What are the Things to Consider?

When trying to understand what might be contributing to challenging behaviors in any person at a certain point in time, the team needs to utilize a broad approach. Thoughtful consideration must be given to the various issues that might be resulting in the individual’s actions. You may want to have your providers explore possible medical and mental health factors (also referred to as applying the principles of differential diagnosis). In this way, they can better evaluate what might set up, trigger, or maintain the behavior.

Some of these concerns might be quite obvious. For example, you would expect pain if a child has a visibly broken arm. However, other issues might require the skills of an expert who knows what subtle signs to look for, such as staring spells that might suggest seizure activity, certain behaviors that might suggest belly discomfort, or patterns that suggest an additional mental health concern.

“Until age 9, generally I lived in my own world relating to things, shiny coins, marbles and sparkly objects that I collected and hid in a secret place. I focused intently on these objects, lining them up over and over in patterns only I understood. If anyone disturbed them I had a tantrum, a meltdown, banging my head against the floor or wall for fifteen minutes. Nothing seemed to assuage my rage, it seemed to run a predictable course. I pulled my hair, picked at my skin and bit my arms. When it was over I was very thirsty and tired. Often, I returned to my activity to repair the interruption. My world was a house of cards, any breeze could collapse it.

I was an escape artist. I ran wildly, arms flailing until I became too winded to continue. Then I fell down, rolled onto my back and stared at the sky. I usually fell asleep. I believe that I had seizures.

I played with others if I could lead, and control the activities. If not, I left without a word. I seldom fought with other kids, except my bossy older sister who felt responsible for me. I didn’t have a connection to people until I was in grade school.

High School and College I succeeded academically and socially pursuing artistic interests. I had many casual friends, none were close.”

– Ruth Elaine Hane*,
a married woman with High Functioning Autism

*To read more about Mrs. Hane, please refer to Appendix 1 at the end of this section.

It might be helpful to know that in general, people with developmental disabilities (including autism) are more likely to receive inadequate or inappropriate medical treatment. They receive fewer routine physical examinations, less preventative dental care and less mental health care than other Americans. People with communication issues are at greater risk of poor nutrition, overmedication, injury, neglect and abuse. There are likely multiple factors involved in these statistics, but certainly it is harder to care for someone who does not reliably say ‘This hurts,’ or ‘Hey mom, why can’t I see the blackboard at school?’ Often, it is the parent’s ability to be a watchful observer and careful reporter, combined with the skilled listening and evaluation of an experienced provider, that brings the necessary factors of a person with autism’s health and other factors into consideration.

The following chart lists areas of potential consideration for the professionals on your team, and the types of questions you might ask in each area. This list is not complete, but hopefully it will support you and your team in considering topics that might be relevant with respect to your loved one and his concerns. If this list suggests an area that a provider is not investigating, be sure to bring it up. Know that you may have to be persistent or consult with other team members for each of your concerns to get the attention your loved one deserves.
<table>
<thead>
<tr>
<th>Possible Cause</th>
<th>Potential Areas of Focus</th>
<th>Questions to ask</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medical</td>
<td>Pain e.g. ear infection? Toothache?</td>
<td>Could this person be in pain?</td>
</tr>
<tr>
<td></td>
<td>Seizure</td>
<td>Could this be seizure related?</td>
</tr>
<tr>
<td></td>
<td>Sedation / Poly pharmacy (multiple medications)</td>
<td>Is this individual sedated? Is he on too many medications? Is he on the wrong medications or dose?</td>
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<tr>
<td></td>
<td>Insomnia/Inadequate sleep</td>
<td>Does the person get enough sleep?</td>
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<tr>
<td></td>
<td>Allergies</td>
<td>Are there seasonal, food or environmental allergies involved?</td>
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<tr>
<td></td>
<td>GI Issues/Nutrition</td>
<td>Is behavior related to meal times or food? Has there been a change or concern about bowel habits?</td>
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<tr>
<td></td>
<td>Dental concerns</td>
<td>When was the last dental exam? Is there tooth pain?</td>
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<tr>
<td></td>
<td>Vision/Hearing</td>
<td>Is there a change in or problem with perception?</td>
</tr>
<tr>
<td>Genetic</td>
<td>Fragile X, Down Syndrome, etc.</td>
<td>Could this behavior be related to an undiagnosed genetic syndrome?</td>
</tr>
<tr>
<td>Mental health</td>
<td>Co-occurring mental illness</td>
<td>Could he be experiencing anxiety, depression, ADHD? OCD?</td>
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<tr>
<td>Cognitive</td>
<td>Intellectual ability/ Processing abilities</td>
<td>Are the demands on the individual too high or low for his cognitive level?</td>
</tr>
<tr>
<td>Communication</td>
<td>Adequacy of communication system</td>
<td>Does this person have a functional communication system? Does he use it spontaneously (without prompt)?</td>
</tr>
<tr>
<td>Sensory Dys-regulation</td>
<td>Unmet or overwhelming sensory factors</td>
<td>Is the behavior supplying sensory input/ attempting to meet sensory needs?</td>
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<tr>
<td></td>
<td>Sensory defensiveness</td>
<td>Is the behavior in response to sensory overload? Are there big responses to things in the environment? (Loud noises, etc.)</td>
</tr>
<tr>
<td>Environmental factors</td>
<td>Location, time of day, setting, activity</td>
<td>Is he too exhausted at the end of the day to handle this demand? Why is he okay at other doctors’ offices, but not here? Is this task beyond his motor ability?</td>
</tr>
<tr>
<td>Environmental reinforcement of behavior</td>
<td>Family/ Staff / Educator / Caregiver responses to behavior</td>
<td>Is the behavior responded to with attention? Removal of a request? Other?</td>
</tr>
<tr>
<td>Family / Staff dynamics</td>
<td>Changes in family environment</td>
<td>Have we had losses/changes in our family?</td>
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<tr>
<td></td>
<td>Changes in staffing</td>
<td>Has a favored staff member left? Are new staff members adequately trained? Is there a shift in schedules/patterns?</td>
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</table>

Physical Concerns

As the previous chart outlines, there are many potential physical causes of and medical contributors to behavior. Gathering information about pain and symptoms can be especially difficult in individuals with autism due to communication difficulties, variable responses to sensory input and pain and even in those with good verbal ability, a lack of self-awareness.

It is also important for the team to know about medical concerns that often accompany autism, or more specifically, challenging behaviors. Addressing these less obvious concerns can often change behaviors. The most recognized of these include the following:

- **Seizure disorder** or epilepsy occurs in as many as a quarter of individuals with autism. Spotting seizures is sometimes tricky, since some seizures might occur at night but leave daytime effects, and others can appear in milder forms such as *staring spells* or times of ‘spacing out.’ Sometimes the after effects of a seizure can leave the person lethargic or reactive. You can find resources related to epilepsy [here](#).

- **Gastrointestinal complaints or digestive disorders** such as reflux, stomachache, constipation, bowel pain, and diarrhea are often reported in autism. Investigation can be difficult in light of language challenges, but treatment has been shown to improve comfort and increase access to learning environments. See Recommendations for evaluation and treatment of common gastrointestinal problems in children with ASDs.

- **Sleep disorders or disturbances** such as difficulty falling asleep, insomnia, *sleep apnea* (disrupted breathing), and night waking are often reported in autism. Sleep is always an important consideration, both for the individual and the caregiver. Sleep is essential for physical as well as psychological restoration. It is hard to remain calm and keep perspective when you are exhausted, so evaluating and treating sleep concerns is essential. See the ATN Sleep Strategies Guide.

- **Sensory issues** are important to consider, since many individuals with autism respond to sensory input in an altered way. Sounds are louder, lights are brighter, words and visuals cannot be taken in at the same time, and the world is hurtful or confusing. It is also important to remember to assess sensory input. Have your child’s eye sight and hearing checked? Make sure the doctor uses the right tests, since these concerns can be a challenge to evaluate in people with autism. In addition, these issues can change over time. Any of these factors might change a person’s reactivity and promote a behavioral response.

- **Allergies, immune dysfunction, or autoimmune conditions** may show behavioral features that vary with exposure. Seasonal or *food allergies* or *intolerances* only occur at certain times of year, or when a particular food is eaten. Some food intolerances cause discomfort but not obvious rashes or breathing concerns, and may be *difficult to identify*. Immune activation such as eczema, joint pain or other conditions can cause a chronic discomfort that goes unnoticed.

- **Headaches or migraines** can result in a person with autism walking around with pain that you or I might readily fix with an over the counter pain killer. The inability to report pain—or even in more verbal individuals to identify pain in a certain place—can lead to discomfort that results in challenging behavior.

- **Genetic disorders** are associated with autism, and some can be accompanied by additional challenges that are worthy of medical consideration. Sometimes knowing about genetic differences can help you be more aware of other associated conditions, such as seizures.
Reflections on my childhood:

“I had terrible belly pain, and I did not know what to do about it. So I would run. I ran for miles just to try to get away from the pain. Of course, it was a small town and everyone knew me, so eventually I would end up back at home.”

- RT, adult with autism

Other medical conditions have been noted in individuals with autism that may cause significant changes in behavior. These concerns may not immediately come to mind for your medical provider. But there is growing awareness of and investigation into the role they may play in autism, and sometimes in the appearance of challenging behaviors.

- **Whole body condition** is important to consider as autism is being increasingly recognized as a condition of the body, not just the brain. Many of the associations discussed above highlight the idea that there is likely more going on physically than was once thought. Insights into nutrition and various body processes might be worth considering.

- **Missed infections**, such as Lyme’s Disease, PANDAS, an ear infection, an ongoing upper respiratory infection that harbors strep, or other low grade infections might cause immune activation but perhaps not obvious signs like a fever. Sometimes, there are effects on the nervous system as well as physical results of these infections. A doctor might check blood samples to look for titers (evidence of infection in the immune system) if behavior changes, such as extreme lethargy, tics, or a sudden onset of obsessions take place.

- **Catatonia** might be worth investigation if there is behavioral regression and significant changes in motor function (the ability to move, or to control one’s movements). With catatonia, an individual may appear to hesitate, develop strange body postures, limit eating, and develop odd movements and tremors. Behaviors can appear such as self injury and aggression as a result of the individual’s lack of motor control. Though it is not well recognized in the U.S., catatonia has been shown to develop in a significant number of teenagers and young adults with autism in studies in the UK as discussed in *Catatonia in autism* and may be worthy of consideration if these symptoms sound familiar.

- **Changing hormones** and the onset of puberty can make a typical child seem like a stranger, and these same effects can occur in people with autism. However, in autism, additional considerations come into play because of the language and social deficits. It is important to consider whether some of the behavioral features you are seeing are a natural, developmentally appropriate strive towards greater independence. If so, you should consider allowing additional choices and other proactive strategies (described in the next section) that will address this need. In addition, statistics show that individuals with developmental disabilities are at greater risk of abuse, including sexual abuse. The team should give consideration to this as a potential factor in sudden challenging behaviors. You can learn more by visiting the Autism Speaks Safety Project website.

Although it is not specific to autism, the chart of “Common behavior problems and speculations about their causes” might trigger some thoughts of additional considerations in your child (please see Appendices 2 & 3). 

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For some children, evaluations may have been skipped or avoided because of difficulty or fear of the procedures themselves. If anxiety about procedures affects the ability of your medical or dental team to evaluate your child, these tool kits, which were created by the *Autism Treatment Network (ATN)* might be helpful to you or your providers:

- Blood Draw Tool Kit
- Dental Tool Kit for Families
- Dental Tool Kit for Professionals

**Mental Health Considerations**

Studies of individuals on the autism spectrum show frequent overlap with symptoms that meet diagnostic criteria for other mental health conditions. This is a difficult area and interpretation often varies by provider, since many of the features of autism also occur in other named disorders and there is no distinct line. For instance, various providers might use different criteria in distinguishing between the repetitive behaviors of autism and a diagnosis of obsessive-compulsive disorder.

Sometimes the features of *depression, anxiety, ADHD, obsessive compulsive disorder, Tourette's Syndrome, bipolar disorder or schizophrenia* are significant enough that they stand on their own as worthy of specific diagnosis and treatment. When a person has two or more diagnosed conditions, this is called a *co-morbid condition* or *dual diagnosis*. Challenging behaviors are common in individuals with dual diagnoses, and it may be that another mental health concern has not yet been diagnosed or considered.

Statistics for dual diagnosis in individuals on the ‘higher functioning’ end of the spectrum or with Asperger’s Syndrome are high. This might be because they are better able to report concerns. It may be that the combination of the social aspects of autism and the effects of the co-morbid condition combine to cause challenges that drive them to evaluation, services and hopefully, treatment. More information is available through the *National Association of Dual Diagnosis (NADD)*.

The role of the mental health provider might include differential diagnosis, medications, therapy and/or *cognitive behavior* interventions, as well as partnership with other team members. It might be important for a mental health provider to educate the team about the features of a dual diagnosis, so that, for example, the uncontrollable tics of *Tourette’s* might be considered and treated as something different from *behavioral stereotypy*. A mental health provider might ask questions about the behavior, as well as changes in behavior that might reveal new circumstances or areas of concern such as *depression, anxiety, post-traumatic stress, or psychosis*. It is important to note that mental health disorders and symptoms should not be considered purely psychological. There are biological factors that can drive anxiety, anger, tics and other behaviors. Just as it may be impossible to know when a seizure is coming, the biological triggers for some of these symptoms in some individuals, and the resulting behaviors, can be unpredictable. If this is the case, your mental health provider should help you understand this situation better and may be able to help. Together with your behavioral/educational team, you may be able to determine subtle signs that your child is headed towards a surge and then develop approaches that will minimize its effects.
Another potential factor is the role of adolescence in changing behaviors. Puberty is often a time when conditions such as depression and anxiety appear. The physiological changes, as well as the developmentally programmed need for greater independence and breaking away from parental control, are just as real in an individual with autism as they are in a typical teen. For those who have academic and functional skills closer to their peers, such as young people with Asperger’s Syndrome, teenage years can be a sensitive time when a growing awareness of their differences or difficulties making friends and fitting in becomes increasingly frustrating. A mental health provider might be able to help your child, and also aid in your understanding of these changes and how you might adapt to grow with your child as he strives for more autonomy and self-advocacy.

Post-traumatic stress (PTSD) is another condition worthy of consideration, especially for someone who cannot describe what he has experienced. Some individuals may have been in situations that have caused significant stress, such as medical concerns/pain/procedures, changes in surroundings/staff/family, neglect, or abuse. It is important to be aware that research also shows a higher likelihood of sexual abuse in the developmentally disabled population. The possibility of abuse or trauma should be considered when challenging behaviors develop suddenly.

Other individuals may feel additional stress in response to interventions that have targeted challenging behaviors using approaches such as seclusion (putting a person in a place alone), restraints (tying, wrapping or otherwise restricting a person’s ability to move), over correction, aversives’ (interventions that are painful or disliked), or other punishments. In these instances, caregiver/staff responses to challenging behavior may be instrumental in creating a disturbing cycle that raises stress and increases the likelihood of more difficult behaviors. In other words, how the people around your child are responding to his behavior might be making his situation even more stressful and challenging. More discussion of the effects of intervention is included in the behavioral section that comes later in this tool kit.
If your loved one takes medicine, it might also be worthwhile to talk to your doctor about the possible effects on behavior. Many of the medications we use affect more than just the intended outcome. These side effects can sometimes be quite significant and can change an individual’s sensitivity or ability to regulate. For example, some medications can be *ototoxic*—which means they might be damaging to the ears, causing sound sensitivities, dizziness or balance issues. Other medications might cause stomach pain in a person who never had digestive issues before. It is not just traditional *psychotropic* (acting on the brain) medications that need to be considered. It is possible that a prescription for acne medication might be having an effect that might trigger new behavior. Carefully review side effect lists and discuss the side effect profiles of each medicine with your doctor, especially in someone who might not be able to report on his symptoms.

In considering medication, note that proper dosage can be very sensitive, particularly in individuals with autism. Sometimes too much medication can be *over-stimulating* or *sedating* (tiring), perhaps even causing the person to find other ways (through new or difficult behaviors) to try to get back to a sense of stability or normality. Some medications can have unexpected or rebound effects. Layering on multiple medications at one time, called *poly pharmacy*, can also have unintended effects. Some doctors have reported success in slowly taking a person off all medications to re-establish ‘baseline’ in an effort to sort out ‘what is the autism?’ from ‘what is the medication?’

“I recall that when Jack was little our doctor suggested that we try a stimulant. This was meant to calm and focus him. As time went on, Jack didn’t sleep for 48 hours sometimes, and we were all a mess as he was bouncing off the walls. We couldn’t imagine what he would be like without the benefit of those calming meds. Eventually we tried a weekend drug holiday as they often suggest for stimulants, and he was lethargic the whole weekend. Aha! We realized it was the drugs, not the autism, that was causing the behavior. In hindsight it seems obvious, but in the moment, it was hard to see the relationship.”

– SG, parent

As an individual grows and changes, medication may need to do so as well. For example, a larger teen might need more medication to achieve the same effect on attention or anxiety. Medical expertise specific to autism is often quite helpful in carefully determining the right pharmacological interventions for an individual at any point in time.

Families often struggle with decisions about the role of medication in addressing challenging behaviors, and when and what kinds of medication might be useful. This *Medication Guide* is designed to help in defining your values and goals surrounding medication use. It also provides perspective and talking points to assist in speaking with your doctor and making decisions. It can be used for new medication decisions, or in re-evaluating current medications.

If medication is started, it is important to track side effects and look for other concerns to ensure that the medication is helping where it is supposed to help, and not causing other problems. Sometimes a provider might use a measurement tool that involves asking the family or staff questions prior to starting a medication or other intervention. One often-used tool is the *Aberrant Behavior Checklist*. The provider might repeat this test after a few weeks or months as a way of measuring the effects of the medication. It is wise to have multiple responders, as well as to compare baseline and follow-up responses from the same person.
The use of simple tracking scales for both target behaviors and side effects is another way to assess the effects of a medication. This might be undertaken in cooperation with a behavioral provider or team using their data collection systems, or you could create or modify something like this tracking scale:

<table>
<thead>
<tr>
<th>Behavior/Symptom Occurred</th>
<th>Morning</th>
<th>Midday</th>
<th>Evening</th>
</tr>
</thead>
<tbody>
<tr>
<td>Burping</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sleepiness</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Uses iPad to make request</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Hitting</td>
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<td></td>
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<tr>
<td>Kicking</td>
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<td></td>
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<tr>
<td>Other</td>
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</table>

“We did not like the weight gain associated with the meds that Sammy was on, and we weren’t even sure it was helping. So, every few months, I would decrease his dose just as the doctor instructed, and I would start on a Friday so that we would be able to see changes that we wouldn’t see while he was off at school. I would not tell my husband, so that at least one of us was getting a ‘blinded’ view of any changes. By Sunday afternoon, in the midst of some frustrating situation, he would say, ‘are you doing that meds withdrawal experiment with Sammy again?’ And we knew the meds were still working.”

— BW, parent

Sometimes it is helpful to keep some team members or family members ‘blinded’ to a new intervention. Often, if we know something is supposed to help in a certain way, we are more likely to see it, even if it is not really there. For example, if you tell the lead teacher about a new medication but not the classroom aides, you might get better information from the team about the true effects of a medication on your child’s behavior.

Consideration of changes in the effects of medications should be ongoing. Sometimes adjusting dosage, form (some medications come in time-release forms for more even delivery), time of delivery (before vs. after meals, at bedtime instead of morning, etc.), or other factors can help to increase the benefits and reduce the side effects of a medication.

Being a careful observer and a good reporter to your doctor, and discussing both the benefits and downsides of a medication in advance and as the intervention progresses, can often help to manage a medication so that it is most helpful. Using a chart such as the one above can help you to see if the medication is effective. If medical concerns are a feature of your loved one’s profile, it is important to maintain good records and share information among team members.
Behavioral Considerations

When a person behaves in a way we find difficult or offensive, we often reflect on the impact of that person’s actions on us—how we feel threatened or embarrassed or hurt. This is absolutely normal, but not always helpful. Instead, it is important to think about the behavior from the individual’s perspective.

*What is so scary about entering this place that my child is so panicked that he has to bite me? What pain is occurring in his body that he might be trying to over ride it by hitting himself in the head? Is this something biological over which he does not have control? If so, can we help him to learn how to adapt?*

Shifting our thinking from how a particular behavior affects us (and the siblings, the classmates, the furniture, etc.) to what might be happening from the individual’s perspective is an important step in finding ways to understand behavior. Understanding the behavior will allow you to support the replacement of disturbing or *maladaptive* behaviors with functional skills.

Going back to the basics of behavior, it is important to consider the possible purpose or function. *How does this behavior serve the person? Does he get something out of it? Does he get to escape something boring or difficult? Does he get attention? Does it allow him to assert a little bit of control over his life or surroundings? Does it help to block out pain? What is good about the behavior? Is he trying to tell me something?*

Taking the time to understand the function can often give a window into the motivation behind the behavior. Proper evaluation of function is usually essential to crafting an appropriate response.

For example, suppose a child kicks when it is time to go to gym class and the response to his kicking is to put him in a ‘time out.’ This is likely to be an ineffective intervention if the whole reason for kicking was to avoid going to gym. He just got what he wanted, and he learned that kicking is an effective way of making his argument. Next time he doesn’t want to go to gym class, what is he likely to do? But if kicking keeps him out of the loud, echoing chaos of gym that he finds hurtful or disturbing, he is likely to use the communication he has learned *unless and until* he is taught a better way of coping with gym class (e.g. asking for a different activity) or advocating for avoiding the unpleasant situation.
In the field of Applied Behavior Analysis, the three components that are documented and considered in looking at a specific behavioral episode are called *A-B-C (antecedent-behavior-consequence) analysis*, and include the following components:

- a clear description of the behavior (behavior)
- the situation, events and conditions that occurred before the behavior began (antecedent)
- the situation and events that immediately followed the behavior (consequence)

These behaviors may be tracked using a sheet such as this:

**ABC SHEET**

**Student:** ____________________________ **Observer:** ____________________________

**Target Behavior:** ____________________________________________________________

**Antecedent:** The event that occurs immediately before the behavior

**Behavior:** The occurrence of the target problem behavior (record frequency)

**Consequence:** The event that immediately follows the occurrence of the behavior

<table>
<thead>
<tr>
<th>Date</th>
<th>Time</th>
<th>Antecedent</th>
<th>Behavior</th>
<th>Consequence</th>
<th>Comments</th>
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A professional with expertise in behavioral assessment and intervention (e.g. a BCBA) will use a variety of tools to help understand the function of a behavior at any given point in time. It is important to remember that the scales are tools, not answers. A good functional behavior assessment (FBA) will use several measures—questionnaires as listed below, observational assessments, active listening, and the professional’s experience and background.

An FBA should be broad based and should take into account the observations of behaviors and how and when they occur. They should also seek to be empathetic and to understand why the person might feel the need to behave in a certain way. Make sure your provider is using a broad approach, since this is essential to getting a good handle on the concerns, potential causes of the behavior, and possible interventions and solutions for replacing this behavior with skills.

The following resources will help you learn more about how behavior is often evaluated and considered by professionals:

- Parents’ Guide to Functional Assessment
- Functional Behavioral Assessment and Positive Interventions: What Parents Need to Know
- Targeting the Big Three parent training manual

For a school-aged child, the school district is responsible (under the laws of IDEA) to perform a FBA and create positive interventions for a child whose behavior inhibits his learning, or the learning of those around him. If they do not have this expertise on staff, they need to secure these services through other agencies or consultants. Some schools will provide additional training and instruction in the home, or through other community providers such as wraparound supports. Behavioral interventions through your health insurance provider may also be able to provide this support.

If you do not have access to a behavioral support provider or team, you can begin to become a more advanced observer of the elements of behavior yourself. Tools such as Barbara Doyle’s data collection and communication dictionary might be helpful.

After defining and evaluating the behaviors, the behavioral team, teaching staff or other providers should explain the results to you and develop instructional strategies using Positive Behavior Supports (PBS) and Reinforcement Strategies. Using Positive Behavior Supports is a way to promote functional skill development and motivation and can be used at home, school, work, and in the community. These supports often need to be individualized to the needs of the child, and the functions of his behaviors, to be effective. Classroom based supports are often not sufficient for challenging behaviors, so you may have to advocate for these to be individualized. More on positive behavior supports, training and resources for families, schools and staff, and strategies for building positive behavior are included in the next chapter.

If the function of the behavior is to gain attention, challenging behavior can be reduced if attention and interaction are no longer given when the individual engages in the problem behavior. This means not giving direct eye contact or calling the individual’s name, no reprimands, no reasoning and lecturing, or showing that you’re upset. Attempts to redirect the behavior by giving attention may inadvertently increase the problem behavior.

Note: Ignoring challenging behavior may initially increase the challenging behavior because that is how he communicated what he wanted and how he got his way until now. Keep the faith. Ignoring will ultimately decrease the likelihood that the individual will engage in challenging behavior to gain attention.

-Page 73 Targeting the Big Three
Other Concerns to Consider

Communication Issues

Teachers, behavioral providers and/or speech pathologists should also evaluate the functional communication skills available to an individual, as this can be a critical factor. After all, behavior is often a form of communication—sometimes the only form available to an individual who has not learned other skills.

It will be helpful to consider: Did he understand what I said? Can he independently use speech or other forms of communication to raise concerns? Report pain? Make requests? Ask to get away? If not verbally, does he have cards or a device that he uses independently for this? Even if he can speak well, does he have the language or the confidence to make his needs and concerns known verbally? If not, it is likely he is finding other ways to express wants, frustration, fear or other information.

Many individuals with autism have difficulty processing information—hearing all the parts of what someone said, matching what they see to what they hear, or being able to decide what information is important and relevant in light of all the possible sights, sounds, smells, etc. Many people with autism are visual learners, or otherwise benefit from information presented in pictures, words or video. Verbal information (speech) disappears as soon as it is said, but visuals have staying power—they can be available and accessed as long or as often as the individual needs.

It is essential that the functional communication system is something that your child can initiate and use independently. Often a speech pathologist can perform an evaluation and design appropriate interventions. Many skilled autism intervention teams have also developed expertise in communication supports and development. If supports and training in functional communication are needed, there are a variety of systems that the team should explore, such as PECS and voice output devices, to find a fit for the individual and his specific needs and preferences.

“I remember how he would throw himself to the floor when he was thirsty. The speech pathologist taught me how to take his little hand and shape his fingers into a point, then lead his hand to touch the cup. We did this hundreds of times, moving from the cup to toys and movies he wanted to watch. When he pointed, he got what he wanted. He started pointing. He was learning to ask!”

- TO, parent

Sometimes even highly functional individuals with autism can have difficulty communicating certain concerns. For example, many individuals with Asperger’s Syndrome lack self-awareness. So as a result, isolating pain, describing emotions or identifying what is causing a negative feeling can be very difficult. Expectations that a ‘straight A student’ should be able to navigate social situations or other challenging experiences can often leave an individual unsupported, and as a result, increasingly anxious and reactive. Specific instruction in social and self-awareness can be hugely beneficial for someone who might have an incredible vocabulary but difficulty communicating about socially relevant concerns.
Sensory Concerns

Individuals with autism often report on their different ways of experiencing the world, and it is helpful to keep these issues in mind when considering a person’s specific behaviors. A child may scream or run out of the singing of the Happy Birthday song not to be difficult, but because the singing and/or the cheering that follows is truly painful for him. Often these responses are more like reflexes than behavioral choices. When a person stays away from certain experiences—sounds, touch, smells, food tastes/textures, certain types of movement, etc., it is often called sensory avoidance or sensory defensiveness. Even in these same individuals, there is often a contrasting need for additional stimulation of certain senses as a way of maintaining attention or achieving a calmer state. This is called sensory-seeking behavior.

It is important to consider whether the individual has some sensory need that is otherwise not being met. Is he jumping up and down because it feels good? Alternatively, is there sensory defensiveness? Is there something about this tag in his shirt, this lighting, this sound, this crowd, these odors that he finds painful or overwhelming?

“He had a fascination with birthday parties and blowing out candles, and at one point we would have to re-light, re-sing, and re-blow – 20 times or more each birthday. We developed a program to teach Joey how to end Birthday Parties. Of course all of this was after at age 5, because until then he couldn’t tolerate listening to the song ‘Happy Birthday’ at all.”

—BH, Parent

To investigate whether sensory factors might be a consideration with your loved one, an Occupational Therapist or other provider might use an age-appropriate form of the Sensory Profile or the Sensory Processing Measure (SPM). A sensory checklist and additional information are available at the Sensory Processing Disorder Foundation website. More information can be found here.

Support Systems and Environment—Family, Staff, Supports Dynamics

Change is difficult for any of us, but it may be more so for those who do not understand what changes are taking place and why. Consider potential contributing factors that might be leaving your loved one with autism feeling confused or anxious.

If challenging behaviors come on suddenly or intensify, it is important to ask what changes have occurred in his life. Have there been changes in schedules? School, work or residential placement? Changes in the family environment? A sibling heading off to college? Loss of a family member? Have there been changes in staff? Loss of a preferred staff member? If there is a behavior plan, is it being followed consistently? Perhaps new staff who need additional training or who employ methods that are stressful? Is there any concerning behavior in caregivers? What is their stress level?
Resources:

General:

Ask and Tell, Self-Advocacy and Disclosure for People on the Autism Spectrum
*Autism Solutions; How to Create a Healthy and Meaningful Life for Your Child,* Ricki G. Robinson, MD, MPH
National Autism Center’s A Parent’s Guide to Evidence-Based Practice and Autism

Behavior Function and Evaluation:

*Functional Behavioral Assessment and Positive Interventions: What Parents Need to Know*  
*How to Think Like a Behavior Analyst,* Jon Bailey and Mary Burch  
Parents’ Guide to Functional Assessment

*To Walk in Troubling Shoes: Another Way to Think About the Challenging Behavior of Children and Adolescents,* Bernic Fabry PhD, 2000

*Targeting the Big Three: Challenging Behaviors, Mealtime Behaviors, and Toileting*  
IBR Autism Speaks Family Services Grant Challenging Behaviors Curriculum

Skill Evaluation/Development:

*The ABLLS-R; The Assessment of Basic Language and Learning Skills,* James Partington and the AFLS too!

*Severe Behavior Problems: A Functional Communication Training Approach (Treatment Manuals for Practitioners),* V. Mark Durand

*Sensory Profile*  

*Sensory Processing Measure (SPM)*  
Medical/Medication:

Buie T, Campbell DB, Fuchs GJ, et al.,
*Evaluation, diagnosis, and treatment of gastrointestinal disorders in individuals with ASDs: a consensus report.*
[Consensus Development Conference, Journal Article, Research Support, Non-U.S. Gov’t]
http://pediatrics.aappublications.org/content/125/Supplement_1/S1.long

Buie, et al.
*Recommendations for evaluation and treatment of common gastrointestinal problems in children with ASDs.*
http://pediatrics.aappublications.org/content/125/Supplement_1/S19.long

Herbert, Martha,
*The Autism Revolution*
www.marthaherbert.org

Loschen, EL and Doyle, B,
*Considerations in the Use of Medication to Change the Behavior of People with Autism Spectrum Disorders*

*Psychotropic Medications in Children with Autism Spectrum Disorders: A Systematic Review and Synthesis for Evidence-Based Practice.*

Siegel, M,
*Psychopharmacology of Autism Spectrum Disorder: Evidence and Practice,*
Child and Adolescent Psychiatry Clinics of North America, 2012, in press,

Appendix 1

Ruth Elaine Hane, who was diagnosed with High Functioning Autism in 1995, lives in Minneapolis, with her husband and their two cats. Contributing author to *Ask and Tell, Self-Advocacy and Disclosure for People on the Autism Spectrum* and *Sharing Our Stories* and numerous other publications, Ruth Elaine mesmerizes audiences with her vivid memories of growing up in a large family without knowing the characteristics of autism. Born as a Rubella measles baby; unable to swallow or tolerate touch, Ruth Elaine did not talk until nearly five years old, when she began using full sentences with reciprocal language. Her strength lies in her unique view of how things are, and an insatiable desire to improve her life by learning to read faces and understanding complex nonverbal messages. Ruth Elaine mentors and coaches others, effectively teaching the skills she has learned, and serves on boards and task forces for many autism organizations. Presently she is focusing on developing her Face Window idea to work to overcome face blindness , by assisting in Child Psychology research at the Fraser Family Services and the University of Minnesota. Ruth Elaine is a gifted healer, utilizing Reiki Energy to balance the whole body system, believing that an underlying deficit in autism is an unbalanced whole-body system.
Appendix 2

Common "problem" behaviors and speculations about their causes

Ruth Myers, MD, James Salbenblatt, MD, Melodie Blackridge, MD

“High pain tolerance”
- A lot of experience with pain.
- Fear of expressing opinion.
- Delerium
- Neuropathy (disease of the nerves)/many causes

Fist jammed in mouth/down throat
- Gastroesophageal reflux
- Eruption of teeth
- Asthma
- Rumination
- Nausea

Biting side of hand/whole mouth
- Sinus problems
- Eustachian tube/ear problems
- Eruption of wisdom teeth
- Dental problems
- Paresthesias/painful sensation (e.g., pins and needles) in the hand

Biting thumb/objects with front teeth
- Sinus problems
- Ears/Eustachian tubes

Biting with back teeth
- Dental
- Otitis (ear)

Uneven seat
- Hip pain
- Genital discomfort
- Rectal discomfort

Odd unpleasurable masturbation
- Prostatitis
- Urinary tract infection
- Candidal vagina
- Pinworms
- Repetition phenomena, PTSD

Waving head side to side
- Declining peripheral vision or reliance on peripheral vision

Walking on toes
- Arthritis in ankles, feet, hips or knees
- Tight heel cords

Intense rocking/preoccupied look
- Visceral pain
- Headache
- Depression

Won’t sit
- Akathisia (inner feeling of restlessness)
- Back pain
- Rectal problem
- Anxiety disorder

Whipping head forward
- Atlantoaxial dislocation (dislocation between vertebrae in the neck)
- Dental problems

Left handed or fingertip handshake
- Frightening previous setting
- Pain in hands/arthritis

Sudden sitting down
- Atlantoaxial dislocation (dislocation between vertebrae in the neck)
- Cardiac problems
- Seizures
- Syncope/orthostasis (fainting or light-headedness caused by medication or other physical conditions)
- Vertigo
- Otitis (thrown off balance by problems in the ear)

Waving fingers in front of eyes
- Migraine
- Cataract
- Seizure
- Rubbing caused by blepharitis (inflammation of the eyelid) or corneal abrasion.

Pica
- General: OCD, hypothalamic problems, history of under-stimulating environments
- Cigarette butts: nicotine addiction, generalized anxiety disorder
- Glass: suicidality
- Paint chips: lead intoxication
- Sticks, rocks, other jagged objects: endogenous opiate addiction.
- Dirt: iron or other deficiency state
- Feces: PTSD, psychosis
Common "problem" behaviors and speculations about their causes continued

Ruth Myers, MD, James Salbenblatt, MD, Melodie Blackridge, MD

**General scratching**
- Eczema
- Drug effects
- Liver/renal disorders
- Scabies

**Self-restraint/binding**
- Pain
- Tic or other movement disorder
- Seizures
- Severe sensory integration deficits
- PTSD
- Parasthesias

**Scratching stomach**
- Gastritis
- Ulcer
- Pancreatitis (also pulling at back)
- Porphyria (bile pigment that causes, among other things, skin disorders)
- Gall bladder disease

**Scratching/hugging chest**
- Asthma
- Pneumonia
- Gastroesophageal reflux
- Costochondritis/“slipped rib syndrome”
- Angina

**Head banging**
- Pain
- Depression
- Migraine
- Dental
- Seizure
- Otitis (ear ache)
- Mastoiditis (inflammation of bone behind the ear)
- Sinus problems
- Tinea capitis (fungal infection in the head)

**Stretched forward**
- Gastroesophageal reflux
- Hip pain
- Back pain

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