VANDERBILT KENNEDY CENTER

A Comprehensive Guide for Clinicians and Researchers with a Focus on Needlesticks and Blood Draws: Helping your Patients with Intellectual and Developmental Disabilities

This toolkit provides strategies that you, your practice, or your research team can use to help children with Intellectual and Developmental Disability (IDD) more easily complete medical and research visits including blood draws and needlesticks while reducing the stress felt by patients and their caregivers. The techniques presented here may be helpful with persons of any age or ability.

↘ Introduction to Intellectual and Developmental Disabilities

What are Intellectual and Developmental Disabilities (IDD)?

Developmental disabilities may affect learning, language, and behavior. Intellectual disabilities may affect cognitive function such as reasoning, learning, and problem solving. They may also impact adaptive behavior such as social and life skills. Together, these are commonly referred to as intellectual and developmental disabilities (IDD). Examples of intellectual and developmental disabilities can include autism spectrum disorder (ASD), Down syndrome, fetal alcohol syndrome, spina bifida, Prader-Willi syndrome (PWS), and Fragile X syndrome. In children, these are also often referred to as neurodevelopmental disorders.

Working with Patients with IDD

IDD 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 IDD.

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

The information in this resource is an adapted excerpt from *Taking the Work out of Blood Work: Helping Your Child With ASD,* a product sponsored by Vanderbilt Consortium LEND in coordination with Autism Speaks Autism Care Network.[1]

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1. Original source of content: Loring, W., Reeslund, K., Dove, D., Reising, M., McDaniel, M. Lee, E., Newsom, C.R. (2011). *Taking the Work out of Blood Work: Helping Your Child With ASD* [Website and Brochure]. Sponsored by Autism Speaks Autism Care Network, Maternal and Child Health Bureau, and Vanderbilt LEND. To access the original website and associated printable materials, please visit: vkc.vumc.org/asdbloodwork/

↘ Preparing for the Visit

Gather Information

Contact families prior to visit. Talk with caregivers about accommodations that your clinic or research team can provide to make the visit a success. The caregivers may have comments on which strategies are more or less likely to be successful. The communication you start with the parents ahead of time establishes an environment where they can feel heard. This allows them to be more engaged in their child's care and feel less anxious about the visit.

Ask about:

» Past experiences that were positive or negative,
» How the child communicates,
» The child's strengths and interests (ask them to bring the **child's favorite toy or activity**), and
» What type of support helps their child if they are having a hard time.

A phone call or a written questionnaire may be the best way to gather child-specific information. Go to vkc.vumc.org/asdbloodwork/provider/gathering.php to obtain a sample triage questionnaire. Such a questionnaire can be used as a script for pre-visit phone calls.

Offer online or printed tools to prepare families ahead of the visit:
Create a clinic-specific packet with information the caregivers can use in preparing the child. This might include a video link or photos of your clinic and team, any visual supports you may have to use in clinic (see page 10), a list of the kind of materials that may be used in the visit that they could expose the child to before the appointment (e.g., a tourniquet, Band-Aid, blood pressure cuff, etc.), and any pertinent details of the visit that may be surprising to the child.

You may want to provide families with a packet of patient information on preparing for venipuncture in patients with IDD. One is available at vkc.vumc.org/needlestick-toolkit.

Discuss **behavioral strategies and techniques** with the family (see pages 9-14). Families can practice these ahead of time as well as during the visit.

Consider a **mock visit** before the scheduled clinic appointment. Ask the caregiver to prepare by simulating some of the procedures at home or by reviewing pictures of the clinic setting.

Coordinate Appointments

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

Minimize the waiting time in environments that can be over-stimulating or anxiety provoking (e.g., busy waiting rooms, phlebotomy lab). If possible, ask if the patient would prefer to stay in the waiting room or would feel more comfortable going directly to a clinic room to avoid the potential crowds in the waiting room.

Labs

» 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, consider scheduling the blood draw** while the patient is under sedation.

Prepare the Room

Set up equipment and all necessary materials prior to the patient entering the room. Be aware of the placement of materials in the room to ensure they are out of reach with the least amount of clutter possible near the patient.

Consider using **child-friendly equipment**, such as winged infusion sets that allow for more movement.

Ease the stress of the patient and family by outlining what they should expect during the visit using a **visual schedule** (see page 12).

Set 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 the patient from leaving the room in an unsafe way.

Obtaining Consent and Assent

In addition to the standard elements of consent and assent, consider the following measures to build trust and ensure transparency and understanding with the caregiver providing consent and the child with IDD providing assent.

☑ Engage **families and caregivers** while respecting the autonomy of children with IDD to provide assent.

☑ Employ the **teach-back method** to ensure understanding:
  - Please tell me, in your own words, what is this study about?
  - What will you be doing if you take part in this study?
  - What are the risks of being in this study?
  - When I say your taking part is completely voluntary, what does that mean to you?
  - When I say that your answers will be kept confidential, what does that mean to you?
  - What can you do if you start the study but don't want to finish it?

☑ Cater to **diverse learning styles** by employing summaries, pictures, and videos to communicate the goals and expectations of the project.

☑ Consider **low-risk studies**. Recent studies have indicated that many individuals with intellectual disabilities likely can provide their own consent to participate in low-risk studies. It is important to remember to use simple and plain language when consenting.

☑ Take **time** to ensure understanding and create a non-pressuring, comfortable, quiet environment. Send the consent and assent form ahead of time to give ample time for participants to understand and be comfortable.

☑ As a part of your **IRB** submission, it may be important to cite publications to support the added measures you are using to enroll members of this protected population. You can use the reference list at the end of this toolkit.

☑ Obtaining consent and assent is an **ongoing** process. Ensure that throughout the study, the child and family have an understanding of what is happening and are free to ask questions, assess their benefits in being in the study, and withdraw at any time.

During the Visit

- Use **visual supports** or Social Stories™ for patients who respond better to this type of communication (see page 10).
- Provide appropriate **distraction** toys that match the sensory needs of a particular patient. Many children with IDD may have a narrowed set of interests so rely on the information gathered from caregivers.
- Have appropriate **rewards and reinforcers** available (see page 13).
- **Remain calm and flexible**. Avoid appearing emotionally reactive or "frazzled" by the patient's behavior. Remain matter of fact and positive in your interactions. 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, which chair they can sit in, etc.).
- 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 caregivers' input of their child's sensory vulnerabilities.
- **Explain what you are doing before you do it**. Check for understanding. Be direct about what you are doing and whether it may hurt, if the child asks.
- Use **simple, concrete language** in short sentences without abstract language idioms, irony, or metaphors (e.g., saying "place your arm here" versus "cooperate").

- **Give direct requests** (e.g., saying "Please sit here" versus "Why don't you come over here and sit?")
- **Refer to the caregiver** for behavior management, communication, and patient preferences. Let them know you are happy to help but want to follow their lead.
- A small child can be seated in a caregiver's **lap to stabilize a patient's arm during blood draws.**
- **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.

Create and Reference Internal Protocols

A **brief written protocol or checklist** may help your staff, research team, and practitioners become more coordinated in their approach to patients with IDD. This may include things like the best room to use, a kit of visual supports (see page 10), and some basic questions that are asked at the beginning of the visit to ensure the patient's comfort and safety.

Have a **backup plan** determined before the procedure begins (i.e., determine ahead of time when to stop the procedure, move more quickly, or call for more assistance). Discuss all plans with the caregiver at the beginning of the visit.

Ensure **additional staff** is available to help with complex needs.

When to Change the Pace of the Procedure

In general, procedures should move quickly and efficiently to avoid escalation of anxiety or irritability. Too much unstructured down time between procedures (e.g., while preparing materials, etc.) can often cause additional uncertainty or stress that may lead to challenges.

The clinical team can 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

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

- ⃠ **The results are not clinically essential.** Before ordering, a practitioner should consider how they will use the information for clinical decision making or research. The practitioner and the clinic team should be clear about the priority of the situation: routine, urgent, or critical.

- ⃠ **Insufficient staffing or equipment.** The clinic staff or research team 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 caregiver is a critical part of the team, but it should not be assumed that the caregiver 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 or other medical settings and may make future medical visits difficult to complete and anxiety-provoking for the patient.

↘ Pain Management

Children with IDD may not interpret or express pain in the same way as a typically developing child. Do not assume that this means that children with IDD have a high pain tolerance. Communication differences may hinder a child's ability to tell you about the pain experienced. Their inability to effectively 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 IDD rather than relying on the child's self-report alone.

Monitoring 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
- Vocal expressions and body postures
- Changes in breathing, skin color, sweating, urinating
- Changes in blood pressure, heart rate

↘ Behavioral Strategies: Relaxation

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

Why Relaxation is Important

Relaxation can significantly reduce children's stress and pain. Research shows that stress leads to increased tension, which contributes to higher levels of pain. Because there is a large psychological component to pain perception, relaxation and distraction techniques play an important role.

Relaxation for Patients with IDD

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

How to Use Relaxation during Needlesticks or Blood Draws

To help keep your patient calm during a procedure or visit, you can use, or coach the caregiver to use, simple relaxation and distraction techniques. If possible, you can share the relaxation tips below with caregivers as part of the pre-visit information and encourage them to practice these things before the visit.

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. Caregivers 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.

↘ Behavioral Strategies: Distraction

What is Distraction?

Distraction may help by taking a patient's mind off stressful events, thoughts, or emotions and shifting focus to other positive thoughts or activities.

How to Use Distraction with Patients with IDD

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 caregivers 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.

Visual supports can:

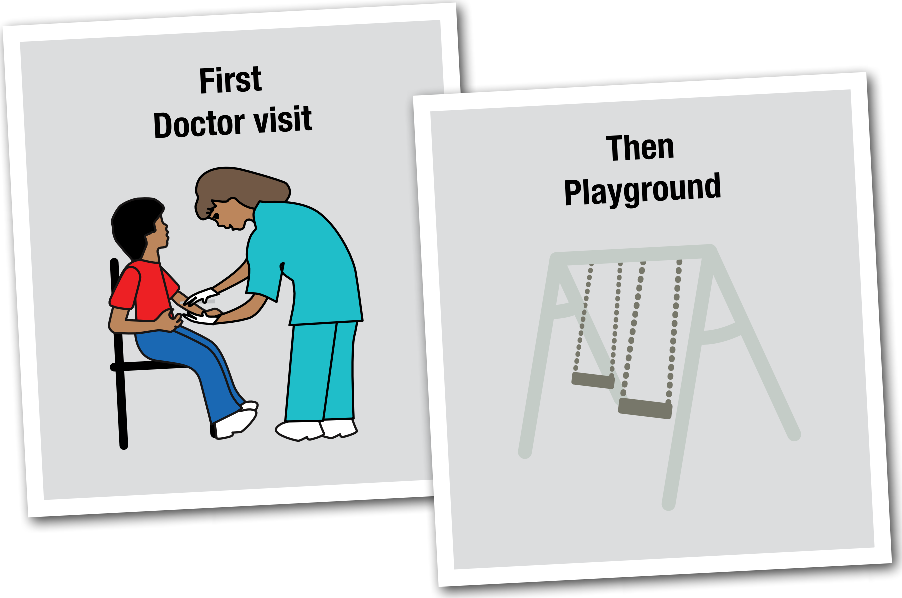
- Assist in more effectively communicating expectations during medical procedures and provide a more concrete and motivating promise of reward
- Clarify the activities that will occur and decrease frustration and problem behaviors that may be a result of misunderstanding during medical procedures
- Establish 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 IDD in effectively tolerating medical procedures are **First-Then Boards** and **visual schedules**.

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.

While it may seem overwhelming to make First-Then Boards for each patient, many clinics have found it useful to create one visual board along with detachable pieces that can be easily adapted to meet the needs of the patient. It is helpful to create these visual pieces using Velcro or similar material that can be placed on and off the board quickly and easily. Please see examples below.



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?

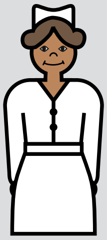
A visual schedule is an illustrated way to communicate what will happen during the day or during the appointment. Specifically related to medical procedures, it is helpful in decreasing anxiety and rigidity surrounding transitions by communicating when certain activities will occur throughout the day or during the appointment. (The tourniquet is for blood draws).

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** before the first activity on the schedule and remain visible/available throughout the rest of the activities.
- When it is time for an activity on the schedule to occur give a **brief verbal instruction** at the beginning of each 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. However, this may make other children more anxious, and, for that child, a more general schedule might be more appropriate.

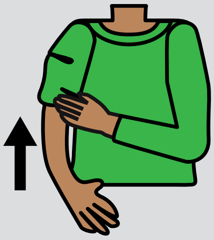
1

Nurse



2

Push up sleeves

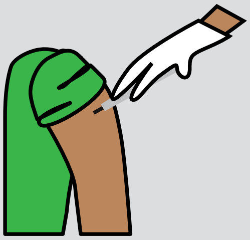


3

Feel pinch

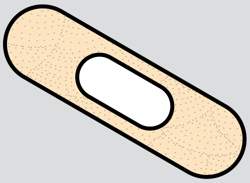
4

Needle stick



5

Bandaid



6

Special activity

- 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 to provide the patient with something positive to focus on and motivation to complete the items on the schedule.

Behavioral Strategies: Reinforcers

What are Reinforcers?

Using specific positive activities or items serves to provide an association between these procedures and something that is enjoyable.

How to Use Reinforcers with Patients with IDD
Identify things that are specifically motivating to your patient. They may **relate to your patient's sensory** or restricted interests. **Ask the caregiver** for ideas.
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).
Choose a **novel reward** that your patient does not always have available so it can be more motivating during something like a blood draw or needlestick.
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.

Examples of Reinforcers for Sensory-Specific Interests

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

It is helpful to have a bin of possible options that meet these different categories of sensory interests or suggestions for where they can be quickly accessed (e.g., the closest elevator in the building or the nearest playground).

Additional Tips

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 caregiver to introduce the strategies outlined in this pamphlet prior to the visit and to practice them during preferred daily activities.

↘ Want More Information?

- Visit vkc.vumc.org/vkc/resources/healthdevelopment/ for more detail, examples, and printable tools.
- Visit vkc.vumc.org/asdbloodwork/ for tips and ideas for working with patients with IDD.

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