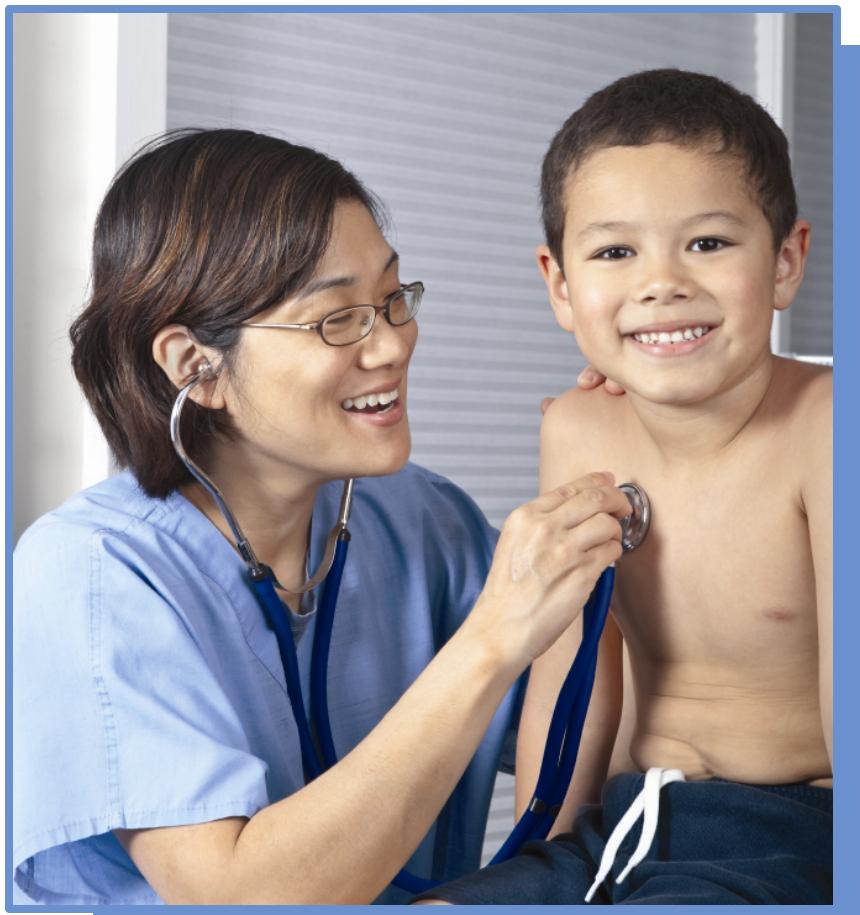


Taking the Work Out of Blood Work: Helping Your Patient With Autism



A Provider's Guide



These materials are the product of on-going activities of the Autism Speaks Autism Treatment Network, a funded program of Autism Speaks. It is supported by cooperative agreement UA3 MC 11054 through the U.S. Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Research Program to the Massachusetts General Hospital.

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INTRODUCTION TO AUTISM SPECTRUM DISORDERS

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. For details, examples, and printable tools, visit kc.vanderbilt.edu/asdbloodwork/

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.

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/).

➤ 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.** Individuals with ASD may have absent or limited speech. If they have speech, they may use it to recite or repeat words. They would 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; changes in routine may lead to anxiety or resistance. Another characteristic is what some describe as “sensory over-load.” For these individuals, a sound seems louder, lights brighter, and/or smells stronger.

➤ Quick Tips!

- Schedule patients with ASD for the first or last appointment of the day (when the office is less busy).
- 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.

A phone call or a written questionnaire may be the best way to gather child-specific information (see **Appendix A** 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.

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).
- 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.

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.

➤ Quick Tips!

- **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).
- **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 parent** for behavior management, communication, and patient preferences.

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

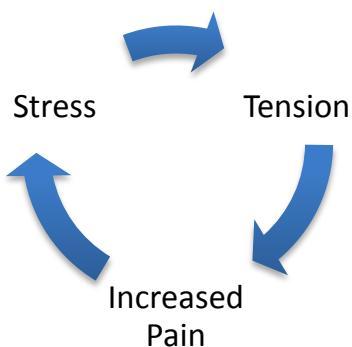
The approaches for treating pain include the injection of local anesthetics, the topical application of anesthetic gels or creams, and topical application of vapocoolant sprays.

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 the website below 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. See Appendix B for scripts and visuals to support deep breathing.
- **Muscle Tensing/Relaxing.*** 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. See Appendix C for a relaxation script and visuals.
- **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 the child has lost consciousness during prior blood draws, deep breathing or muscle relaxation may be contraindicated.*

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. See Appendix E for distraction tips.

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.
- 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.
- Visual supports can clarify the activities that will occur and decrease frustration and problem behaviors that may be a result of misunderstanding during medical procedures.
- Visual supports can establish predictability, reduce anxiety, and promote more effective coping during a medical visit.

Two examples of basic ways to use visual supports to aid your patient with ASD in more effectively tolerating medical procedures, specifically blood draws, are First-Then Boards and visual schedules. For printable visual supports, see Appendix F.

What Is A First-Then Board?

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-Then Board

FIRST	THEN	FIRST	THEN
 Feel pinch	 Play with cars	 Doctor visit	 Playground

Phlebotomy Toolkit for Providers Treating Children with Autism

How To Use A First-Then Board

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.

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”).

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?

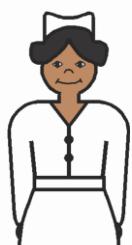
A visual schedule is a visual representation of what is going to happen throughout the day or within a task or activity. Specifically related to medical procedures, it is helpful in decreasing anxiety and rigidity surrounding transitions by communicating when certain activities will occur throughout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

How To Use A Visual Schedule

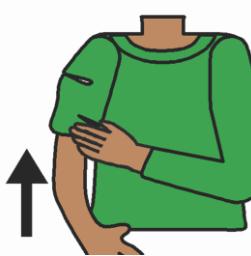
1. **Choose the activities that you will include on the schedule.** Try to mix in preferred activities with non-preferred ones.
2. **Assemble the visuals on the schedule in the order** that they are likely to happen. This can be a portable schedule such as a binder or clipboard. The schedule should be 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.
3. 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.
4. **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.

Visual Schedule

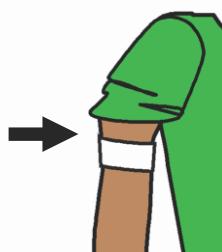
NURSE



PUSH UP SLEEVES



TOUNIQUET



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., providing one reinforcer for sitting in the waiting room, providing another for getting vitals taken, and providing a third for completing the blood draw).

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.

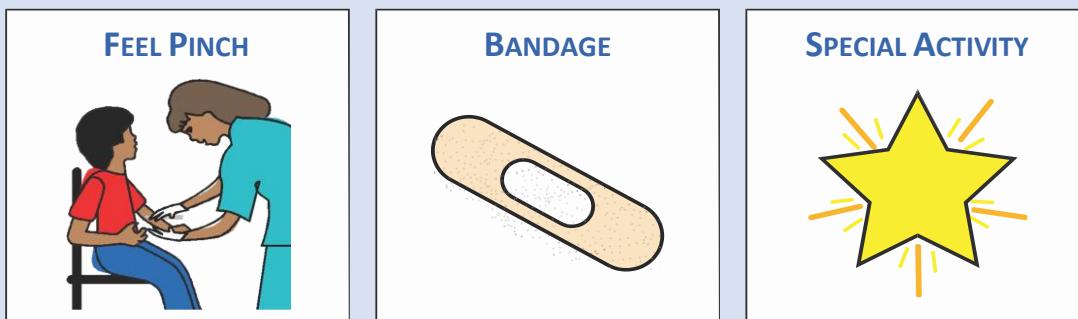
➤ **If I know my patient's sensory interests, what are some examples of items to consider for reinforcers?**

- **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 dough, 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

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 brief statements or a visual that tell 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.



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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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VANDERBILT KENNEDY CENTER

LEND—LEADERSHIP EDUCATION IN NEURODEVELOPMENTAL DISABILITIES

APPENDIX

APPENDIX A: TRIAGE QUESTIONNAIRE FOR ROUTINE CLINIC PROCEDURES

We are interested in helping your child's medical visit be a positive experience. We want to reduce any anxiety or discomfort your child may experience. Your answers to the questions below will help us tailor your child's visit to his/her individual needs.

Below is a list of items that describe children. For each item that describes your child now or within the past year, please circle 2 if the item is very true or often true of your child. Circle 1 if the item is somewhat or sometimes true. If the item is rarely or not true of your child, circle 0. Please answer all items, even if some do not seem to apply to your child.

0 = Rarely True or Not True 1 = Somewhat or Sometimes True 2 = Very True or Often True

0	1	2	My child appears anxious or upset when waiting in public areas.
0	1	2	My child appears anxious or upset in situations that are unfamiliar or unexpected.
0	1	2	My child appears anxious or upset around unfamiliar adults.
0	1	2	My child appears anxious or upset around objects that are noisy, bright, flashy, scented, or textured (specify _____).
0	1	2	My child appears anxious or upset during routine doctor's visits.
0	1	2	My child appears anxious or upset when having blood pressure taken.
0	1	2	My child appears anxious or upset when undergoing physical examinations.
0	1	2	My child appears anxious or upset when having blood taken.
0	1	2	My child faints or becomes lightheaded at the sight of blood or needles.
0	1	2	When upset or anxious, my child's behavior may be unpredictable (for example, aggression, self-injury, tantrums)
0	1	2	In the past, my child's reaction to a routine medical procedure has resulted in injury to my child.
0	1	2	In the past, my child's reaction to a routine medical procedure has resulted in injury to others.

Please answer the following questions.

1. What do you typically do to help your child relax in stressful situations?

2. Please share any additional comments or concerns you have about your child's pending medical visit:

APPENDIX B: DEEP BREATHING

Belly Breathing Instructions for Children with ASD:

1. Get comfortable. Lie on the floor or sit up straight.
2. Put one hand on your chest and the other hand over your belly.
3. Breathe in through your nose, 1...2...3...4. When you breathe in, feel your belly rise like a balloon blowing up. Watch your hand on your belly rise, while the hand on your chest stays still.
4. Breathe out slowly through your nose 1...2...3...4. Feel your belly go back in, like a balloon deflating.
5. Keep breathing like this a few more times.
6. The more you practice...the easier it will become!

Giving the child a visual—like a picture to pair with belly breathing, blowing bubbles or blowing a pinwheel--will help make practicing deep breathing more enjoyable and easier to follow. This can also provide a distraction during a stressful medical routine.

Note: If the child with ASD has lost consciousness during prior blood draws, check with a physician before using deep breathing or muscle relaxation.

Blowing Bubbles

This technique is simple, yet soothing. Have the child get comfortable (for example, lean back in a chair). First try blowing bubbles using quick, shallow breaths. Watch how the bubbles pop immediately.

Now practice blowing the bubbles using slow, deep breaths. The slower the child breathes out, the more bubbles he or she will make. Have the child focus on watching all the bubbles fall and repeat the process.

Pinwheel

Encourage the child to take a deep breath and blow out slowly on the pinwheel. See how long the child can make the pinwheel move – the longer he or she exhales, the longer the pinwheel will spin.

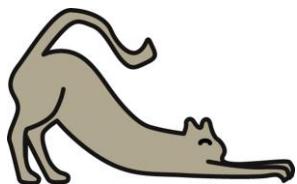
APPENDIX C: MUSCLE RELAXING TRAINING SCRIPT

When you feel tense, upset, or nervous, muscles in your body tighten. By practicing tensing certain muscles in your body, you will learn to relax them. Now get comfortable! (Note: If the child with ASD has lost consciousness during prior blood draws, check with a physician before using deep breathing or muscle relaxation.)



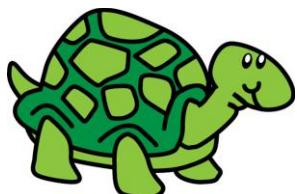
Hands and Arms: Squeeze a Lemon

Pretend you have a whole lemon in each hand. Now squeeze it hard. Try to squeeze all the juice out! Feel the tightness in your hand and arm as you squeeze. Squeeze hard! Don't leave a single drop. (*Hold for 10 seconds.*) Now relax and let the lemon drop from your hand. See how much better your hand and arm feel when they are relaxed.



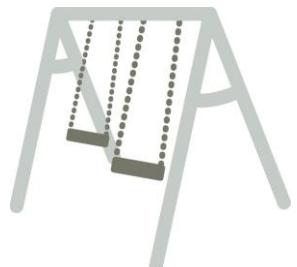
Arms and Shoulders: Stretch Like a Cat

Pretend you are a furry, lazy cat and you just woke up from a nap. Stretch your arms out in front of you. Now raise them way up high over your head. Feel the pull in your shoulders. Stretch higher and try to touch the ceiling. (*Hold for 10 seconds.*) Great! Let them drop very quickly and feel how good it is to be relaxed. It feels good and warm and lazy.



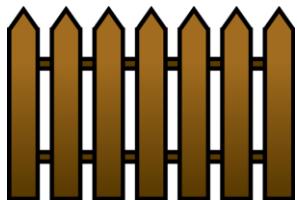
Shoulders and Neck: Hide in Your Shell

Now pretend you are a turtle. Try to pull your head into your shell. Try to pull your shoulders up to your ears and push your head down into your shoulders. Hold it tight! (*Hold for 10 seconds.*) Okay, you can come out now. Feel your shoulders relax.



Back: Swing up High

Pretend you are on a swing at the park. Swing your upper body back and forth, back and forth. To get really high, use your arms to help you swing! Keep swinging! (*Hold for 10 seconds.*) Great. You're all done on the swing. Sit back and relax.



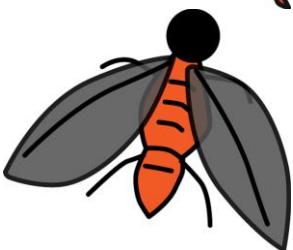
Stomach: Squeeze through a Fence

Now pretend that you want to squeeze through a narrow fence. You'll have to make yourself very skinny if you're going to make it through. Suck your stomach in, try to squeeze it against your back bone. Get it real small and tight. Hold it as tight as you can! (*Hold for 10 seconds.*) Okay, you've made it! You got through the fence. Settle back and let your stomach come back out where it belongs.



Jaw: Chew that Carrot

Now, pretend that you are trying to eat a giant, hard carrot. It is very hard to chew. Bite down on it as hard as you can. We want to turn that carrot into mush! Keep biting. (*Hold for 10 seconds.*) Good. Now relax. You've eaten the carrot. Let yourself go as loose as you can.



Face and Nose: Get That Fly off Your Nose

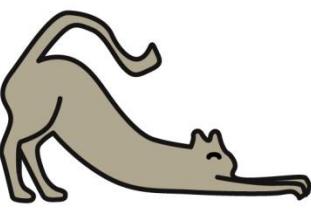
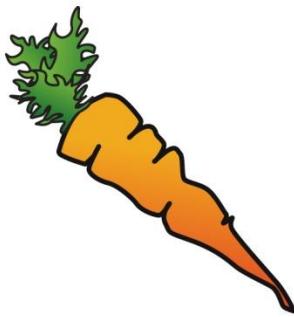
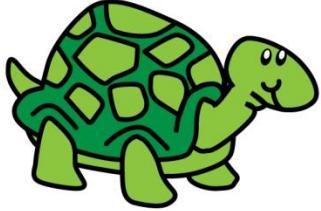
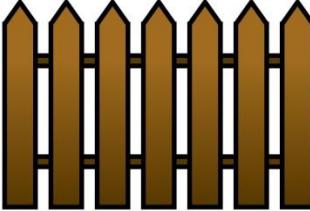
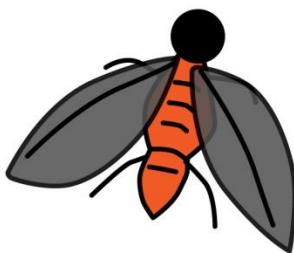
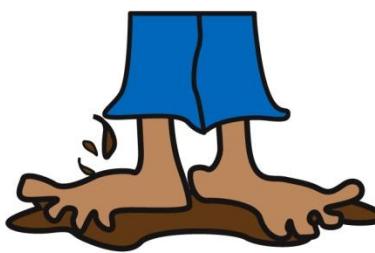
Here comes a pesky old fly and he has landed on your nose! Try to get him off without using your hands. Wrinkle up your nose. Make as many wrinkles in your nose as you can. Scrunch up your nose real hard and hold it just as tight as you can. Notice that when you scrunch up your nose, your cheeks and your mouth and your forehead and your eyes all help you and they get tight too. (*Hold for 10 seconds.*) Good. You've chased him away. Now you can just relax and let your whole face go smooth.



Legs and Feet: Squish your Toes in the Mud

Now pretend that you are standing barefoot in a big, fat mud puddle. Squish your toes down deep into the mud. Try to get your feet down to the bottom of the mud puddle. You'll probably need your legs to help you push. Squish your toes down. Push your feet, hard! (*Hold for 10 seconds.*) Okay, come back out now. Relax your feet, relax your legs, and relax your toes. It feels so good to be relaxed. No tenseness anywhere. You feel warm and tingly.

APPENDIX D: MUSCLE RELAXING PICTURE CHART

Squeeze a lemon 	Stretch like a cat 	Chew that carrot 
Hide in your shell 	Swing up high 	Squeeze through a fence 
Get that fly off your nose 	Squish your toes in the mud 	Relax 

APPENDIX E: IDEAS FOR DISTRACTION

The following are useful tools, toys, or ideas to have available in the clinic for use by patients and families during medical appointments.

Tips:

For medical appointments involving blood draws, the following distraction tools may be helpful:

- Sensory objects to put near the site of the blood draw (e.g., cold pack, vibrating toy)
- EMLA cream or sprays, if available
- Other additional, specific tools for blood draws (e.g., “Buzzy” buzzy4shots.com is used at some hospitals)

Characteristics of Good Distraction Supplies:

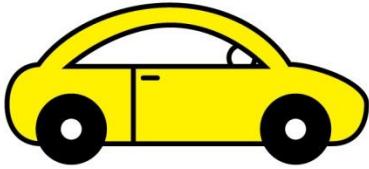
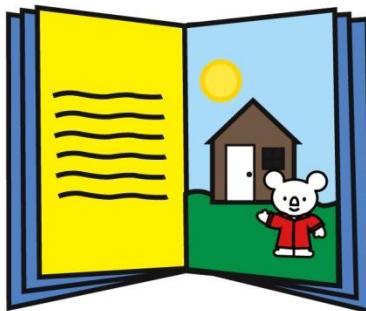
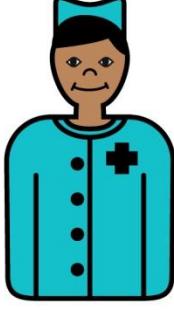
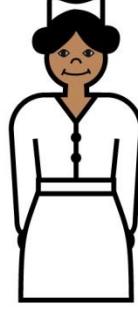
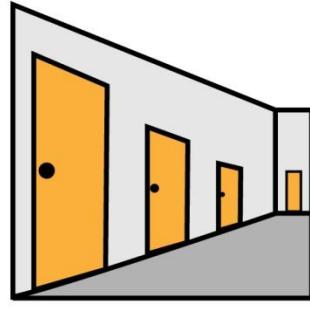
- Familiar and liked by patient
- Stimulating and novel
- Portable
- Allowed in hospital or clinic rooms
- Can be used with minimal movement by patient (and with one hand, if possible)
- Able to sustain child’s attention

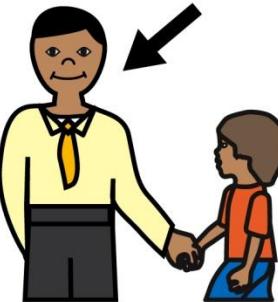
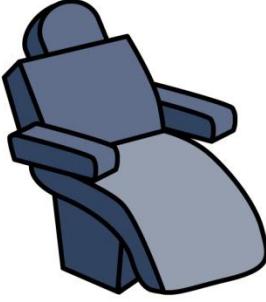
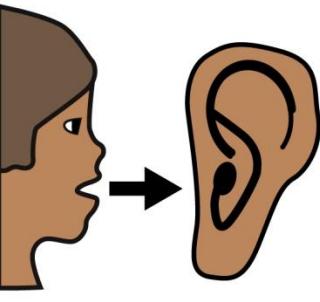
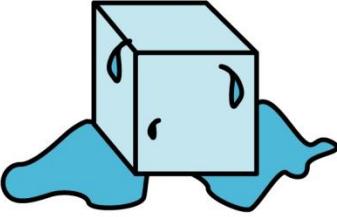
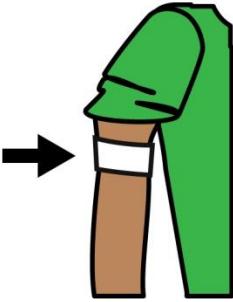
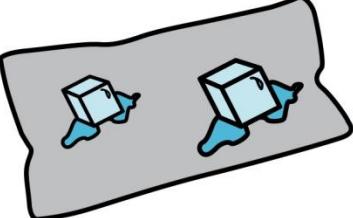
Examples of Good Distraction Supplies

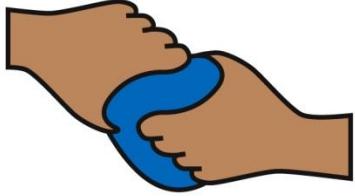
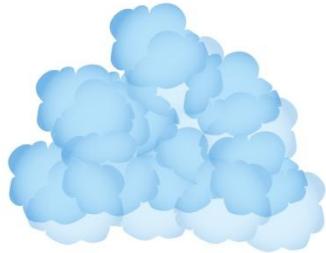
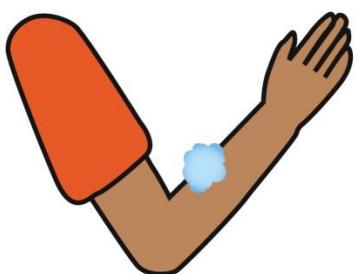
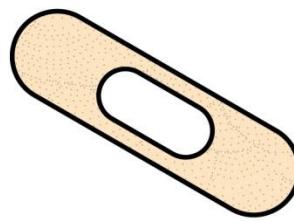
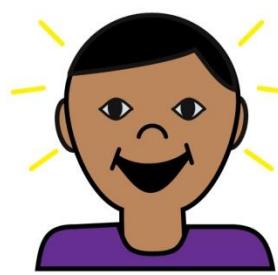
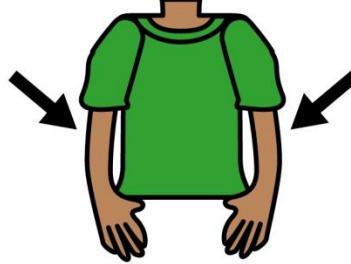
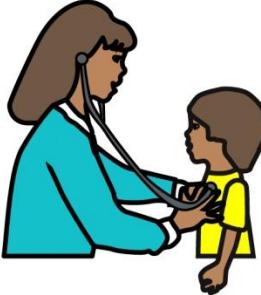
- Portable device to play videos or music that the patient likes
- Games that require little or no movement that the patient likes (e.g., Rock, Paper, Scissors)
- Laughter (e.g., a game where you think of different types of laughter and imitate what they might sound like)
- Favorite toys or stuffed animals that can sustain attention
- Toys that are visually stimulating (e.g., toys that light up, pinwheels, colorful toys)
- Tactile toys or objects (e.g., toys with interesting textures, stress squeeze balls, toys that vibrate)
- Novel toys that are visually interesting, make innocuous noise, or are tactile (e.g., rain sticks, glow sticks, relaxation toys, bubbles)
- Relaxation techniques (e.g., deep breathing or progressive muscle relaxation) can also be distracting
- Topics of interest to the patient. Often patients with ASD will have a restricted interest. Engaging the patient in conversation about this topic can be distracting (e.g., trains, elevators, a particular television show or movie)

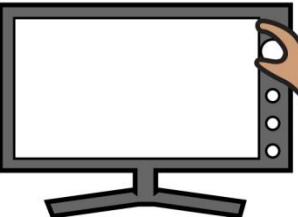
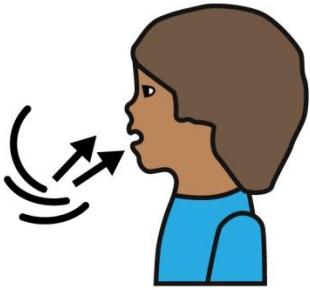
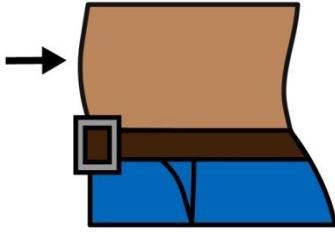
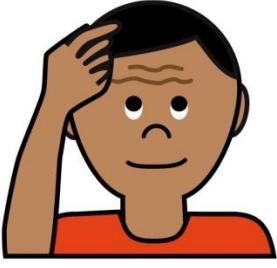
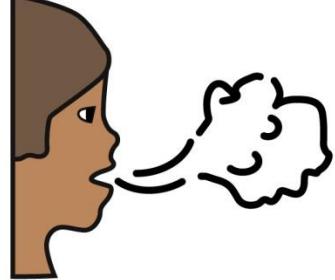
APPENDIX F: VISUAL SUPPORTS

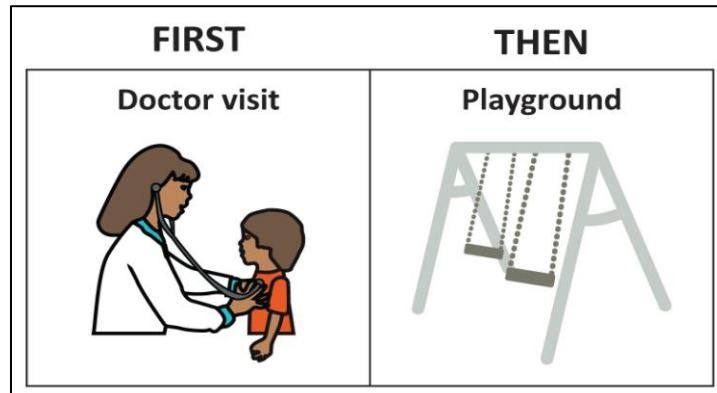
Below are some icons you might find helpful to use with your patient before and during a blood draw.

Car 	Drive 	Check in 
Waiting room 	Book 	Listen to music 
Nurse 	Nurse 	Go down the hall 

Walk 	Mom 	Dad 
Chair 	Sit down 	Listen 
Push up sleeves 	Wipe off arm 	Cold 
Tourniquet 	Cold spray 	Ice pack 

Squeeze ball 	Feel pinch 	Cotton balls 
Cotton ball on arm 	Bandaid 	All done 
Happy 	Doctor visit 	Keep arms at sides 
Blood pressure 	Please wait 	Doctor visit 

Laugh	Pinwheel	Change channel
		
Take deep breath	Belly breathing	Stretch
		
Think	Blow	Blow bubbles
		



APPENDIX G: FOLLOW-UP PARENT QUESTIONNAIRE FOR ROUTINE CLINIC PROCEDURES

We are interested in learning about how your child tolerated his/her medical visit. Your answers to these questions will be used to improve the care of children and reduce discomfort and anxiety associated with medical visits.

Below is a list of items that describe a child's medical visit. For each item, think about your child's medical visit. Please circle **2** if the item is **very true** of your child. Circle **1** if the item is **somewhat true**. If the item is **not true** of your child, circle **0**. Please answer all items, even if some do not seem to apply to your child.

0 = Not True **1** = Somewhat True **2** = Very True

0	1	2	My child tolerated waiting in the waiting and exam room.
0	1	2	My child was transitioned well between activities.
0	1	2	My child appeared comfortable with doctors and nurses.
0	1	2	The toys or items available were interesting to my child.
0	1	2	My child tolerated having blood pressure taken.
0	1	2	My child tolerated the physical exam.
0	1	2	My child tolerated having blood taken.
0	1	2	My child's behavior allowed him/her to remain safe and uninjured during the procedure.
0	1	2	My child's behavior allowed others to remain safe and uninjured during the procedure.
0	1	2	My child's discomfort and anxiety were reduced by the strategies used for this medical visit.
0	1	2	Overall, I was satisfied with the experience my child had today during this medical visit.

Please answer the following questions.

1. What strategies used during this visit helped your child remain calm and relaxed?

2. Please share any comments or concerns: