



# Autism Spectrum Disorder-Specific Anticipatory Guidance

Endorsed by the American Academy of Pediatrics and the  
Society of Developmental and Behavioral Pediatrics

Developed in partnership with  
Health Resources and Services Administration  
Maternal and Child Health Bureau





# Autism Spectrum Disorder-Specific Anticipatory Guidance



## Abstract

Jack, a 3 ½ -year-old boy with an autism spectrum disorder (ASD), is brought in for a well-child visit. His mother reports he is having trouble in several areas common among children with ASD: sleep, toileting, and eating. You examine him and ask his mother some questions about his sleep habits, his diet, and efforts in toilet training. You offer ASD-specific anticipatory guidance to help his family address the problems he's having. Based on his mother's report of snoring, you refer him for a sleep study. You also give Jack a stool softener for constipation and ask that they stop toilet training for now. You schedule a follow-up appointment so you can devote more time to discussing these issues.

## Case Goal

Children with ASD present with similar development issues and challenges to typically-developing children, but special consideration may be needed when evaluating these issues and providing anticipatory guidance to families.

*After completion of this module, learners will be able to:*

1. Recognize some of the common developmental issues that present in children with ASD and how to evaluate them.
2. Identify management approaches and strategies for the common developmental issues seen in children with ASD.

## Three Steps to Prepare - In 15 Minutes or Less!

- 1 Read through the Facilitator's Guide and make copies of the case and learner worksheet for distribution.
- 2 Identify the key topics you wish to address. Consider:
  - Knowledge level of learners
  - Available time
  - Your familiarity with the subject
- 3 Select and prepare the optional teaching tools you wish to use. *Each case provides a variety of **optional materials to enhance the learning environment, support facilitator style, focus on different themes, or accommodate different time limitations. These materials are optional for facilitators to use at their discretion.***
  - Handouts: select any you wish to use and make copies for distribution
  - PowerPoint: decide if you wish to use and confirm necessary technical equipment
  - Video: review embedded video and video library, decide if you wish to use, confirm necessary technical equipment, and conduct test run

The following case was developed by the authors. It does not necessarily reflect the views or policies of the Department of Health and Human Services (HHS) or the Centers for Disease Control and Prevention (CDC).

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## Key Learning Points of This Case

1. *Recognize some of the common developmental issues that present in children with ASD and how to evaluate them.*
  - a. Describe the different types of sleep problems seen in children with ASD. (Prompt 1.1 and Handout I: Causes of Insomnia in Children with ASD)
  - b. Provide a differential diagnosis for feeding problems in children with ASD. (Prompt 2.2)
  - c. Describe the common challenges to toilet training in children with ASD. (Prompt 2.4)
2. *Identify management approaches and strategies for the common developmental issues seen in children with ASD.*
  - a. Describe behavioral strategies that may promote improved sleep in children with ASD (Prompt 1.5)
  - b. Identify the indications for using medications in the treatment of sleep difficulties (Prompt 1.6)
  - c. Recognize strategies to improve eating habits in children with ASD (Prompt 2.5)
  - d. Become familiar with techniques for toilet training children with ASD (Prompt 2.8)

## Only Have 30 Minutes to Teach? :30

Focus your discussion on sleeping patterns, feeding, OR toilet training. Use:

### **Sleeping Patterns**

- Prompts 1.1-1.8
- Handout I: Causes of Insomnia in Children with ASD

### **Feeding**

- Prompts 2.3 and 2.6

### **Toilet Training**

- Prompts 2.5 and 2.9

## Materials Provided

- Case Worksheet for Learners
- The Case Study: Part I, II, and III (available in Facilitator's Guide and on CD)
- Optional Teaching Tools
  - PowerPoint with Embedded Videos (available on CD)
  - Handouts (available in Facilitator's Guide and on CD)
    - Handout I: Handout I: Causes of Insomnia in Children with ASD
    - Handout II: Clinical Properties of Selected Medications Used for Pediatric Insomnia
    - Handout III: TEACCH Toilet Chart with Picture Icons
  - Video Library (available on CD)
- References

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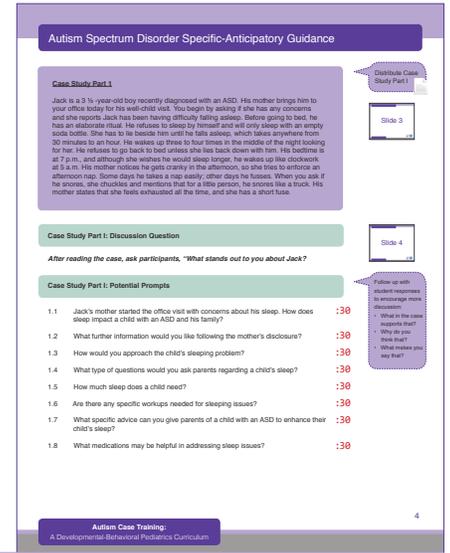
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## Getting Started

This case is designed to be an interactive discussion of a scenario residents may encounter in their practices. Participation and discussion are essential to a complete learning experience. This Facilitator's Guide provides potential prompts, suggestions for directing the discussion, and ideas for incorporating the optional teaching tools. It is not designed as a lecture.

Case study icons:

-  Call-out: step-by-step teaching instructions
-  Note: tips and clarification
-  Slide: optional slide, if using PowerPoint
-  Filmstrip: optional slide contains an embedded video
-  Paper: potential place to distribute an optional handout
-  :30 Digital clock: tips if you only have '30 Minutes to Teach'



## Why is This Case Important?

Anticipatory guidance is a vital component of pediatricians' work. Parents turn to their pediatrician for advice on how to deal with their child's needs and expect them to provide their expertise on a variety of issues. Families of children who have autism spectrum disorder (ASD) often feel alone because their child may not act like other children when going through different developmental stages. Being able to offer anticipatory guidance that is geared toward the child with an ASD is important for every primary care provider (PCP).

Introduce the session goal and format of the case study

This case discusses the use of medications, some which are off label, for which FDA approved uses are limited. A PCP may encounter a child with an ASD on one or more of these medications in the course of his/her practice. It is important to be aware of side effect profiles, contraindications and health monitoring in children on these medications. While these side effects should be monitored by the prescriber, the PCP needs to make sure these are monitored, be aware of the possible drug interactions with medications he/she will prescribe, and know the side effects so they can be considered in the differential diagnosis of symptoms brought to the PCP office for treatment.

Slide 1-2

## Cultural Competence

It is important for clinicians to understand how different childrearing practices and cultural norms may influence key decisions that parents make regarding their child including obtaining evaluations and treatment, future planning, and acceptance of the child's diagnosis. Clinicians can approach parents openly and honestly by asking them about their unique style of parenting and how the information or recommendations provided are received.

See the curriculum introduction for additional information on cultural competence and potential discussion questions.

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## Case Study Part 1

Jack is a 3 ½ -year-old boy recently diagnosed with an ASD. His mother brings him to your office today for his well-child visit. You begin by asking if she has any concerns and she reports Jack has been having difficulty falling asleep. Before going to bed, he has an elaborate ritual. He refuses to sleep by himself and will only sleep with an empty soda bottle. She has to lie beside him until he falls asleep, which takes anywhere from 30 minutes to an hour. He wakes up three to four times in the middle of the night looking for her. He refuses to go back to bed unless she lies back down with him. His bedtime is at 7 p.m., and although she wishes he would sleep longer, he wakes up like clockwork at 5 a.m. His mother notices he gets cranky in the afternoon, so she tries to enforce an afternoon nap. Some days he takes a nap easily; other days he fusses. When you ask if he snores, she chuckles and mentions that for a little person, he snores like a truck. His mother states that she feels exhausted all the time, and she has a short fuse.

Distribute Case Study Part I

Slide 3

## Case Study Part I: Discussion Question

*After reading the case, ask participants, “What stands out to you about Jack?”*

Slide 4

## Case Study Part I: Potential Prompts

- |     |   |     |
|-----|---|-----|
| 1.1 | Jack’s mother started the office visit with concerns about his sleep. How does sleep impact a child with an ASD and his family? | :30 |
| 1.2 | What further information would you like following the mother’s disclosure?  | :30 |
| 1.3 | How would you approach the child’s sleeping problem?  | :30 |
| 1.4 | What type of questions would you ask parents regarding a child’s sleep?   | :30 |
| 1.5 | How much sleep does a child need?   | :30 |
| 1.6 | Are there any specific workups needed for sleeping issues?  | :30 |
| 1.7 | What specific advice can you give parents of a child with an ASD to enhance their child’s sleep?                                | :30 |
| 1.8 | What medications may be helpful in addressing sleep issues?   | :30 |

Follow up with student responses to encourage more discussion:

- What in the case supports that?
- Why do you think that?
- What makes you say that?

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## Supporting Information for Potential Prompts

- 1.1 *Jack's mother started the office visit with concerns about his sleep. How does sleep impact a child with an ASD and his family?*

:30

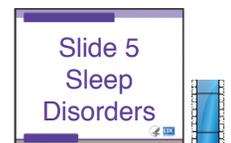
Sleep is a very common issue that all parents have to deal with on a nightly basis. Thirty percent of typically developing children are reported to have **sleep disorders**. Children on the autism spectrum appear to have a higher prevalence, as well as more severe sleep disturbances, compared with typically developing children.

On average, children with ASD are reported to have sleep problems 50-80% of the time. They experience a wide array of sleep problems, including:

- Difficulty falling asleep
- Restless or disrupted sleep patterns
- Early morning awakening
- Sleep parasomnias
- Snoring

Successfully addressing these issues is critical because quality of sleep is known to affect a child's overall functioning.

- Lack of sleep makes it difficult to attend and focus and has a negative impact on one's learning capacity.
- Disrupted sleep results in irritability and mood disturbance, further aggravating an already predisposed dysregulated behavior pattern, as commonly seen in children with ASD.
- Lack of sleep affects quality of life for the family as a whole. Parents themselves experience a disrupted sleep pattern, an additional strain on their already overwhelming task as caregivers.



- 1.2 *What further information would you like following the mother's disclosure?*

:30

It is always important to explore the strengths of a child with an autism spectrum disorder or developmental delays. Parents and clinicians may become so focused on the deficits, and in some cases the behavioral issues that a child is having, that they aren't able to notice what the child does well. By asking a family about what a child is good at, and what their positive traits are, one is able to frame recommendations for intervention and treatment in the context of these strengths. In addition, asking about what a child likes can be used when discussing next steps. Finally, in addition to exploring the strengths of the child, it is helpful to think about the strengths of the family and how these can be used when discussing options and next steps for treatment. If parents are unable to offer strengths and positive attributes of the child, it is important to acknowledge how difficult and stressful things seem for them at this time. It is always helpful for clinicians to take the time to note changes and improvements in functioning and positive features of the child, and narrate these observations to parents.

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## 1.3 How would you approach the child's sleeping problem?

:30

I. Causes of  
Insomnia in Children  
with ASD



Sleep disturbance is caused by interplay of intrinsic and extrinsic factors that need to be identified and addressed accordingly.

Pinpointing the physiologic and environmental elements that affect a child's ability to sleep well is essential in addressing the root of the problem. This could be done by obtaining a detailed sleep history, keeping in mind that children with ASD generally have more variations in their sleep patterns and more elaborate sleep rituals than their typically-developing peers.

It is important to have a clear idea of the child's **bedtime routine, sleeping habits, and sleep environment.**

- Parents usually employ a variety of tricks and techniques to help a child fall asleep more easily.
- Children themselves may have certain attachments or self-soothing strategies to fall asleep.
- Parents who co-sleep may not openly share this fact as they are wary of their doctor's disapproval. A thorough, but diplomatic approach is needed to identify all sleep-related factors.

Documentation of a child's actual sleep schedule is important in determining how much sleep a child is getting in a 24-hour period. Ask about a child's bedtime, wake-up time, and naptime.

- It is important to differentiate between the time the child is put to bed and when he actually falls asleep.
- Prolonged nighttime awakenings can significantly lessen the total amount of nighttime sleep a child is actually getting.
- It is important to identify any day-to-day variations in a child's sleep schedule, such as comparing weekdays to weekends, as this may be the reason why a child has difficulty falling asleep.

Sleep disturbance may take the form of sleep talking, sleep walking, restlessness, confusional arousal, night terror, or nightmares. Parents are usually able to describe such events in full detail.

Finding out if the child snores or has disrupted breathing patterns is crucial in determining whether further workup is necessary.

The bottom line is to figure out if the child is getting adequate and restful sleep. This can be determined in part by the ease with which a child wakes up in the morning and whether any daytime drowsiness is observed.

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## 1.4 *What type of questions would you ask parents regarding a child's sleep?*

:30

- Can you describe your child's sleeping environment?
- What is your child's bedtime routine? Does he/she need any specific toy or object to fall asleep?
- What is your child's sleep schedule?
  - What time do you put your child to bed? What time does he/she actually fall asleep?
  - Does your child wake up in the middle of the night? How long does it take before he/she falls back to sleep?
  - What time does your child wake up in the morning? How easy is it for you to wake him/her up? Does he/she spontaneously wake up?
  - Does your child take any naps during the day? What time and how long are his/her naps?
- Do you notice your child having any sleep disturbances?
  - Does he/she sleep talk or walk? Does your child have nightmares or night terrors?
  - Is your child a restless sleeper?
  - Does he/she snore? Do you notice any breathing difficulties while your child is sleeping?

## 1.5 *How much sleep does a child need?*

:30

Parents commonly complain that their child is not getting enough sleep. Inappropriate parental expectations about sleep requirements may feed into a child's disrupted sleep pattern. Putting a child in bed earlier than the natural time they are likely to fall asleep or enforcing a nap when a child is outgrowing this habit is counterproductive. This practice ends up in an unpleasant power struggle, placing additional strain on the parent-child interaction and further disrupting the child's sleep pattern. Having a clear understanding and realistic expectations of how much sleep a child needs to function optimally is crucial in avoiding this struggle.

Some children with ASD reportedly have a lower sleep requirement. This emphasizes the importance of obtaining a comprehensive sleep history to determine whether a child is getting sufficient sleep. If parents have a difficult time describing a child's sleep pattern, recommend they use a sleep diary/chart to help provide clear documentation of a child's day-to-day sleeping schedule

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## 1.6 Are there any specific workups needed for sleeping issues?

:30

Further workup is generally not indicated for the majority of sleep disturbances except for a number of clinical scenarios.

- Report of **snoring or any sleep-disordered breathing** definitely warrants further investigation with possibly a referral to an otolaryngologist or a sleep study to rule out obstructive sleep apnea (OSA). Vigilant surveillance for OSA is becoming even more important with the increasing prevalence of obesity among children. OSA is said to affect as many as 4% of children; it is as high as 20% - 30% in children who are obese.
- **A relationship between sleep disturbance and iron deficiency** in children with ASD has been reported. Iron therapy, in turn, has been shown to improve overall sleep in such situations. Therefore, for a child with an ASD reported to be restless during sleep, check the complete blood count, serum iron, total iron binding capacity, and ferritin level.
- For other sleep parasomnias, such as nightmares, sleep terrors, somnambulism, or sleep talking, further workup is unnecessary unless the presentation is indistinguishable from that of a **seizure**. Given the higher prevalence of epilepsy among children with ASD, it is important to rule out seizures.

## 1.7 What specific advice can you give parents of a child with ASD to enhance their child's sleep?

:30

The cornerstone of quality sleep is **proper sleep hygiene**. This includes creating an environment conducive to sleeping and following positive bedtime routines and a regular sleep schedule. Nevertheless, establishing proper sleep hygiene can be particularly difficult for children with ASD because of the challenging behavioral patterns specific to their diagnosis.

- **Safety** is a key component in creating the proper sleeping environment. This is especially true for a child with an ASD who has a tendency to wander or sleep walk. Suggest parents consider removing potentially harmful furniture, constructing a gate by the doorway, and using alarm systems.
- **Minimizing distractions** is also essential in establishing the proper sleep environment. Children with ASD tend to be very sensitive to auditory stimuli, so “white-noise machines” may be helpful to block out noises that can potentially disrupt a child’s sleep. Lights may be distracting for children with ASD, so a dark room can be helpful; a small nightlight can be used for a child who is afraid of the dark. Encourage parents to take some time with trial and error and use creative strategies.
- A **positive bedtime routine** is one that involves a quiet, calming activity like listening to music or reading a book. It should be brief, lasting no more than 20 minutes.
  - Although a fixed routine is ideal, children with ASD have a tendency of becoming overly fixated on routines to the point of refusing to go to sleep unless the specific routine is followed. It is therefore important to introduce minor variations

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to the routine every now and then to encourage flexibility.

- Children with ASD tend to become dependent on inappropriate sleep associations, like the presence of their parents, in order to fall asleep. It is essential for a child to **learn to fall asleep independently** and to be able to self-soothe and remain in bed for the entire duration of the night.

Children with ASD have been found to have a disrupted sleep schedule for a variety of reasons. They have an increased sleep onset delay, more frequent and longer nighttime awakenings, and decreased overall sleep duration.

- Inform parents of the importance of keeping a strict sleep schedule to increase the child's sleep efficiency. Bedtime, wake-up time, and naptimes should be kept the same from day to day. There should be no more than an hour's difference between weekdays and weekends, as any variation in timing can potentially affect sleep latency.
- Bedtime should be set close to the time a child is most likely to fall asleep, keeping in mind a child's actual sleep requirement and the fact that children with ASD tend to require less sleep. Ideally, the child should fall asleep within 15 minutes of being put to bed. Sleep latency of an hour or more is possibly an indication that the bedtime is too early.
- A child with an ASD who wakes up very early in the morning should not be left in bed lying awake for a prolonged period of time, as it can lead to more fragmented sleep during the night. If the family is not yet ready to start the day, safe games and activities can be made available in the room for the child to play quietly once he or she is awake.

Setting the stage for proper sleep entails a whole process; however, once it becomes a habit, things tend to flow smoothly and the process becomes second nature. This is particularly helpful for children with ASD given their preference for having fixed schedules. Ultimately, given the proven effectiveness and benefits of having good sleep hygiene, the effort and investment involved in establishing it is definitely a worthwhile endeavor.

A toolkit to help parents with sleep strategies has been developed through Autism Speaks Autism Treatment Network and can be downloaded by going to <http://www.autismspeaks.org/science/resources-programs/autism-treatment-network/tools-you-can-use/sleep-tool-kit>.

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## 1.8 What medications may be helpful in addressing sleep issues?

:30

Medication is rarely the first line of treatment; neither is it used in isolation when addressing sleep issues. Nevertheless, a trial of medication in conjunction with nonpharmacologic strategies is reasonable for refractory sleep issues after behavioral interventions have been exhausted.

When parents request medication to help with their child's sleep, be sure to discuss with them that there are no Food and Drug Administration (FDA)-approved medications for pediatric insomnia. That being said, research has been done on certain pharmacological agents like **melatonin** and **clonidine**, supporting their effectiveness in improving the sleep of children with ASD.

- **Melatonin** is neurohormone secreted by the pineal gland that is known to organize the body's circadian rhythm and thus help promote sleep.
  - A number of studies have shown that melatonin shortens sleep initiation latency, increases total sleep time, and improves sleep efficiency in children with ASD.
  - Given that it is relatively safe, well-tolerated, and readily available, it is something parents are generally willing to try. At most, the reported side effects are morning drowsiness and headaches.
  - Melatonin has a relatively short half-life and should be given approximately 30 minutes before the desired bedtime. For children with sleep-maintenance difficulties, controlled-released formulations are available. Liquid formulations and dissolvable strips are available for children who are unable to swallow pills.
- **Clonidine**, a centrally acting alpha-2 agonist, is another medication that has been studied to reduce sleep initiation latency and night awakening in children with ASD.
  - Clonidine should be used with caution because it can potentially cause bradycardia and hypertension. An EKG is usually done before initiation to ensure proper cardiac functioning. Once a child is on clonidine, it should not be discontinued abruptly because of possible rebound hypertension.
  - Transdermal patches are available for children who are unable to swallow pills; however, caution is warranted for children who have a tendency to eat nonedible items because of the risk of patch ingestion.

II. Clinical Properties  
of Selected Medications  
Used for Pediatric  
Insomnia



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## Case Study Part I: Discussion Question

*Before moving to Part II, ask participants, “What would you do next?”*

Slide 6

Distribute “Case Study Part II”

Slide 7

### Case Study Part II

Realizing that you must move on with the visit, you ask about Jack’s eating habits. Jack’s mother describes him as a picky eater who refuses to drink milk. He prefers to eat chicken nuggets, crackers, toast, cheese, and grapes, and he drinks mostly juice.

With such a limited diet, you ask whether he has problems with constipation or diarrhea. In fact, he is only stooling every few days, and his stools are very hard. Jack’s mother has been trying to toilet train him for the past six months without success. He has never had a bowel movement on the toilet. Recently, she started having him sit on the toilet once a day after dinner, right before his bedtime routine. Jack will urinate in the toilet when asked to do so, but does not go to the bathroom on his own to urinate.

## Case Study Part II: Discussion Question

*How would you approach Jack’s problem?*

Slide 8

## Case Study Part II: Potential Prompts

- 2.1 What are potential feeding problems for typically-developing children and children with ASD?
- 2.2 What further information would you like following the mother’s disclosure?
- 2.3 When evaluating a child with an ASD who has feeding issues, what medical problems should be considered before assigning a purely behavioral diagnosis? **:30**
- 2.4 When talking with a parent who complains that his/her child is a picky eater, what additional questions might you ask?
- 2.5 What would your next steps be if you suspect a nutritional deficiency? **:30**
- 2.6 What would you recommend to help a parent encourage positive eating habits? **:30**
- 2.7 What are some barriers children with ASD may encounter when toilet training?
- 2.8 What medical issues may impact the toileting process?
- 2.9 What might you recommend to Jack’s mother to help with toilet training? **:30**

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## **Supporting Information for Potential Prompts**

### *2.1 What are potential feeding problems for typically-developing children and children with ASD?*

Feeding problems are common in typically-developing children and can occur even more frequently in children with ASD. Specifically, when compared with children without ASD, children with ASD tend to:

- Refuse more foods
- Require more special utensils
- Require food be presented in specific ways
- Prefer food with less texture
- Eat fewer foods

In addition, children with ASD may have pica, compulsive eating, mouth packing, or gagging and emesis. They may also associate discomfort (e.g., from constipation) with a certain food if the pain occurred just before or after consuming the food. Thus, they will repeatedly refuse that particular food item.

### *2.2 What further information would you like following the mother's disclosure?*

It is always important to explore the strengths of a child with an autism spectrum disorder (ASD) or developmental delays. Parents and clinicians may become so focused on the deficits and, in some cases, the behavioral issues that a child is having that they aren't able to notice what the child does well. By asking a family about what a child is good at, and what their positive traits are, one is able to frame recommendations for intervention and treatment in the context of these strengths. In addition, asking about what a child likes can be used when discussing next steps. Finally, in addition to exploring the strengths of the child, it is helpful to think about the strengths of the family and how these can be used when discussing options and next steps for treatment. If parents are unable to offer strengths and positive attributes of the child, it is important to acknowledge how difficult and stressful things seem for them at this time. It is always helpful for clinicians to take the time to note changes and improvements in functioning and positive features of the child and narrate these observations to parents.

### *2.3 When evaluating a child with an ASD who has feeding issues, what medical problems should be considered before assigning a purely behavioral diagnosis?*

**:30**

Consider the following medical problems:

- GERD
- Dental pain
- Oral motor dysfunction
- Food allergy
- Lactose intolerance

Other problems to consider for a child with an ASD and feeding problems include:

- Developmental delay

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- Obsessions/rituals related to food (color, texture) and environment (silverware, plates)
- Anxiety
- Sensory issues
- Learned behaviors (parental response to escalating behavior)

2.4 *When talking with a parent who complains that his/her child is a picky eater, what additional questions might you ask?*

- What foods/drinks does your child typically consume?
- Do you have scheduled meals and snacks?
- Do you eat together as a family?
- Is your child consuming nonedible items (pica)?
- Are you worried about your child's nutrition?
- How do your child's food preferences affect mealtimes and family life?
- What foods does your child avoid?

2.5 *What would your next steps be if you suspect a nutritional deficiency?*

:30

Because children with ASD have narrow food preferences, there is a concern about malnutrition. Adequate evidence to support these concerns is lacking. However, questions about a particular nutrient deficiency (e.g., iron) may require further evaluation.

Your history and physical exam will determine your diagnostic evaluation and treatment plan.

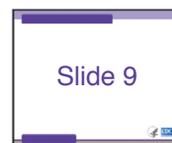
- If you suspect a nutritional deficiency, such as anemia, you may consider laboratory studies to evaluate for this.
- A nutrition consult may be helpful to determine a child's nutritional needs and make recommendations to the family. Providing the family with strategies to promote healthy eating habits is essential for the picky eater.
- For severe feeding problems (i.e., resulting in failure to thrive), you may need to employ the help of trained professionals in this area. These can include psychologists, occupational therapists, and speech therapists who are often part of a multidisciplinary team that specialize in feeding problems.

2.6 *What would you recommend to help a parent encourage positive eating habits?*

:30

Encourage parents to establish routine meal and snack times. At mealtime, parents should:

- Minimize distractions (i.e., shut off TV, telephone)
- Keep meals calm and strive for an enjoyable experience
- Adults should sit down with children and eat the same foods
- Offer the child what everyone else is eating, but also provide one of their preferred foods
- Refrain from pleading and threatening to get the child to eat
- After the family is finished, allow the child to leave the table
- Food should not be provided until the next scheduled meal/snack



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### 2.7 *What are some barriers children with ASD may encounter when toilet training?*

For typically-developing children, toilet training usually begins between 2 and 3 years of age, and a child-oriented approach is usually recommended.

- Readiness signs for toileting include an interest when others use the bathroom, a desire to be clean when soiled, and an awareness of stooling that may be verbalized to parents or may result in hiding during bowel movements.
- Children should also have the motor skills to get to the toilet (able to walk) and pull down their pants/underwear. A child's motivation to toilet train is highly regarded, and parents often use a social reward system to reinforce appropriate toileting behavior.

There are several **barriers to toilet training children with ASD**.

1. Most obvious may be their communication delays, which inhibit their ability to verbalize when they have soiled or if they need to use the bathroom.
2. In addition to expressive language delays, they may have difficulties with language comprehension. Therefore, they may not understand what is expected of them for the toileting process.
3. A social reward system, used in typically-developing children, is ineffective for children with ASD because of their difficulties with social relationships. During the toileting process, typically-developing children are praised for toileting in the potty and have a sense of accomplishment for a job well done. Children with ASD may not possess the social motivation to please their parents by stooling in the toilet. They may not understand the difference between their diaper and the toilet.
4. A strict adherence to routines can also make toileting difficult. Children with ASD often have difficulty with changes in their routine, so adding toileting to their daily schedule can be disruptive.
5. Many sensory issues can arise during the toileting process.
  - Sitting on the toilet seat unclothed is a new experience that may require a gradual approach (see prompt 2.9 for techniques).
  - They may be hyposensitive to toileting cues (urge to defecate) making it difficult to rely on their own body's signals for using the toilet.
  - Flushing the toilet may be an issue if they are overly sensitive to sound.
6. Because of the many new experiences that go along with toileting, children with ASD can become very anxious about the entire process. Thus, adding another barrier to successful toilet training.

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## 2.8 What medical issues may impact the toileting process?

For any child with toileting problems, it is important to rule out constipation as a contributing problem. As constipation is a frequent issue, ask parents about it regularly.

- Remember to review the child's medication list for potential side effects (e.g., constipation with atypical neuroleptics).
- Other medical problems to consider include urinary tract infections, tethered cord, or possible sexual abuse or trauma (may result from self-stimulation behavior).

## 2.9 What might you recommend to Jack's mother to help with toilet training?

Toilet training is an important milestone for any child to reach, but it can be especially challenging for a child with an ASD. Providing careful guidance to the family of a child with an ASD can make this process less difficult. When addressing toileting issues for a child with an ASD, there are several techniques that can be employed, including timed sitting, visual supports such as picture icons, and awareness of sensory issues. There are resources available to families (e.g., Toilet Training for Individuals with Autism and Related Disorders by Maria Wheeler).

If the child with an ASD is not able to communicate the need to use the bathroom, timed sits can be introduced.

- For several days before having the child sit on the toilet, the parent or caregiver should record the child's bowel habits – times that the child stools and frequency of wet diapers. With this information, they can identify patterns to the child's stooling.
- Have the child sit on the toilet fully clothed then gradually remove clothing with subsequent sits. Provide some type of positive reinforcement for cooperative sitting on the toilet, such as a favorite book or toy. A time can be used to help the child know how long they are expected to sit there.

Children with ASD usually respond better to visual cues than to verbal ones.

- Breaking down the steps of toileting into pictures can help the child understand what is expected of them.
- Parents can use standard pictures or they may take pictures of their child going through the different steps and use those.
- Parents can post a photograph of a toilet around the house and encourage the child to point to it when he or she needs to go.

A toileting toolkit has been created by Autism Speaks Autism Treatment Network to help families address the needs of a child with an ASD. The toolkit can be downloaded by going to <http://www.autismspeaks.org/science/resources-programs/autism-treatment-network/atn-air-p-toilet-training>.

III. TEACCH  
Toileting Chart

:30



# Autism Spectrum Disorder-Specific Anticipatory Guidance

Distribute "Case Study Part III"

## Case Study Part III – Epilogue

You are concerned about the history of constipation and ask Jack's mother a few more questions while you perform the physical exam.

- Has he had any diarrhea (i.e., overflow leakage of stool associated with constipation)?
- Is there blood with the stools?
- Can she tell, or can Jack communicate, whether he experiences pain with the bowel movements?
- What has she tried to help the constipation?

He has not had any recent diarrhea or blood with his stools. She is unsure whether he is having pain with bowel movements because he goes in his diapers. She thought the fruit juice would help, so she lets him have it whenever he asks.

Your abdominal physical exam is normal, although Jack was slightly uncooperative. You decide to defer the rectal exam.

You give Jack a stool softener and ask his mother to stop toilet training at this time. You schedule a follow-up appointment so you can devote more time to discussing Jack's diet, toileting issues, and sleep. You also refer him to an otolaryngologist for evaluation of possible sleep apnea.

Slide 10

## Case Study Part III – Epilogue: Discussion Questions

*How would you apply the information in this case?*

*What did you learn through this case?*

Slide 11

## Case Study Part III – Epilogue: Potential Prompts

- 3.1 Based on this history, can you identify 3–4 problems/issues going on with Jack? Which one(s) should you address first?
- 3.2 What further information would you like following the mother's disclosure?
- 3.3 Is there a relationship between ASD and gastrointestinal problems?
- 3.4 How might Jack's problems with sleeping, feeding, and toileting be related?

# Autism Spectrum Disorder-Specific Anticipatory Guidance

## Supporting Information for Potential Prompts

- 3.1 *Based on this history, can you identify 3-4 problems/issues going on with Jack? Which one(s) should you address first?*

Based on Jack's history, constipation seems to be a significant problem that should be addressed first. Constipation is a common problem in children and should be addressed in a timely manner. In Jack's case, constipation may be a result of multiple factors, including a diet low in fiber and toileting refusal. Additional concerns raised by the history include problems with sleep, picky eating, and toileting.

- 3.2 *What further information would you like following the mother's disclosure?*

It is always important to explore the strengths of a child with an autism spectrum disorder (ASD) or developmental delays. Parents and clinicians may become too focused on the deficits and, in some cases, the behavioral issues that a child is having that they aren't able to notice what the child does well. By asking a family about what a child is good at, and what their positive traits are, one is able to frame recommendations for intervention and treatment in the context of these strengths. In addition, asking about what a child likes can be used when discussing next steps. Finally, in addition to exploring the strengths of the child, it is helpful to think about the strengths of the family and how these can be used when discussing options and next steps for treatment. If parents are unable to offer strengths and positive attributes of the child, it is important to acknowledge how difficult and stressful things seem for them at this time. It is always helpful for clinicians to take the time to note changes and improvements in functioning and positive features of the child and narrate these observations to parents.

- 3.3 *Is there a relationship between ASD and gastrointestinal problems?*

No clear relationship has been established between ASD and gastrointestinal (GI) problems. Most of the research in this area has been from specialty clinics without an appropriate control sample and has relied on parental recall or medical records. Based on these reports, the prevalence of GI symptoms in children with ASD is between 9% and 91%. The GI symptoms frequently reported are bloating, abdominal discomfort, diarrhea, and constipation.

- The Autism Treatment Network Gastroenterology Committee recently reported atypical symptoms, such as self harm, may indicate constipation in children with ASD. They recommend evaluation for an underlying cause of constipation when appropriate and treatment should be provided. Close follow-up should also occur to monitor for treatment tolerance and effectiveness.
- There are many causes of constipation in children. It can occur when the diet is very limited, particularly when it is low in fiber. Children with ASD are often described as picky eaters (as in our case study) and therefore may not be eating enough fiber. Diet modification therapies, such as gluten-free/casein-free diets, also limit the variety of foods a child eats.
- Another cause for constipation in children with ASD is resistance to toilet training. Their lack of social awareness, communication skills, and behavior problems (i.e., rigidity, sensory issues) pose unique challenges to toilet training.

Handout IV

# Autism Spectrum Disorder-Specific Anticipatory Guidance

Treatment of constipation in children with ASD should include both medical management and behavioral intervention.

- Depending on the severity of the constipation, several medications can be used, including stool softeners, bowel stimulants, laxatives, and enemas.
- Manipulation of the diet should include increasing the fiber content and fluid intake.
- Behavioral management may address parental education regarding a child's normal bowel habits and appropriate toilet training techniques.
- Follow up should be arranged to assess improvement in GI symptoms and development of an ongoing plan to prevent recurrence.

Handout IV

When dealing with a child with an ASD and GI complaints, families play an important role in the treatment plan as they know their child best and how they may react to certain treatments (e.g., enemas).

## 3.4 *How might Jack's problems with sleeping, feeding, and toileting be related?*

Each of these issues is commonly seen in children with ASD. Therefore, they are important issues to address in ongoing care of children.

- Constipation is a common problem in pediatrics and can occur in children with ASD.
- Certain factors such as a limited diet or toileting difficulties, which are common in children with ASD, can predispose a child to having constipation.
- Constipation, which may be associated with discomfort, can disrupt normal sleep patterns.
- Sleep is a common problem for all children, but especially for children with ASD.

Slides 12-13

## Case Worksheet for Learners

### Case Goal

Children with autism spectrum disorder (ASD) present with similar development issues and challenges to typically developing children, but special consideration may be needed when evaluating these issues and providing anticipatory guidance to families.

### Key Learning Points of This Case

1. *Recognize some of the common developmental issues that present in children with ASD and how to evaluate them.*
  - a. Describe the different types of sleep problems seen in children with ASD \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_
  - b. Provide a differential diagnosis for feeding problems in children with ASD \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_
  - c. Describe the common challenges to toilet training in children with ASD \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_
2. *Identify management approaches and strategies for the common developmental issues seen in children with ASD*
  - a. Describe behavioral strategies that may promote improved sleep in children with ASD \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_
  - b. Identify the indications for using medications in the treatment of sleep difficulties. \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_
  - c. Recognize strategies to improve eating habits in children with ASD \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_
  - d. Become familiar with techniques for toilet training children with ASD \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

### Post Learning Exercise

Read the article:

Kodak T, Piazza C. Assessment and behavioral treatment of feeding and sleeping disorders in children with autism spectrum disorders; *Child Adolesc Psychiatr Clin N Am.* 2008;17(4):887-905

## Case Study Part I

Jack is a 3 ½-year-old boy recently diagnosed with an ASD. His mother brings him to your office today for his well-child visit. You begin by asking if she has any concerns and she reports Jack has been having difficulty falling asleep. Before going to bed, he has an elaborate ritual. He refuses to sleep by himself and will only sleep with an empty soda bottle. She has to lie beside him until he falls asleep, which takes anywhere from 30 minutes to an hour. He wakes up three to four times in the middle of the night looking for her. He refuses to go back to bed unless she lies back down with him. His bedtime is at 7 p.m. and, although she wishes he would sleep longer, he wakes up like clockwork at 5 a.m. His mother notices he gets cranky in the afternoon, so she tries to enforce an afternoon nap. Some days he takes a nap easily; other days he fusses. When you ask if he snores, she chuckles and mentions that for a little person, he snores like a truck. His mother states that she feels exhausted all the time, and she has a short fuse.

## Case Authors

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- **Anna Maria S. Ocampo**, MD, Children's Hospital Boston, Harvard Medical School

### Case Study Part II

Realizing that you must move on with the visit, you ask about Jack's eating habits. Jack's mother describes him as a picky eater who refuses to drink milk. He prefers to eat chicken nuggets, crackers, toast, cheese, and grapes, and he drinks mostly juice.

With such a limited diet, you ask whether he has problems with constipation or diarrhea. In fact, he is only stooling every few days, and his stools are very hard. Jack's mother has been trying to toilet train him for the past six months without success. He has never had a bowel movement on the toilet. Recently, she started having him sit on the toilet once a day after dinner, right before his bedtime routine. Jack will urinate in the toilet when asked to do so, but does not go to the bathroom on his own to urinate.

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- **Anna Maria S. Ocampo**, MD, Children's Hospital Boston, Harvard Medical School

### Case Study Handout Part III – Epilogue

You are concerned about the history of constipation and ask Jack's mother a few more questions while you perform the physical exam.

- Has he had any diarrhea (i.e., overflow leakage of stool associated with constipation)?
- Is there blood with the stools?
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- What has she tried to help the constipation?

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- **Anna Maria S. Ocampo, MD**, Children's Hospital Boston, Harvard Medical School

# Handout I: Causes of Insomnia in Children with ASD

Neurobiological (e.g., synaptic transmission deficiency, metabolism)

GABA

Melatonin

Behavioral

Inadequate sleep hygiene

Inappropriate sleep-onset association

Improper limit-setting

Coexisting neurologic disorders (e.g., epilepsy)

Coexisting medical disorders (e.g., gastrointestinal, gastroesophageal reflux disease)

Coexisting psychiatric disorder (e.g., anxiety)

Food and medications (e.g., caffeine, corticosteroids, bronchodilators)

Other sleep disorders

Obstructive sleep apnea

Restless leg syndrome

Periodic limb movements of sleep

Delayed sleep-phase disorder

Irregular sleep-wake rhythm

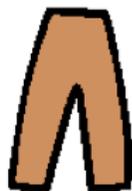
Johnson KP, Malow BA. Assessment and Pharmacologic Treatment of Sleep Disturbance in Autism. *Child and Adolescent Psychiatric Clinics of North America*; Vol 17;2008;pp. 773-785.

## Handout II: Clinical Properties of Selected Medications Used for Pediatric Insomnia

Drug	Side Effect
Alpha-2 agonist Clonidine	Dry mouth, dizziness, drowsiness, headache, sedation, fatigue, weakness, constipation
Antihistamines Diphenhydramine Bronpheniramine Chlorpheniramine Hydroxyzine	Daytime drowsiness, GI problems (appetite loss, nausea/vomiting), constipation, dry mouth), paradoxical excitation
Atypical antidepressants Trazodone	Dizziness, CNS overstimulation, cardiac arrhythmias, hypotension, priapism
Benzodiazepine receptor agonists Benzodiazepine Clonazepam Flurazepam Quazepam Temazepam Estazolam Triazolam	Residual daytime sedation, rebound insomnia on discontinuation, psychomotor/cognitive impairment, anterograde amnesia (dose dependent), impairment of respiratory function
Benzodiazepine receptor agonists Non-benzodiazepine Zolpidem Zaleplon Eszopiclone	Headache, retrograde amnesia, few residual next-day effects
Melatonin	Drowsiness and headaches
Synthetic melatonin receptor agonist Ramelteon	No significant side effects

Suggested Citation: Kralovic, S., Ocampo, A.M.S. Clinical Properties of Selected Medications Used for Pediatric Insomnia. Developed for the *Autism Case Training: A Developmental-Behavioral Pediatrics Curriculum*. 2011.

## Handout III: TEACCH Toileting Chart with Picture Icons



Pull down pants



Pull down underwear



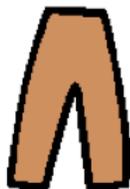
Sit on toilet



Use toilet paper



Pull up underwear



Pull up pants



Flush toilet



Go play

*Boswell S, Gray D. Applying Structured Teaching Principles to Toilet Training. TEACCH Autism Program website. 2006. <http://teacch.com/educational-approaches/applying-structured-teaching-principles-to-toilet-training-susan-boswell-and-debbie-gray>. Accessed January 21, 2013.*



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