

Taking the Work Out of Blood Work: Helping Your Patient with an Autism Spectrum Disorder

A Provider's Guide

INTRODUCTION TO AUTISM SPECTRUM DISORDERS (ASD)

Whether you work in a hospital or a physician's office, you may find yourself caring for children with Autism Spectrum Disorders (ASD). By preparing to meet the unique needs of each child, you can ensure a productive and less stressful visit. The purpose of this toolkit is to provide a guide to strategies that you and your practice can use to help children with ASD more easily complete routine medical procedures and blood draws while reducing the stress felt by your patients and their parents. Although completing phlebotomy with children with ASD is the main focus of these materials, the information and techniques presented here will apply to other aspects of a clinic visit (e.g., measuring vital signs, physical exams, developmental assessments) and may be helpful with persons of any age or developmental disability.

□ What Are Autism Spectrum Disorders (ASD)?

ASD are "spectrum disorders" and can range from mild to severe. Although individuals with ASD differ in the severity of symptoms and the exact nature of symptoms, they are likely to have challenges in three areas:

- **Communication.** This may include absent or limited speech. If they have speech, they may use it to recite or repeat words. They may have limited ability to use words to convey their wants or needs and limited ability to use them in conversation and social interaction.
- **Social Interactions.** Individuals with ASD have difficulty understanding social cues, e.g., tone of voice or facial expressions. They may also have difficulty maintaining eye contact.
- **Play and Routines.** Individuals with ASD are likely to engage in repetitive behaviors or have narrow and intense interests. Routine is also very important, and changes in routine may lead to anxiety or resistance. Another characteristic of ASD is what some describe as "sensory overload." For these individuals, sounds seem louder, lights brighter, or smells stronger.



□ Working With Patients With ASD

ASD may affect an individual's ability to communicate effectively, report medical conditions, self-regulate behaviors, and interact with others to get needs met. Simplifying language and using visual supports can improve communication between you and your patient with ASD.

All children can benefit from an organized approach to routine clinic procedures, but this is especially important for children with ASD. Patient flow, planning, and team communication are some of the key factors that can affect the experience that patients with ASD have in medical settings.

*For details, examples, and printable tools:
Visit kc.vanderbilt.edu/asdbloodwork/*

PREPARING FOR THE VISIT

□ Gathering Information

Contact families prior to visit. Talk with parents about accommodations that your clinic can provide to make the clinic visit a success. The parent may have comments on which strategies are more or less likely to be successful. Past experiences that were positive or negative are worth discussing with parents. You may want to provide families with a packet of patient information on preparing for venipuncture in patients with ASD (Parent information is available at kc.vanderbilt.edu/asdbloodwork/).

A phone call or a written questionnaire may be the best way to gather child-specific information (go to kc.vanderbilt.edu/asdbloodwork/ to obtain a sample triage questionnaire). Such a questionnaire can be used as a script for telephone triage, mailed to patients prior to the visit, or completed by patients in the waiting room. A questionnaire can be used to improve care for an individual patient or as a part of a quality improvement initiative to improve the performance of a clinic.

□ Quick Tips To Prepare For The Visit

- Schedule patients with ASD for the **first or last appointment of the day** (when the office is less busy).
- If the patient will require **multiple blood tests, consider coordinating with other providers** to complete all needed tests during one blood draw rather than multiple sticks.
- If the patient will be **sedated for a different procedure, considering scheduling the blood draw** while the patient is under sedation.
- A **brief written protocol** may help staff and practitioners become more coordinated in their approach to patients with ASD.
- Since many children with ASD have restricted or preferred **interests, find out ahead of time** what these might be. Ask the parent to bring an activity or toy that relates to this interest, which may help make the appointment run more smoothly.
- **Have a backup plan** determined before the procedure begins (e.g., when to stop the procedure, move more quickly, call for more assistance). Discuss all plans with the parent.
- **Set up equipment and all necessary materials prior** to the patient entering the room.
- Consider using **child-friendly equipment**, such as winged infusion sets that allow for more movement.

RESPONDING DURING THE VISIT

□ Accommodations

Children with ASD may need additional accommodations during clinic visits, such as:

- **Minimizing the waiting time** in environments that can be over-stimulating or anxiety provoking (e.g., busy waiting rooms, phlebotomy lab).
- **Setting up the room** so the patient is at the farthest point from the door and staff is positioned between the door and the patient to discourage elopement.
- **Ensuring that adequate resources are available.** Recruit additional staff to participate with complex patients.
- **Using visual supports** or Social Stories™ for patients who respond better to this type of communication; discuss with parent in advance of visit.
- Providing **appropriate distraction** toys that match the sensory needs of a particular patient.
- Having **appropriate rewards and reinforcers** available.
- Any additional accommodations based on parent input or the clinical team's experience with a particular patient.

□ Quick Tips For During The Visit

- **Remain calm and flexible.** Avoid appearing emotionally reactive or “frazzled” by the patient's behavior. Do not take the behavior personally.
- **Allow the child to feel they have some control** by allowing choice whenever possible (e.g., pick the color of a bandage or wrap).
- Consider **exposing the child to certain items** that he or she may have a strong reaction to before they are used in the procedure (e.g., allow them to see what the alcohol smells like, what the texture of the tourniquet feels like, etc.) based on parent's input of their child's sensory vulnerabilities.
- **Prioritize what is most important** to accomplish in this visit and avoid power struggles. Consider changing any aspects of the appointment that will get the patient to the next step successfully.
- **Explain what you are doing before you do it.** Check for understanding. Be direct about what you are doing and whether it will hurt, if the child asks.
- Use **simple, concrete language** in short sentences without idioms, irony, or metaphors.
- **Give direct requests** (e.g., “Please sit here” vs. “Why don't you come over here and sit?”)
- **Refer to the parent** for behavior management, communication, and patient preferences.

When To Change The Pace Of The Procedure

- In general, procedures should move quickly and efficiently to avoid escalation of anxiety or irritability.
- The clinical team will have to use judgment to determine if taking extra time to explain, distract, or comfort would be beneficial. Concerns about safety or comfort should prompt careful consideration.
- Taking a short break or slowing the pace of a routine procedure may be necessary.
- The team should discuss ahead of time the types of scenarios that would change the course of the procedure. For example, a child with increasing agitation may benefit from the implementation of guided relaxation techniques before proceeding.

When To Stop Or Reschedule The Procedure

Although the information that results from the phlebotomy and laboratory analyses may be clinically important, the clinical staff must constantly evaluate the benefits and risks of continuing a procedure.

For children with ASD, there are many reasons to consider discontinuing a routine procedure:

- **The results are not clinically essential.** Before ordering a test, a practitioner should consider how they will use the information for clinical decision making. The practitioner and the clinic team should be clear about the priority of the situation: routine, urgent, critical.
- **Insufficient staffing or equipment.** The clinic staff should consider discontinuing a procedure if there is not enough staff to safely execute a procedure or readily respond if additional help is needed. The child's parent is a critical part of the team, but it should not be assumed that the parent is physically able to help with the process.
- **Increasing agitation or aggression.** Increasing agitation or aggression may put the patient or staff members at serious risk for physical injury. If the risk cannot be alleviated, the procedure should be stopped. Additional equipment, additional staff, or additional planning may be necessary before re-attempting the procedure.
- Creating a **negative association** for future procedures. Completing a procedure despite the patient showing signs of severe anxiety or agitation may cause the patient to have a negative association with these types of procedures in the future. These feelings may extend to other procedures conducted at your practice and other medical settings and may make future medical visits difficult to complete and anxiety provoking for the patient.

PAIN MANAGEMENT

Children with ASD may not interpret or express pain in the same way as a typically developing child. Do not assume that this means that children with ASD have a high pain tolerance. Language problems may hinder a child's ability to tell you about the pain experienced. Their inability to communicate pain may result in increased frustration, anxiety, or challenging behaviors. Therefore, it is important to determine the best ways to monitor and address pain in order to ensure the comfort of your patients with ASD.

Monitoring Pain

Research has found that children with ASD display significant facial pain reactions, and these reactions are comparable to children without ASD [1] [2].

Although not typically monitored during routine clinic procedures like venipuncture, changes in vital signs also may reflect pain.

Facial Cues For Pain*

- Furrowed brow – eyebrows are lowered and pulled together
- Clinched eyes – partially closed eyes, tensed eyelids, and/or blinking
- Flared nostrils – nostrils dilate
- Grimaces – may include lips being vertically stretched, jaw dropping open, upper lip rising to expose upper teeth, cheeks rising to scrunch the area under the eyes

*Adapted from Postoperative Pain Expression in Preschool Children: Validation of the Child Facial Coding System [3].

Preventing And Treating Pain

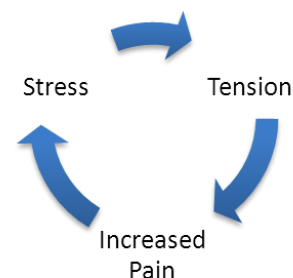
The approaches for treating pain include the injection of local anesthetics, the topical application of anesthetic gels or creams, and topical application of vapocoolant sprays.

Because there is a large psychological component to pain perception, relaxation and distraction techniques play an important role.

Behavioral Strategies: Relaxation

When children with ASD think about going to the doctor, many become worried about the visit. You can help by teaching your patient simple relaxation techniques.

Research shows that stress leads to increased tension, which contributes to higher levels of pain:



□ How You Can Help

Relaxation can significantly reduce children's stress and pain.

To help keep your patient calm during a procedure or visit, you can use, or coach the parent to use, simple relaxation and distraction techniques. Visit kc.vanderbilt.edu/asdbloodwork/ for scripts, examples, and visual materials to support implementation of these techniques.

□ Relaxation For Patients With ASD

Professionals may find that typical approaches to applying relaxation techniques are not always effective in working with children with ASD. The approaches that follow have been modified to address the aspects of relaxation that are sometimes difficult for individuals with ASD.

□ Ways To Use Relaxation During Blood Draws

- **Deep Breathing.*** Teach your patient to take a deep breath, hold the breath for a few seconds and then release it. For young children, blowing a pinwheel or bubbles can help them focus on their breathing and distract from their stress.
- **Muscle Tensing.*** This is a method of having your patient relax by focusing on different muscles of the body and alternatively tensing and relaxing them one at a time.
- **Visualization.** Encourage the child to imagine something nice and visualize that scene with eyes closed. Tell the child to think about the smells, sounds, and touch of what is imagined. Parents may use pictures or objects to remind their child of favorite places or activities to help this strategy be more successful.

*** IF YOUR PATIENT HAS LOST CONSCIOUSNESS DURING PRIOR BLOOD DRAWS, DEEP BREATHING OR MUSCLE RELAXATION MAY BE CONTRAINDICATED.**

Visit kc.vanderbilt.edu/asdbloodwork/ for more information and printable tools.

BEHAVIORAL STRATEGIES: DISTRACTION

□ What Is Distraction?

Distraction may help by taking a patient's mind off stressful events, thoughts, or emotions and putting attention on other positive thoughts or activities.

□ How To Use Distraction With Patients With ASD

- **Get to know the patient.** Ask the family about what the patient is interested in or what holds his or her attention (e.g., a favorite toy, a particularly engaging topic of conversation, a game that does not require movement).
- **Encourage parents to engage their child** in distracting activities before the procedure begins.
- **Play their favorite** music or video or sing a silly song.
- Have **toys or distracting objects** (e.g., anything with sensory properties) available and/or ask families about topics that are especially engaging to the patient.
- Encourage your staff to **begin engaging the patient in distracting activities**, toys, or topics of conversation before the procedure begins, and if possible, before the patient becomes upset.

BEHAVIORAL STRATEGIES: VISUAL SUPPORTS

Visual supports are evidenced-based strategies to supplement verbal communication through nonverbal and visual means. They can be photographs, drawings, objects, written words, or lists.

□ Why Visual Supports Are Important

Visual supports can:

- Assist in more effectively communicating expectations during medical procedures and provide a more concrete and motivating reward for compliance
- Clarify the activities that will occur and decrease frustration and problem behaviors that may be a result of misunderstanding during medical procedures
- Establish predictability, reduce anxiety, and promote more effective coping during a medical visit

Two examples of ways to use visual supports to aid your patient with ASD in effectively tolerating medical procedures are **First-Then Boards** and **visual schedules**.

FIRST
Doctor visit



THEN
Playground



A **First-Then board** is a visual display that motivates patients to engage in medical procedures that are not preferred by clarifying the preferred items/activities that will be available after it is over.

FIRST
Feel pinch



THEN
Play with cars



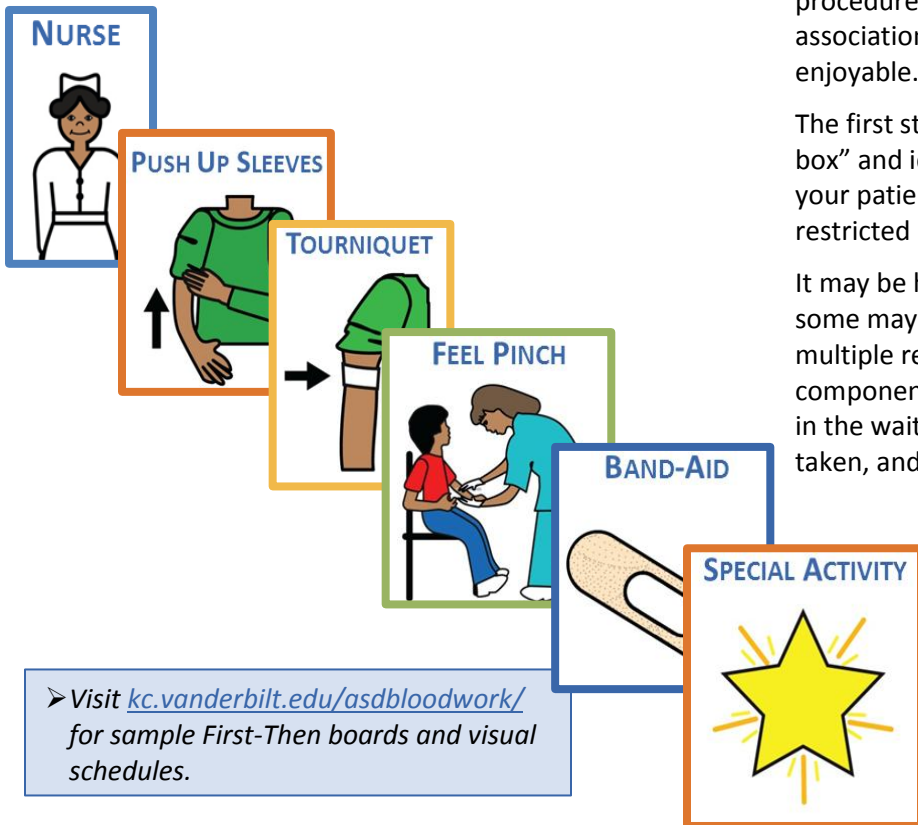
➤ How To Use A First-Then Board

- 1) **Determine what task you want your patient to complete** (what goes in the “First” box) and choose the item or activity (what goes in the “Then” box) that he or she can realistically have access to immediately following the “First” task.

Depending on the need of the patient, this can be the general overall procedure (e.g., “First go to the doctor, Then playground”) or can be broken down to specific tasks during the process that can each be paired with reinforcement.
- 2) **Show the board to your patient with a very brief statement** (“First take temperature, Then candy”) before starting the “First” task. If needed, refer to the board while the child is doing the task (“One more minute, then candy”).
- 3) As soon as the “**First**” task is over, refer back to the **board** (“All done with the doctor, now the playground!”) and immediately provide access to the “Then” activity.

☐ What Is A Visual Schedule?

A visual schedule is a visual representation of what is going to happen throughout the day or within a task or activity. Specifically related to medical procedures, it is helpful in decreasing anxiety and rigidity surrounding transitions by communicating when certain activities will occur throughout the day or during the appointment.



☐ How to Use a Visual Schedule

- Choose the activities that you will include on the schedule. Try to mix in preferred activities with non-preferred ones.
- Assemble the visuals on the schedule in the order that they are likely to happen. This can be a portable schedule such as a binder or clipboard. The schedule should be visible and available to the individual prior to the beginning of the first activity on the schedule and continue to be available throughout the remaining activities.
- When it is time for an activity on the schedule to occur, let your patient know with a brief verbal instruction at the beginning of the next activity. When that task is completed, tell your patient to check the schedule again and transition to the next activity. Some children may respond best to breaking down each task that will occur during the procedure in a very detailed way. This may make other children more anxious and, for that child, a more general schedule might be more appropriate.
- Provide praise and/or other reinforcement to the patient for following the schedule, transitioning between activities, and completing activities on the schedule. Place a preferred activity at the end of the schedule in order to provide the patient with something positive to focus on and motivation to complete the items on the schedule.

BEHAVIORAL STRATEGIES: REINFORCERS

☐ Using Reinforcers With Patients With ASD

Use specific reinforcers when conducting medical procedures with children with ASD in order to provide an association between these procedures and something that is enjoyable.

The first step in choosing reinforcers is to think “outside the box” and identify things that are specifically motivating to your patient. They may relate to your patient’s sensory or restricted interests. Ask the parent for ideas.

It may be helpful to identify 3 to 5 reinforcers to use since some may not be available the day of the procedure and/or multiple reinforcers may be needed during the different components of the procedure (e.g., one reinforcer for sitting in the waiting room, providing another for getting vitals taken, and providing a third for completing the blood draw).

Continued on the next page...

➤ **If I know my patient's sensory interests, what are some examples of items to consider for reinforcers?**

- **Visual.** Portable television/DVD player, portable video games, light-up items, mirrors, bubbles, items that spin/twirl, pouring water or squeezing water from a sponge to watch it drip, slinky
- **Auditory.** Music/headphones, sound-producing toys
- **Vestibular.** Swinging, rocking, jumping on trampoline, tickling, trip to playground
- **Tactile.** Massager, feathers, Play Doh, lotion, ice pack, heating pad, shaving cream, water/sand table
- **Edible/Oral.** Candy, salty snacks, drinks, teething toy
- **Activity.** Elevator ride, playing board game, or a planned activity with the parent to occur after the visit
- **Social.** Praise, pat on the back, hug, smile, high five, special one-on-one time with a caregiver where the child gets to choose the activity

Tips For Using Reinforcement During Blood Draws

- Choose a reward that your patient does not always have available and is novel enough to be motivating during something like a blood draw.
- Give reinforcement as soon as you can. If this is not possible, provide some type of visual way to let your patient know that the reward is coming soon (e.g., a picture of the activity, a token).
- Be clear about what the reward is and exactly what your patient did to earn it (e.g., sat still, walked in without help).
- Always follow through and provide the reward you promised.

What if challenging behaviors occur?

Continue to focus on the task and praise the aspects of the procedure that the child is completing. Rather than shifting attention to the unwanted behavior, provide a visual or a brief statement that tells the child what you would like for them to do (e.g., "Hold your arm out").

If you anticipate challenging behaviors, encourage the parent to introduce the strategies outlined in this pamphlet prior to the visit and to practice them during preferred daily activities.

REFERENCES AND RESOURCES

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WANT MORE INFORMATION?

Visit kc.vanderbilt.edu/asdbloodwork/ for tips and ideas for working with patients with ASD.

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RESOURCES ON AUTISM SPECTRUM DISORDERS

- www.autismspeaks.org
- www.autism-society.org
- kc.vanderbilt.edu

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