quantifiably” below age expectations.

**Social (Pragmatic) Communication Disorder (SCD)**
The diagnostic criteria for SCD, a new diagnosis for DSM, are “persistent difficulties in the social use of verbal and nonverbal communication,” which include deficits in “using communication for social purposes,” “impairment in the ability to change communication to match context or the needs of the listener,” “difficulties following rules for conversation and storytelling,” and “difficulties understanding what is not explicitly stated…and nonliteral or ambiguous meaning of language.” Furthermore, “The symptoms are not attributable to another medical or neurological condition or to low abilities in the domains of word structure and grammar.” Children who meet the ASD criteria are not diagnosed with SCD. DSM-5 indicates that SCD rarely occurs in children younger than 4 years.

A separate diagnostic classification for SCD is supported by research (eg, Bishop, Whitehouse, Watt, & Line, 2008; Leyfer, Tager-Flusberg, Dowd, Tomblin, & Folstein, 2008; Tomblin & Zhang, 2006). Research demonstrates that children with SCD have deficits in the area of pragmatics, such as initiating and changing topics in conversation, but typically have a relative strength in vocabulary and grammar.

**Speech Sound Disorder**
The key diagnostic criterion for Speech Sound Disorder includes “persistent difficulty with speech sound production that interferes with speech intelligibility or prevents verbal communication of messages.”

**Childhood-Onset Fluency Disorder (Stuttering)**
The diagnostic criteria for Childhood-Onset Fluency Disorder are “disturbances in the normal fluency and time patterning of speech” and the disturbance causes “anxiety about speaking.”

continued on page 9
Implications
Speech-language pathologists (SLPs) need to ensure that children with other neurodevelopmental disorders, such as autism spectrum disorder (ASD), receive a concomitant diagnosis of Language Disorder when they present with spoken and written language disorders. Spoken language impairments are no longer included in DSM-5 as a criterion for diagnosing ASD. The criteria are “persistent deficits in social communication and social interaction” and “restricted, repetitive patterns of behavior, interests, or activities.” Clinicians can specify whether ASD is associated with language impairment.

If a child has difficulties with social communication and interactions, but does not show restricted/repetitive behaviors, SCD may apply. Distinguishing between ASD and SCD is the role of SLPs, as is distinguishing between SCD and low abilities in word structure and grammar. Appropriate diagnosis is critical for individuals to receive needed services.

Concerns/Questions
Social (Pragmatic) Communication: Although SCD is a new diagnosis in DSM-5, the diagnosis is not new for SLPs. Assessment and treatment of such disorders have been and continue to be within the SLP scope of practice. SLPs have treated social communication disorders for many years with very good outcomes. According to ASHA’s National Outcomes Measurement System, gains following speech-language pathology intervention were seen for spoken language comprehension and pragmatics with 72% and 63% of children achieving one or more levels of progress, respectively. Furthermore, ASHA has had guidance for practice in this area for decades, informed by the literature on pragmatics.

Speech-Language Pathologist Role: SLPs continue to be the professionals to assess, diagnose, and treat communication disorders. SLPs also assess, diagnose, and treat ASD, typically as a member of a team.

Coding and Billing: Clinicians want to know how to code Asperger’s syndrome and SCD. It’s still early to know exactly how health plans as payers will react to the diagnostic changes in DSM-5. We know that the APA proposed a new code for ICD-10-CM for SCD. That proposal is being considered and has ASHA’s support. ASHA monitors payer/program changes that result from the diagnostic criteria in DSM-5 (McCarty, 2013).

References

About the author:
Diane Paul, PhD, CCC-SLP, CAE, is the director of Clinical Issues in Speech-Language Pathology at the American Speech-Language-Hearing Association (ASHA) in Rockville, MD, where she has worked for 25 years. An ASHA Fellow, Dr. Paul provides professional consultation, tracks trends, develops education programs and products, and creates resources for professionals and consumers on a wide range of clinical topics, including DSM-5. She has written numerous speech-language pathology practice articles, assessment tools, and books. Dr. Paul served on the DSM-5 Communication Disorders Advisory Committee. She can be reached at dpaul@asha.org.
Positive Parenting in a 15 Minute Visit!

By John C Duby, MD, FAAP, CPE

It happens every day! A parent asks for help with a behavior problem, often at the end of a visit that was for a minor health concern. You were lucky to have 15 minutes for the appointment, but there are now only 2 minutes left, and you have patients lined up in the waiting room. How can you avoid this challenging situation, and what can you do to help in a brief encounter?

It all begins with being sure to get the full agenda from the beginning of the visit so that you can avoid those “hand on the doorknob” complaints. Then you need strategies that allow you to obtain sufficient history to understand the problem without having the family ramble. You need to have a solid framework for differential diagnosis and options for helping the family keep track of the problem behavior. After obtaining permission to offer a formulation and advice, you need a few effective interventions for the family to consider.

Setting the Agenda
It is not unusual for a family to make an appointment for something like a cold or stomachache when their true agenda is something very different. It is possible that they just haven’t had a chance to fully formulate their concern about their child’s behavior. They may not be sure whether it is appropriate to talk about behavior problems in a medical visit. They may be worried about stigma or confidentiality issues.

It is important to be sure that you and your staff take an extra moment to be sure that there aren’t additional concerns that need to be addressed. Sometimes simply asking, “is there anything else?” may be enough to open the door for the true concern.

Getting the History
Families can tend to ramble about their concerns about their child’s behavior. They often feel the need to tell you about every incident that has ever happened. Asking the parent to describe the most recent episode in detail can help to streamline the history, and provides for a more accurate history.

Ask for the most recent example of the problem behavior. Frame it using the ABC’s of behavior. Antecedent. Behavior. Consequences.

Start by asking what was happening just before the problem behavior occurred, the Antecedent. Then ask for a description of the behavior itself, while focusing on potential functions of the Behavior. Was it attention seeking or escape-avoidant? Then identify the Consequences that occur either intentionally or unintentionally as a result of the behavior. “What happened right after the behavior?

When you have heard the example, you can then summarize what you have heard, and check to see if that example is typical. If it is, and it usually is, then you can move on and will have understood the problem in less than 2 minutes!

In addition, you will want to understand the onset, course, frequency, and duration of the problem. It will also help to check in on whether there are any family stressors that coincide with the onset of the behavior problem. A question that can help is: “Has anything, bad, scary, or sad happened?” This can be a quick way to determine if there may be environmental factors that might be affecting the child’s behavior.

This information should allow you to begin to formulate a differential diagnosis.

Differential Diagnosis
Often, the child’s temperament, which is part of their genetic make-up, plays a role in how they respond to stressful situations. It is important to consider this from the outset. Qualities such as sociability, reactivity, persistence, and activity level will contribute to a child’s response to a difficult situation.

continued on page 11
The interaction between a child, their own temperament, and the family environment are typically what leads to problematic behavior. There may be challenges in the goodness of fit between the child’s and the caregivers’ temperaments. Other factors in the family environment to consider include the possibility that the child is receiving accidental rewards for misbehavior, or that the child is simply imitating behavior that he has learned from watching others in the family. There is the possibility that the parent is being pulled into an escalation trap, arguing with the child, and then occasionally getting frustrated and giving into the child. The problem could be in the fact that messages from the parent are emotionally laden, or that ineffective instructions are given that are unclear, given from another room without the child’s complete attention, or include questions with a potential answer that is problematic.

Additional factors to consider are ineffective use of punishment, unrealistic beliefs or expectations, lack of partner support, parental mental health concerns, and significant stress in the family.

Sources of stress can be probed using the IHELP framework:
- Income: Do you have enough money to make ends meet?
- Housing: Are you concerned about the safety or stability of your housing?
- Education: Are you concerned about your child’s learning, performance, or behavior in school?
- Legal Status: Are you concerned about your family’s health and stability for any legal or immigration-related reason?
- Personal and Family Stability: Do you feel unsafe at home?

You should also consider potential influences outside the home, such as peers and friends, school, social and other media and technology.

This information should help you formulate an impression, and then guide your decision making in how to best begin to track the child’s challenging behavior. To help prevent any feelings of loss of control, it is always helpful to ask permission to share your impression.

Keeping Track of Challenging Behaviors

We all know that measurement leads to behavior change. This is true when helping families to understand and manage challenging behaviors. It is not unusual that once a family begins to track a behavior, they quickly gain insight that may lead to a solution that they find on their own. Several simple tools are available to help families track their child’s behavior. These include the following:

- **Tally sheets** allow a simple way to check each occurrence of the behavior. They are best for discrete behaviors with a clear beginning and clear end such as swearing, hitting, and completing chores. They are most useful if the behavior occurs less than 10-15 times per day.

- **Time samples** are for problems occurring more than 10-15 times per day. They should be used for behaviors that come and go quickly and often over a short period of time, such as non-compliance, arguing, and whining, which may not have a clear beginning or end. Families should be advised to pick a 2-3 hour high risk time period to track.

- **Behavior diaries** give the most information and help identify patterns in behavior. They assist with determining frequency, help determine if the behavior is managed consistently and identify high risk times and situations, as well as possible triggers and rewards. Behavior diaries are best for relatively low frequency problems. A table that provides space for documentation of the time, the antecedent, a description of the behavior, the consequences, and any other observations can provide a rich sample that will facilitate better understanding of the behavior.

- **Duration records** track how long a behavior lasts, such as crying, homework, or getting dressed. You can look at time for each episode or total time in a day that the problem behavior occurs.

Samples of these tools can be found at: [www.aap.org/sections/dbpeds/practice-training.asp](http://www.aap.org/sections/dbpeds/practice-training.asp)

You might be saying to yourself right now: “How can I do all this in 15 minutes?” The fact is that you should think about this as several 15 minute visits. The first visit includes defining the problem, formulating an impression of the potential causes, and identifying a strategy for tracking the behavior. You can then schedule a return visit in 1-2 weeks to review the tracking data and offer guidance for positive parenting.
Guidance for Positive Parenting

Whenever possible, it is important to support the family in identifying their own solutions to the problem behavior. Start out by asking for their interpretation of the data they have collected. What have they learned from their measurements? What are they doing differently since starting to measure? What do they think they could do differently? If they have trouble thinking of changes, ask them to think of a time when things go well. What is different about those times? Could changes be made to align more frequently with the times that things go well.

If the family is having trouble identifying solutions, ask permission to offer several options to consider. Using specific praise, giving clear, calm instructions, and teaching the child to label their emotions are 3 strategies that can be helpful in many problem situations.

Specific praise is just that! Instruct caregivers to be very clear and specific, describing the behavior they like and want to see more often. They should be sincere, but also enthusiastic. Specific praise works much better than general approval, and teaches the child to receive and be motivated by compliments.

Giving clear, calm instructions is one of the most important strategies for behavior management. The parent should be sure to have the child’s full attention, be at their eye level, and give a simple, calm, instruction. The child should be given 5 seconds to comply and praised for compliance. If the child is non-compliant, the instruction should be repeated, with 5 seconds given for compliance. To avoid escalation traps, the instructions should be given no more than twice. Noncompliance with the second request should be followed by an immediate logical consequence. The child should be taught this approach to giving instructions outside the “heat of the battle” so they are prepared for this new approach and fully understand it.

Teaching children to label their emotions can reduce tantrums, meltdowns, aggression, and destructive behavior. Have the caregiver label their own emotions and responses throughout the day. For example, saying “mommy is really frustrated sitting in traffic right now.” Have the caregiver help the child label their emotions. “It looks like you are upset that you have to wait your turn.” Encourage the child to label their own emotions throughout the day to practice. “How are you feeling right now?”

Once you and the family agree on a strategy to try, you can encourage them to continue to track the behavior with their chart, and schedule a return visit in a few weeks to update the progress. Hopefully, they will be doing well, but if not, this visit will provide an opportunity to jointly decide on whether additional supports, including a possible referral are warranted. Families that are experiencing significant stress, lack of partner support, or with caregivers who are struggling with their own mental health concerns may need referral sooner rather than later.

Summary

Pediatricians are well positioned to support children with behavior challenges. Be sure to focus on getting the full agenda at the beginning of the visit. Remember the ABC’s of behavior and use them to collect a brief example of the problem, and to assist with tracking the behavior. Formulate a differential diagnosis for the cause of the behavior, considering the contributions of the child, the family environment, and the community. Always ask permission to offer your formulation and your advice, strengthening your alliance with the family. Support the family in identifying potential solutions to the problem themselves. When needed, offer options such as using specific praise, giving clear, calm instructions, and teaching children to label their emotions. Be sure to schedule return visits to check on progress and make additional recommendations or referrals if needed.

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SODBP Speaks Up for Children on Capitol Hill

By Devin Miller, AAP Advocacy and Public Affairs Assistant

For pediatricians and members of the American Academy of Pediatrics (AAP), child health advocacy does not stop within the walls of a practice, clinic, or hospital.

In February, more than 20 members of the AAP SODBP proved that to be true when they travelled to Washington, DC, to take part in a day-long federal advocacy training and brought 3 important child health topics to their legislators on Capitol Hill: promoting children’s mental health services, reauthorizing the Combating Autism Act, and supporting the Convention on the Rights for Persons with Disabilities.

Although the Academy hosts several advocacy trainings throughout the year for AAP members, this was the first training initiated entirely by an AAP section. Having designated federal advocacy a priority in its strategic plan, SODBP approached the AAP Washington Office with interest in hosting a federal advocacy workshop that was tailored to the specific interests and specialties of the section.

Upon their arrival at the AAP Washington Office, participants were greeted by Nathan Blum, MD, FAAP, chair of SODBP, who previously attended one of AAP’s Advocacy Day trainings and discussed the importance of coming to the nation’s capital to speak up for children who cannot speak up for themselves.

Participants hailing from as far as Hawaii explained their background and interest in federal advocacy. The group included both seasoned and first-time advocates, all of whom shared a desire to learn more about the process and bring their own perspectives to the 3 advocacy topics at-hand.

Following introductions, AAP Department of Federal Affairs staff provided a general overview of advocacy and reviewed the structure of the federal government. Next, participants received a briefing on all 3 of the child health issues to be discussed on Capitol Hill and were given key messages to highlight in their meetings with federal legislative staff.

In addition, Jeffrey Okamoto, MD, FAAP, offered additional congressional insight, sharing his experiences as a Joseph P. Kennedy Jr. Foundation Public Policy Fellow in Sen. Barbara Mikulski’s office.

"The extra advocacy work outside of the office really pays off in spades for the kids we treat," said Dr. Okamoto.

Guest speaker Kim Musheno, Director of Legislative Affairs at the Association of University Centers on Disabilities, concluded the morning portion of the training with an in-depth look at the current state of play of the Convention on the Rights for Persons with Disabilities.

After attendees participated in a brief role play session and were armed with their key messages on all 3 child health issues, the group headed out to Capitol Hill to meet with their federal legislators and staff.

“It was my first time on the Hill and the morning training really helped to demystify the entire process,” said Nerissa Bauer, MD, MPH, FAAP, member of the SODBP Executive Committee.

Throughout the afternoon, participants met with 40 different congressional offices, urging their senators and representatives to support policies that integrate children’s mental health services into the primary care setting, reauthorize the Combating Autism Act, and support the Convention on the Rights for Persons with Disabilities.

continued on page 14
It’s Not About Me  
*By Francis T. Pleban, PhD*

That was my mantra as I exited the taxi cab on the corner of Constitution and Delaware Avenue. The beginning of which would be the first of my 3 inaugural Capitol Hill advocacy experiences. Minutes earlier I was in the comfortable confines of the AAP Department of Federal Affairs office, bounded by pediatricians, all gathered for a common cause. A singular foundation, to put children first, with a specific emphasis, to advocate for strong policies upholding the developmental and behavioral health needs of children.

The morning of February 27, 2014 found me immersed in unfamiliar surroundings; with unfamiliar people. A diverse group comprised of individuals from Hawaii to Connecticut. Individuals with a myriad of life and clinical experiences. I felt comfort appreciating the fact that I was surrounded by special people, who go to work every day; making a profound impact on the lives of others.

However, referencing myself, there was also another element that I perceived would make the day’s events just a little bit more daunting.

Just a little about me.

I am not a pediatrician. I am not even a medical doctor. I had to ask for assistance in filling out the 8½ x 11 sheet of paper representing a physician’s prescription pad for use in our Capital Hill visits.

I am a university professor, with no clinical background, whose principal connection was having the sincere pleasure to serve as an affiliate member on the AAP Section on Developmental & Behavioral Pediatrics (SODB); representing the section on Advocacy Day in Washington, DC. Why? Why did I put myself in unfamiliar surroundings, with unfamiliar people, in, what turned out to be, for me, taxing and uncomfortable meetings with Capitol Hill congressional staff? Dr. Randy Pausch, professor of computer science at Carnegie Mellon University and author of *The Last Lecture*, perhaps said it best, “People are more important than things”.  

*continued on page 15*
Enough about me.

The applicability of our experiences — interacting together in advocacy training and with our respective representatives in their Capital Hill offices — is how we spend our time. Are we spending one of our most valuable resources, time, on what matters most? Advocacy, political or otherwise, is a process. And — prefacing this statement with the most sincere respect and personal ignorance to the clinical undertakings of pediatricians — similar to the care administered to your young patients. The care is not a means to an end, but a process to foster proper health and wellness. Both take time. Both, at times, may make one or another feel uncomfortable. Both are not, or at least should not be, about us. We take the skills we have learned, the talents afforded to us, and time we have; applying each facet to what matters most — the betterment of others. We are a conduit for those typically not in a position, or capable, to represent themselves.

Or, maybe the applicability of our experiences could be better stated through a historical perspective. History as written about Mother Teresa, Dietrich Bonhoeffer, Mohandas Gandhi, and others who were in the service of humanity for the sake of their beliefs. They became instrumental not through power or wealth, not through might, nor through possessions, but through the services they rendered to humanity. They preached their respective teachings, but never left either on the podium. They carried the lectern to the streets, regardless if they were openly welcomed or adversely challenged. They dedicated their individual service to better the condition of humanity. The AAP is “dedicated to the health of all children”™.

Finally, during our advocacy training session, a reoccurring theme was to personalize our communication; peppering in personal stories. These personal stories, I’m certain, were shared throughout the day, time-and-time again. These accounts may or may not have had a direct benefit to the people in the room. Some may have been told to honor a particular memory. All, I strongly believe, were told with the hopes that further accounts specific to the developmental and behavioral health needs of children would not need to be shared in the future.

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International Developmental-Behavioral Pediatrics

Editor’s Note: This section highlights Developmental-Behavioral Pediatrics (DBP) in China, with a review of a collaborative seminar between the AAP, Chinese Pediatric Society, and Shanghai municipal government, as well as an article by an esteemed Hong Kong neurologist and developmental pediatrician.

SODBP Delegates Participate in Sino-US Seminar on Collaboration of Medical Service and School Health System

By Carolyn Bridgemohan, MD, FAAP and Nathan Blum, MD, FAAP, SODBP Executive Committee Members

In September 2013, SODBp executive committee members Carolyn Bridgemohan and Nathan Blum participated in a collaborative seminar between the AAP, Chinese Pediatric Society and Shanghai municipal government in Shanghai, China. The AAP delegation also included Jeff Okamoto and Tom Young from the Council on School Health (COSH), President Thomas McInerny, President-Elect Jim Perrin, and Associate Executive Director Jon Klein. The goal of this exchange was to strengthen the AAP’s international connections and to promote collaboration between school and health systems by learning from the United States experience and new programs being implemented in Shanghai Province.

A 14-hour flight from Newark, NJ took us over the North Pole, to Shanghai where we arrived well rested. We were met by Chinese colleagues at the airport and had our first introduction to the generous hospitality that would become the hallmark of this trip. We were whisked away to the Shanghai Children’s Medical Center where we met with Dr. Jin Xingmin, pioneer in the field of DBP.
and chairwoman of the newly established Chinese DBP Association, and Mr. Jiang Zhongyi, the president of the hospital. We won’t forget the slide that listed the 4 most important divisions at the Hospital: Cardiology, Critical Care, Hematology-Oncology and Developmental-Behavioral Pediatrics. (We have requested the slide for anyone meeting with their Department Chair or hospital leadership.) The evening concluded with a banquet in a restaurant overlooking the beautiful Huangpu River and lights of the historic Bund district.

The highlight of the next day was our tour of the Yuyuan Garden and Old City God Taoist temple, tea at the Huxingting Teahouse, and shopping among the many stores for souvenirs including silk scarves and dresses, fans, and candy. We enjoyed meeting with local artisans who carried on the traditional handicraft of paper cutting called jianzhi. The conference opened that evening with a welcome banquet hosted by former Shanghai vice-mayor, Dr. Shen Xiaoping. Dr. Shen has been described as “a pioneer in advancing the health of children in Shanghai and all of China” (Lancet vol 379 March 3, 2012 page 795) for implementing important public health initiatives addressing lead poisoning, newborn hearing screening, universal medical insurance, and health registries.

The first day of the seminar was attended by about 100 medical and special education professionals from the region. Presentations by Chinese and AAP leadership described the current state of school and medical services for children with special health care needs in each country. The presentations were simultaneously interpreted by professional translators and transmitted to head sets (like those used in the United Nations). The event was covered by the press allowing our hosts to highlight the innovations in Shanghai to the nation. Interestingly one of the Chinese speakers expressed concern about over diagnosis of ADHD and showed some data suggesting that pressure to start children in school at a young age may increase the risk of the child being diagnosed with ADHD. After lunch, we visited 2 schools for children with special needs, considered model examples for the region. The Pudong Special Education School serves children with cerebral palsy (CP) and intellectual disability (ID) and Luwan Special Education School serves children with autism spectrum disorder (ASD) and other developmental disabilities. The dedicated staff at each facility highlighted the ability for this model to allow more specialized programming and staff expertise, although we were struck with the difference from the emphasis on least restrictive environment in the United States. The evening concluded with a banquet in a beautiful restaurant again overlooking the river. The banquet included many typical Shanghai delicacies and our first chance to taste sea cucumber.

The second day of the seminar was limited to a smaller group of key professionals in the medical and educational fields. The format consisted of grouped presentations followed by interactive discussions. For each grouping, an educator and/or medical professional from Shanghai and one of the AAP delegation would present on a common theme. We would then have discussion with the rest of the participants. The presentations were wide ranging and included talks about systems to integrate medical and school systems such as special needs networks, the role of DBP in school health, and models for engaging the community in caring for children with special health care needs.

Shanghai is a huge city with a population of 24 million, 1,660 elementary schools, and 22 special education schools. The Minister of Education designates who is eligible for special education services. There are 7 recognized disabilities with 4 levels of severity; level 1 students attend regular schools, level 2-4 students attend special education schools. Special education covers all children with special needs but in practice those with milder disabilities are not included. There is increased awareness among educators, however, about the need for more individualized approaches for these students. In China there are 20 million children with ADHD, for example. One presentation described a public service e-platform in Shanghai that integrated health and education records. Presentations included discussion of future plans to increase integration of educational and medical evaluations with periodic reassessments, promote curriculum reform for special education, develop an individualized plan for each child, and develop in home services for children with more severe disabilities who may not attend school. The US presenters discussed the consequences of not including children with special needs in regular education and advocated for special education law to ensure fair and equitable education.

The seminar closed with high energy and optimism with the closing speaker noting the “theme has been social progress and the essence of humanity” and reminding us that “The good heart of the city is the symbol of civilization”.

What did we learn?
It is clear that the professionals we met are dedicated, forward thinking, and interested in evidence based practices. They share our interests in improving methods for identifying children with special needs and optimizing medical care and special education. They
also share our struggles with trying to bridge different systems and educating parents about their role in promoting development. They share some of our questions about the role of treatments such as medications, and figuring out how to leverage the knowledge they have by creating networks and databases. They have some different resources and challenges in a country where the government can mandate policies be implemented nationwide. We were struck by the model where innovation centers such as Shanghai can pilot and develop strategies that can then be implemented nationally. In Shanghai, for example, they have implemented universal newborn hearing screening and through public health initiatives have dramatically reduced the rates of lead poisoning.

All the participants were interested in learning from our experiences in the US. For example, questions from the Chinese participants included wanting to know more about how we accomplish joint assessments through the medical and educational systems and what happens when the medical and education systems disagree. They wanted to know who provides early intervention services and how we determine the educational setting for a particular child.

There is a huge role for us in the international arena – our medical colleagues in countries where DBP is less developed are eager for our input as they develop the field in their own countries. We can learn from them as they adapt DBP to local cultures, systems and economies. In particular, some models may work better in certain populations in the US. Interchange and exchange with colleagues from other countries provides an opportunity for us to examine our own practices and assumptions – and makes us realize that we might want to rethink some of our established ideas. For example, we strongly support educating children with special needs in the least restrictive environment. However, we acknowledge that for some children, attending a highly specialized school with more expert staff and resources may allow for more effective developmental progress. In addition, working with colleagues in a country the size of China forces us to think about which of our practices can be scaled up and which might need to be modified or reconfigured. It was impressive to think about the sheer numbers of children in Shanghai and what that means for a municipal education and health system. It was also thought provoking to contemplate the dichotomy of opportunity and limitation presented by a government system such as China’s.

What is the next step?
We are working with the AAP and colleagues in Shanghai to plan for a follow up event that will take place as part of the NCE in San Diego in October 2014 and will be open to all members. Our Chinese guests will also be invited to both the COSH and the SODBPH programs so there will be opportunities for further exchange. Stay tuned for more information.

About the authors:

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Advocacy for Childhood Attention Deficit/Hyperactivity Disorder (ADHD) – An Overview in Hong Kong 2014

By Dr. Chok-wan Chan, President, Hong Kong (HK) Society of Child Neurology and Developmental Pediatrics

Background
Despite a vast body of research, knowledge, and practice experience on ADHD in many countries over the past decades, Hong Kong’s awareness and support systems for persons with ADHD have been mainly limited to the medical sector. More recently, students with behavioral problems are increasingly recognized as having in-child factors such as ADHD that require specific identification and help. In Hong Kong’s 2005 Rehabilitation Program Plan Review, ADHD was brought up as a distinct entity requiring multi-sectoral attention and resources, and was admitted into the Plan as a formal category of disabilities.

In response to a need to develop policies that provide effective and integrated systems of support, a Working Party on ADHD was formed within the Hong Kong Society of Child Neurology and Developmental Pediatrics (HKCNDP) in November 2005 to lead deliberations on the subject. The group performed literature reviews, stock taking of local service systems and professional readiness, and drafted proposals to meet identified challenges. In-depth consultative input to the paper was obtained including the fields of child psychiatry, social work, and health economics, and an open forum held with key players and stakeholders on the draft paper. This final position paper was eventually issued to academic, professional, and practicing communities for reference, and to policy makers and administrators for further actions.

What is ADHD?

Definition
ADHD is a condition with neurobiological origin that interferes with a person’s ability to focus and sustain attention on a task, or inhibit impulsive behavior. It is characterized by developmentally inappropriate attention skills and/or impulsivity and hyperactivity that are maladaptive, persistent and present across different settings, with onset of symptoms occurring before 7 years of age. ADHD is not a type of specific learning disability although these may occur in the same individual.

Etiology
ADHD is considered a generalized disorder of impulse control and performance monitoring. Converging neuropsychological neuroimaging and neurochemical studies have implicated fronto-striatal network abnormalities. Behavioral genetic studies support the view that ADHD is at least partially familial and genetically mediated. Molecular genetic studies show evidence for dopamine D4 receptor (D4DR) gene, dopamine transporter (DAT1) gene, serotonin transporter (5-HTT) gene and dopamine D5 receptor (DRD5) gene to be strongly associated with ADHD. A meta-analysis by Faraone, Doyle, & Mick et al (2001) showed the association between DRD4 and ADHD is real but small in magnitude. In addition, environmental factors may play a role through biological compromising events during development of the nervous system or negative psychological factors. It is worthy of note that negative parenting may conversely arise as a reaction to the difficult child as well as parents’ own ADHD and other emotional disorders. Emergence of oppositional defiant disorder (ODD) or conduct disorder (CD) may in part be a result of parental malpractices, but also of partly shared genetic liability of ODD/CD with ADHD.

How Common is ADHD?
Epidemiological reports on ADHD vary with variations in diagnostic criteria. Prevalence rates for children are reported as around 3-7% in USA, 3% in China, and 3-9% in other countries. Male to female ratio ranges from 2:1 to 9:1.

Management of ADHD

Diagnosis
Symptoms of ADHD are dimensional in nature, and the diagnosis of ADHD hinges on careful developmental history taking that addresses the full range of symptomatology and current functioning over situational contexts in key domains of family functioning, peer relationships, and academic function, and observation of behaviors as reported by adults or measured in home and clinic settings. Common comorbidities such as dyslexia and ODD have to be looked out for.

Management
Current practice guidelines in management involve a multidisciplinary approach including medication and behavioral interventions. Stimulant medication has been shown to significantly improve symptoms of ADHD. Behavioral modification programs involve continued on page 19
children, parents, and teachers. Specific skills are used, and problematic behaviors are identified for intervention. Education programs for parents are helpful for assisting them to develop appropriate skills for managing disruptive behaviors of their children. The Multimodal Treatment Study showed that children who received medical treatment alone or combined medical and behavioral treatment demonstrated a significantly greater improvement than those who just received behavioral treatment or routine community care.

The core symptoms of ADHD may be the underlying causes of persistent academic problems such as failed grades and expulsions. Educational interventions include academic instructional strategies, behavioral interventions, and classroom accommodations. Positive results occur with effective home and school collaboration.

Overall, an approach involving pharmacological, behavioral, educational, and social interventions in partnership with the family is currently the most efficacious and preferred treatment.

Costs to Society
The developmental impact of ADHD ranges from short-term impairments to long-term sequelae to the individual and severe costs to the family and society. For the individual, there may be serious issues in social interactions and relationships, self-esteem, academic problems and failure, occupational difficulties, injury and accidents, and substance abuse. In addition to higher direct medical costs for treatment of ADHD, there are increased costs for treating comorbidities such as conduct and mood disorders, and costs related to accidents including those as a result of poor driving habits of persons with poor attention and impulse control. Economic burden is also incurred to schools because of increased need for school-based supportive or special education services, to the parents because of missed work for managing the child and its consequent implications to the parents’ employers, to the society because of higher association of adults with ADHD and criminality, and work loss in adults with ADHD due to poor performance and absence from work. Medication treatment of ADHD has been shown to be cost effective, as it is likely to reduce the overall economic burden of ADHD by improving the child’s function and reducing the direct and indirect costs to families and other third parties.

How Does the Condition Apply to the Chinese Population and Hong Kong?

Local prevalence rate
A prevalence rate of 6.1% was found in a large sample of local school boys (Leung 1996). In young adolescents, prevalence estimates are 5.7% for boys and 3.2% for girls. From the records of the Child Assessment Service of Hong Kong Department of Health, the boys to girls ratio was 6-8 to 1 during the period 2003-2006.

Local Studies
Validity of ADHD disorder in the Chinese population (versus ADHD being a culture-bound disorder of the Western culture) was studied. Factor analysis of teacher and parent questionnaires confirmed the presence of ADHD behaviors separable from anti-social or neurotic/emotional factors, and positive association with external correlates including observed clinical features, higher exposure to biological risks during pre-, peri- and post-natal periods, history of other developmental delays and greater abnormal neurological findings. These correlations were not demonstrated in Chinese children with conduct disorder in whom social adversity was associated instead (Leung et al, 1996).

Genetic studies of Chinese children showed an association between the 2R allele of the DRD4 gene and ADHD in Han Chinese children, where the 2R allele may be derived from the 7R allele and functions similarly to 7R. In the study, there was a biased transmission of the 2R allele from the parents to their children with ADHD (Leung et al, 2005).

Neuroimaging studies of Chinese children in Hong Kong using a voxel based MRI study showed restricted structural brain abnormalities localized to brain systems known to be necessary for attention and executive function (McAlonan GM, 2007).

Assessment tools including the Conners Teacher Rating Scale (1989) and the Child Behavior Checklist (CBCL) with its Teacher Report Form and Youth Self-Report were re-validated for use in Hong Kong (Leung et al, 2006).

Intervention studies include an Enhancement of Learning Behavior Project through cooperation between schools, families, and community in helping children with ADHD (So, Leung & Hung, 2004), and a multi-modal intervention project consisting of medication, clinic based parent training, child training, and consultation and liaison work with schools (Heung & Ho, 2003, Heung V, 2004).
What is the Service Situation in Hong Kong?

Governmental Policies
Local services have been managed largely separately within the medical, education and social sectors, although some liaison efforts have been made in some serious cases. ADHD is recognized by the Education and Manpower Bureau in recent years as a category of special needs, while the Health & Welfare Bureau’s rehabilitation program incorporated ADHD as a category of disability in 2007.

Medical Services
Child assessment centers of the Department of Health (DH) (government department for health regulation) and the Hospital Authority (HA) (a quasi-government organization governing all public hospitals in Hong Kong mainly for provision of hospital services for the public sector) provide diagnostic and interim support services, while child and adolescent psychiatric services of HA provide diagnosis, treatment, long-term follow up and consultative support to other medical and educational settings. A proportion of children receive support from the private sector.

Educational support in mainstream schools may be provided with additional resources and professional backend support for students identified with ADHD. Support for learning and behavioral management varies widely in nature and intensity between schools.

Community programs on parent skills training for managing children with ADHD are available. However the nature and effectiveness of these programs have generally not been validated.

What are Hong Kong’s Challenges and Proposals for Future Development?

Medical Services
Challenges: Waiting time for child and adolescent psychiatry services have reached 1-3 years recently. Manpower deficiencies, including child psychiatrists and pediatricians trained to manage children with ADHD, are serious.

Proposals: A 4-tier service model for division of labor among medical professionals is proposed.
Tier 1: Non-mental health professionals.
Tier 2: Specialized teams with expertise in ADHD management.
Tier 3: Child psychiatry multidisciplinary teams.
Tier 4: In-patient psychiatric care teams.

These teams should work together through triage and mutual referrals as a coordinated network of support in the community and medical settings. In-service training for workers at respective level and opening of posts in public service are needed urgently.

Educational Services
Challenges: Large class size limits the amount of individualized support that teachers could provide to students with ADHD. Manpower issues include the lack of trained teachers and paraprofessionals (or teaching assistants) for helping students with ADHD, and the lack of good quality training provided to them.

Proposals: Reduction of class size is a priority. Specific training should be organized systematically for teachers of ADHD students. Paraprofessionals (teaching assistants) with adequate knowledge and skills about ADHD should be employed in schools, and in-service training and support to school social workers and school guidance personnel on this subject should also be provided.

Coordinated services between teachers, paraprofessionals, social workers, educational psychologists, medical doctors, clinical psychologists, and families are essential for supporting effective learning and behavioral management in schools. A senior member of the school should be designated to head the support team and coordinate various parties involved. School social workers and school guidance personnel could provide case work follow through within this system.

Social Services
Challenges: It is argued that a family-based approach should be adopted (Shek & Tsang, 1993), and objective as well as subjective burdens borne by the parents or caregivers of these children should be seriously taken into account. Unfortunately, even with the

continued on page 21
implementation of integrated family services in Hong Kong, the gap between rehabilitation and family service is still very wide. Parenting training programs and family supportive services geared towards the needs of parents and family members remain grossly inadequate.

Proposals: Resources should be directed to respective operators including community service providers and integrated family service centers. Pre-service, postgraduate, and in-service social work training programs need to be enriched with respect to coverage of ADHD management. Evidence based social work practices have to be developed and promoted for these children and families. Peer support and advocacy groups should be guided by professionals who understand their needs and by social workers familiar with peer support group work.

Service Coordination
Multidisciplinary and multisectoral collaborations are vital to the treatment and rehabilitation of children with ADHD. Affected children may be receiving medication by doctors, behavioral and emotional intervention programs by psychologists and social workers, effective school management by teachers, teachers’ aides, and educational psychologists, while families may be receiving counseling and social group work attention. All parties should be familiar with the systems in place in order to function and advocate effectively for the needs of those individuals.

Professional Training for Management of Children/Students with ADHD
Recommendations made on pre-service, postgraduate, and in-service training programs for pediatricians and family doctors, child psychiatrists, clinical psychologists, educational psychologists, teachers, para-professionals, and social workers are discussed in detail. A time framework of about 10 years is envisaged to bring current deficiencies to a reasonable balance.

Public Education and Research
Public education is needed for recognition of the presence of children with ADHD and their families, and for accurate understanding of its nature and the community’s service needs. Further research on the scientific and cultural aspects of the condition, as well as on effective interventions supported by evidence, are critical for guiding policy and service development.

Progress
Recommendations of the Working Group on AD/HD were summarized on a “Attention Deficit/Hyperactivity in Children: 2007 Position Paper for Hong Kong” and launched officially to the public in a press conference on July 5, 2007 whereby the contents with strategic planning for implementation with short (1-2 years), medium (2-5 years) and long term (5-10 years) targets were clearly stipulated. This is followed by advocacy activities to the policy makers and by both the draft group (HKCNDP) and the patient/parent group (the Association for Attention Deficit/Hyperactivity Disorders of Hong Kong). This is met with encouraging response from the education, medical, and social sectors of professionals as well as enthusiastic support from the general public. The most significant milestone is the inclusion of ADHD into the Rehabilitation Planning Program of the Rehabilitation Council whereby ADHD is officially recognized by the Government as a disability, through which subjects with ADHD were provided with funding for remediation, compensation, and accommodation and resources support at home, at school, and in the community. The current advocacy movement in Hong Kong is our submission of the “Support Services to Students with Specific Learning Disabilities (SLD) in Hong Kong Tertiary Institutions: Proposed Guidelines and Current Situation” to the top management of tertiary institutions for accommodation in admission and in tertiary education at the universities. The ultimate goal is to have ADHD included in the child health policy for the Hong Kong SAR Government under the category of children with special educational needs.

Conclusion
The movement going forward will rely on input and cooperation of multiple sectors and levels, with effective triage mechanisms and transitions between levels of care, delivered with understanding of the cultural and ecological context of the children and their families in Hong Kong. The presence of adequately trained professionals, effective programs supported by available evidence base, and partnerships with families in the natural community setting are essential. As for all complex conditions where biological differences, environment, and culture interact towards outcome, systems of care have to be developed with parameters that can be followed and monitored.

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continued on page 22

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continued on page 23


About the author:

Dr Chok-wan Chan graduated from the University of Hong Kong and was trained in child neurology and developmental pediatrics at Guy’s Hospital, London. Over the years, he has developed special interests in child advocacy, child protection, ethics, childhood epilepsy, behavioral neurology (and others). Dr. Chan is also Past President of the International Pediatric Association (IPA) and Advisor, Department of Child and Adolescent Health, World Health Organization (WHO).
Children With Developmental Disabilities and Emotional/Behavioral Health Issues and the Affordable Care Act (ACA)

By Meg Comeau, MHA

Editor’s Note: This timely article details “Obamacare” as it applies to our patients and their families.

According to recent survey data, approximately 3.5 million children with special health care needs (CSHCN) have ongoing emotional, behavioral, or developmental problems that require treatment or counseling. Like all CSHCN, children with developmental disabilities and emotional/behavioral health issues require health insurance that is universal and continuous, adequate in meeting their needs and affordable for their families. To date, meeting those requirements has been a significant challenge.

While the majority of children with developmental disabilities and emotional/behavioral health issues have insurance (as shown on Table 1), underinsurance (insurance benefits that are inadequate) is a much more prevalent problem (Table 2). The effects of underinsurance impact not only access to care for children with developmental disabilities and emotional/behavioral health issues (Table 3) but also have consequences for family functioning and financial stability (Table 4).

The Affordable Care Act (ACA) holds promise for alleviating some of these problems through new and expanded pathways to coverage, insurance reform, and consumer protection provisions. This article will describe selected ACA provisions related to coverage and benefits that have applicability to increasing access to care for children with developmental disabilities and emotional/behavioral health issues and reducing financial hardship for their families.

A new pathway to coverage created by the ACA are the State Health Insurance Marketplaces. Each state has a Marketplace, although some are run by the federal government or in partnership with it. The Marketplaces offer a choice of individual policies and small group plans (also known as Qualified Health Plans or QHPs). There is help for consumers through the Marketplace in choosing a plan; not just a comparison Web site but also navigators, consumer assistants, and other trained guides in navigating the health insurance maze. For applicants whose family income is between 100% and 400% of the Federal Poverty Level (FPL) ($23,850 to $95,400 for a family of 4) and who don’t have access to other qualified insurance, there are cost assistance subsidies available to help with the affordability of Marketplace insurance.

An important component of the Marketplace plans are the Essential Health Benefits or EHBs. The ACA requires that new individual policies and small group plans sold both through and outside of the Marketplace include the EHBs as their benefit package. Plans covering large groups, grandfathered plans, and self-funded or ERISA plans are exempt from the EHBs.

The ACA defined the EHBs as including health services in the following categories:

- Ambulatory care
- Emergency services
- Hospitalization
- Laboratory services
- Maternity and newborn care
- Pediatric services, including oral and vision care
- Preventative and wellness services, and chronic disease management
- Rehabilitative and habilitative services and devices
- Prescription drugs
- Mental health and substance abuse services; including behavioral health

As with any benefit package, adequacy is dependent on how expansive the scope, duration, and definition of the specific services that are covered under each of these broad categories is. Instead of creating a single national standard for the EHBs, states were authorized to choose 1 of 4 kinds of current plans to use as a model or benchmark. As a result, it is not possible to predict with certainty whether or how generously a specific health service is or is not covered under a state’s EHBs; the chosen state benchmark continued on page 25
plan has to be referenced to be sure. State mandated benefit laws that were passed prior to December 31, 2011 are included in the EHBs. This is significant; according to Autism Speaks, 34 states mandate coverage of Applied Behavioral Analysis or ABA.

In addition, rehabilitative and habilitative services and devices are a specific benefit category under the EHBs. Habilitative services help people gain and develop new skills and functioning for daily living, unlike rehabilitative services that help people regain lost skills due to an injury or illness. Even with habilitative services identified as a service category under the EHBs, there may still be problems. The EHBs were built on existing plans which were used as models. Because habilitative services involve learning a new skill versus regaining a previously acquired one, prior to the ACA private insurance plans often wouldn’t cover them, defining them as educational versus medically necessary. As a result, not every state’s benchmark plan included habilitative services when it was chosen.

The final rules on defining the EHBs said that if the benchmark plan didn’t include a definition of habilitative services, states could create the definition themselves to meet the requirement under the ACA. If they chose not to, they could require insurers subject to the EHBs to offer habilitative services ‘on par’ with rehabilitative services. States could also defer to the insurer to decide on how to cover habilitative services. The insurer would then report their definition to the US Department of Health and Human Services for evaluation. A review of each state’s summary of EHB benefits, limits, and prescription drug coverage on the Center for Consumer Information and Insurance Oversight (CCIIO) Web site indicates that 12 states (AZ, CT, FL, HI, NC, ND, PA, SC, VT, WV, WI and WY) have chosen to allow insurers to define habilitative services under the EHBs.

Another concern stemming from the final rules involves actuarial value—insurers are allowed to substitute benefits within the same EHB category, as long as the relative value remains the same. So an insurer could choose to bump up rehabilitative service benefits at the expense of habilitative ones. Monitoring of state and insurer decisions on these issues will be key to understanding their future impact on access to habilitative services for children with developmental disabilities and emotional/behavioral health issues.

The ACA created expanded pathways to existing Medicaid and Children’s Health Insurance Program (CHIP) coverage in a variety of ways. The US Supreme Court, in its July 2012 decision on the constitutionality of the ACA, determined that the penalty to states for not expanding eligibility for Medicaid to non-pregnant, non-disabled adults ages 19-64 was coercive and therefore not allowed. The Medicaid expansion provision under the ACA to this new population of eligibles with income under 138% of the FPL became in effect optional for states. The Supreme Court decision only applies to the new population of adults. Low income children were an existing mandatory Medicaid-eligible group and so their income eligibility has been raised in every state to 138% of the FPL ($32,499 for a family of 4). States with existing higher income eligibility levels cannot reduce them until at least 2019 due to the Maintenance of Effort (MOE) provision in the ACA. Children under age 21 enrolled in Medicaid already receive a robust benefit package including all medically necessary services under Early, Periodic Screening, Diagnosis and Treatment or EPSDT and the ACA doesn’t change that.

Another provision under the ACA of importance to children, families, and primary care providers is Section 2703 Health Homes for Medicaid enrollees with chronic illnesses. Care coordination has been identified by numerous sources as a fundamental component of achieving the Institute for Healthcare Improvement’s Triple Aim (improving the patient experience, improving population health, and reducing per capita spending). But sustainable financing for the service is a perennial problem. Lack of integration of physical and mental/behavioral health care is another current concern that impacts health care quality and cost. Section 2703 provides significant federal funding (90% of the cost) for care coordination and other support services in those states that create a Health Home State Plan Amendment. (Note: This program is time limited.) Eligibility for enhanced funding for Medicaid enrollees of all ages under this provision include those with:

1. Two chronic conditions (chronic conditions include, but are not limited to, mental health disorders, substance use disorders, asthma, diabetes, heart disease, and being overweight, defined by a body mass index over 25)
2. One chronic condition and the risk of developing another chronic condition; or
3. A serious and persistent mental illness or serious emotional disturbance

The enhanced federal funding supports the following types of services: (1) comprehensive care management, (2) care coordination, (3) health promotion, (4) comprehensive transitional care/follow-up, (5) patient and family support, and (6) referral to community and social support services.
Finally, the ACA includes a number of private insurance reform and consumer protection provisions\textsuperscript{14}, including:

- A prohibition against denying coverage or renewal based on a pre-existing condition
- Dependent coverage under a parent’s family plan up to age 26
- No rescission of coverage
- No denial of coverage or charging higher premiums based on health status or gender
- Prohibition against annual and lifetime dollar caps on benefits (although benefits themselves can still be limited)
- Guaranteed issue and renewal
- Prohibition against discrimination based on health status; genetic information is explicitly listed
- Preventative and screening services must be covered by in-network providers without a deductible, co-pay, or co-insurance being charged. Applicable preventative and screening services include:
  
  - Recommendations of the United States Preventive Services Task Force (USPSTF)  
    \url{http://www.uspreventiveservicestaskforce.org/uspstf/uspsabrecs.htm}
  
  - Recommendations of the Advisory Committee on Immunization Practices (ACIP) adopted by CDC  
    \url{http://www.cdc.gov/vaccines/acip/recs/index.html}
  
  - Comprehensive Guidelines Supported by the Health Resources and Services Administration (HRSA) Bright Futures Recommendations for Pediatric Preventative Health Care  
    \url{http://www.aap.org/en-us/professional-resources/practice-support/Periodicity/Periodicity%20Schedule_FINAL.pdf}
  
  - HRSA’s Women’s Preventive Services: Required Health Plan Coverage Guidelines  
    \url{http://www.hrsa.gov/womensguidelines/}
  
  - Recommendations of the Secretary’s Advisory Committee on Heritable Disorders in Newborns and Children (RUSP)  
    \url{http://www.hrsa.gov/advisorycommittees/mchbadvisory/heritabledisorders/recommendedpanel/index.html}

The ACA introduces the potential for historic opportunities in increasing access to care for children with developmental disabilities and emotional/behavioral health issues and reducing financial hardship for their families. But whether it fulfills its promise will depend in part on decisions made by states and insurers in the future. Monitoring the impact of those decisions in practice and providing feedback on them is an important role pediatric providers can play in supporting what works in national health care reform and improving what doesn’t for this vulnerable population.

<table>
<thead>
<tr>
<th>Table 1. Type of insurance coverage</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
</tr>
<tr>
<td>One or more emotional, behavioral or developmental issue</td>
</tr>
<tr>
<td>No qualifying emotional, behavioral or developmental issue</td>
</tr>
</tbody>
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\textit{continued on page 27}
Table 2. Currently insured CSHCN whose insurance is inadequate

<table>
<thead>
<tr>
<th></th>
<th>Current insurance is NOT adequate</th>
<th>Current insurance is adequate</th>
<th>Total %</th>
</tr>
</thead>
<tbody>
<tr>
<td>One or more emotional, behavioral or developmental issue</td>
<td>40.9%</td>
<td>59.1%</td>
<td>100%</td>
</tr>
<tr>
<td>No qualifying emotional, behavioral or developmental issue</td>
<td>31.3%</td>
<td>68.7%</td>
<td>100%</td>
</tr>
</tbody>
</table>

Table 3. CSHCN with any unmet need for 14 specific health care services or equipment in the past 12 months

<table>
<thead>
<tr>
<th></th>
<th>No unmet need for 14 specific health services</th>
<th>1 unmet need for 14 specific health services</th>
<th>2 or more unmet need for 14 specific health services</th>
<th>Total %</th>
</tr>
</thead>
<tbody>
<tr>
<td>One or more emotional, behavioral or developmental issue</td>
<td>62.9%</td>
<td>20.1%</td>
<td>17.0%</td>
<td>100%</td>
</tr>
<tr>
<td>No qualifying emotional, behavioral or developmental issue</td>
<td>82.6%</td>
<td>12.4%</td>
<td>5.0%</td>
<td>100%</td>
</tr>
</tbody>
</table>

Table 4. Impact on families

<table>
<thead>
<tr>
<th></th>
<th>Expenses less than $250</th>
<th>Expenses are $250 - $500</th>
<th>Expenses are $501 - $1000</th>
<th>Expenses are $1000 or more</th>
<th>Total %</th>
</tr>
</thead>
<tbody>
<tr>
<td>One or more emotional, behavioral or developmental issue</td>
<td>46.8%</td>
<td>16.8%</td>
<td>10.5%</td>
<td>25.8%</td>
<td>100%</td>
</tr>
<tr>
<td>No qualifying emotional, behavioral or developmental issue</td>
<td>43.6%</td>
<td>23.6%</td>
<td>12.5%</td>
<td>20.4%</td>
<td>100%</td>
</tr>
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</table>

CSHCN whose health conditions caused financial problems for the family

<table>
<thead>
<tr>
<th></th>
<th>No financial problems</th>
<th>Yes, financial problems</th>
<th>Total %</th>
</tr>
</thead>
<tbody>
<tr>
<td>One or more emotional, behavioral or developmental issue</td>
<td>67.2%</td>
<td>32.8%</td>
<td>100%</td>
</tr>
<tr>
<td>No qualifying emotional, behavioral or developmental issue</td>
<td>83.7%</td>
<td>16.3%</td>
<td>100%</td>
</tr>
</tbody>
</table>

CSHCN with unmet need for 1 or more specific family support service among those CSHCN whose families needed respite care, mental health counseling and/or genetic counseling

<table>
<thead>
<tr>
<th></th>
<th>Received all needed services</th>
<th>1 or more unmet need(s) for family support services</th>
<th>Total %</th>
</tr>
</thead>
<tbody>
<tr>
<td>One or more emotional, behavioral or developmental issue</td>
<td>59.0%</td>
<td>41.0%</td>
<td>100%</td>
</tr>
<tr>
<td>No qualifying emotional, behavioral or developmental issue</td>
<td>71.7%</td>
<td>28.3%</td>
<td>100%</td>
</tr>
</tbody>
</table>

CSHCN whose health conditions cause family members to cut back or stop working

<table>
<thead>
<tr>
<th></th>
<th>Family members did not cut back hours or stop working</th>
<th>Family members cut back hours and/or stopped working</th>
<th>Total %</th>
</tr>
</thead>
<tbody>
<tr>
<td>One or more emotional, behavioral or developmental issue</td>
<td>61.2%</td>
<td>38.8%</td>
<td>100%</td>
</tr>
<tr>
<td>No qualifying emotional, behavioral or developmental issue</td>
<td>81.4%</td>
<td>18.6%</td>
<td>100%</td>
</tr>
</tbody>
</table>
References


5. Small groups are defined as having less than 50 employees

6. Grandfathered plans are those in existence when the ACA was signed into law on March 23, 2010. A plan loses its grandfathered status by significantly increasing premiums and/or reducing benefits.

7. In effect in 2012, when the decision on benchmark plans were being made by states


11. Loss of all federal funding for a state’s Medicaid program


About the author:

Meg Comeau, MHA is currently the Co-Principal Investigator for the Catalyst Center located in the Boston University School of Public Health. She is a nationally recognized expert on the role of Medicaid in serving children with disabilities, the implications of federal health care reform for children with a broad spectrum of special health care needs, and the causes and consequences of financial hardship among families raising children with special health care needs.