

Taking the Work Out of Blood Work and Needle Sticks: Helping Your Child with an Intellectual and Developmental Disability



This toolkit provides ways for you and your child to cope with the stress and worry that may come with blood draws, needle sticks for vaccines, or both. It provides strategies to make these appointments go more smoothly. Although completing blood draws/needle sticks with children with Intellectual and Developmental Disability (IDD) is the focus, the tips presented here also apply to other parts of a clinic visit.

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 Treatment 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 Treatment Network, Maternal and Child Health Bureau, and Vanderbilt LEND. To access the original website and associated printable materials, please visit: vkc.vumc.org/asdbloodwork/

➤ What Are Intellectual and Developmental Disabilities?

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.



➤ Tips to Help Your Child Have a Successful Needle Stick or Blood Draw

Before The Visit

Discuss what will happen using words and pictures that your child can understand.

Try to **avoid focusing on any aspects that may be perceived by your child as unpleasant or painful** if it will make your child more anxious. Be honest with them, but focus on the positive or neutral components of the visit. For example, instead of saying “I know you hate needles” or “I know how scared you got last time,” focus on what they will be asked to do during the visit and what fun or comforting things they will be allowed to do during and after. For example, letting them know that you will be with them, that they get to bring their favorite stuffed animal with them, or that they get to go to the park after.

Talk with your child’s providers before the visit. Ask what they can do to make the blood draw go more smoothly, such as requesting a certain time of the day, being allowed to go straight to a room instead of the waiting room, completing multiple blood draws at one time, or scheduling with someone familiar with caring for individuals with IDD. Topical lidocaine, which numbs the skin, may be another option to increase comfort.

Plan to **bring toys or visual supports** that you use every day to help your child remain calm and happy. Visual supports are explained more below.



During the Visit

- » **Share your suggestions** with medical staff. This may include whether it would be better for you to be a part of it or not, what materials you might be using to help your child, or the best way to communicate to your child that might make the most sense or be the most reassuring to them.
- » **Remain calm and reassuring.** Controlling your expressions and emotions will help your child do the same.
- » **Resist the “white lie.”** If your child asks, say “it may hurt.” It is better to prepare your child than to say “it will not hurt” if it could hurt. You could describe a needle for a blood draw as a “strong pinch.”
- » **Explain what is happening** in simple, direct language.
- » **Acknowledge feelings but avoid long conversations** and avoid using words like “scared” or “worried.”
- » Help your child **see medical staff as helpers who support them, rather than as those who will hurt them or make them feel more anxious.**
- » Allow your child **time to explore** certain items that they may have a strong reaction to before it has to be used. For example, allow them to see what the alcohol smells like, what the texture of the tourniquet feels like, etc.
- » **Prioritize what you need to accomplish** during the visit. Focus on what is most important to complete.
- » When possible, **provide choices** to help your child feel more in control. For example, let your child pick where to sit, the color of a bandage, or a reward to follow the visit.
- » **Praise your child’s** ability to complete the visit. Praise specific behaviors, like sitting, holding their arm still, etc.

➤ Relaxation and Distraction for Children with IDD

Why Do Relaxation And Distraction Matter?

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

Distraction may help by taking your child’s mind off stressful events, thoughts, or emotions and putting attention on positive thoughts or activities.

Strategies for Relaxation and Distraction During Blood Draws/Needle Sticks	
Deep Breathing*	Teach your child to take a deep breath, hold the breath for a few seconds and then release it. For young children, using a pinwheel or bubbles to practice can help them focus on their breathing and distract from their stress.
Muscle Tensing*	Have your child relax by focusing on different muscles of the body and alternately tensing and relaxing them one at a time. In preparation for a needle stick, have your child specifically relax the muscle where the injection will take place.
Visualization	Encourage your child to imagine something pleasant and to imagine that scene with eyes closed. Suggest thinking about smells, sounds, and touch of what is imagined. Using pictures or objects to remind your child of favorite places or activities can help this strategy be more successful.
Favorite Toys/ Activities	Involve your child in distracting activities before the procedure begins and, if possible, before your child begins to become upset. Use a favorite toy, a particularly engaging topic of conversation, or a game that does not require movement.
Music	Play your child’s favorite music or sing a silly song.
Laughter	Find ways to make your child laugh.

*If your child has lost consciousness during prior blood draws/needle sticks, check with your physician before using deep breathing or muscle relaxation.

Tips For Using Relaxation And Distraction

Caregivers may find that typical approaches to using relaxation may not always be as easy for children with IDD. Certain changes can be made in order to help your child be successful.

- » **Practice makes perfect.** Try to teach relaxation strategies at set times in the day instead of when your child is already anxious. Reward your child immediately after practicing relaxation. This encourages continued practice and adds another positive connection with relaxation. Later when you use these strategies because your child is worried, he or she will be able to use them more easily since they have already learned them when they weren't as worried or upset. Your child will trust that something good will follow, just as it has during practice sessions.
- » **Prevent instead of react.** Try to use these strategies before your child becomes worried, instead of only using them to calm your child down after becoming upset. It is best to use these beforehand (for example, at home before going to the doctor's office, in the car before going into the office, in the waiting room) or when mild signs of anxiety are noticed.
- » **Use visual supports or concrete tools.** It is important to use visual supports (for example, pictures) or other concrete cues while putting relaxation strategies in place. Use them as a quick reminder to your child that it is time to use these strategies. This can be more helpful than trying to explain through talking.



➤ Visual Supports for Children with IDD

What Are Visual Supports?

A visual support refers to using a photograph, drawing, object, or list to communicate with a child who may respond better to this than only using language. Visual supports can be especially helpful when your child has to participate in medical procedures such as vaccination, other injections, or blood draws.

Why Are Visual Supports Important?

Some features of IDD may involve differences in interacting socially, in using language, and in having more focused or repetitive interests and behaviors. They may also show strengths in visual understanding and following routines. Visual supports help support those differences and use their strengths before, during, and after blood draws/needle sticks or other medical procedures.

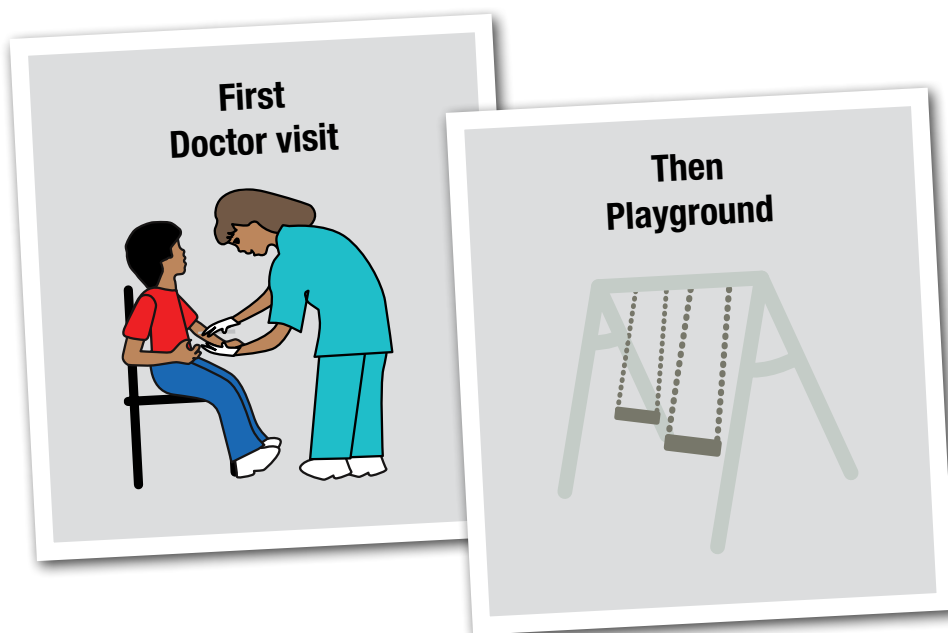
Two kinds of visual supports that might help your child with IDD more successfully complete blood draws are **First-Then Boards** and **visual schedules**.

First-Then Board

A First-Then board is a visual display of something preferred that will happen after completing something that is not as preferred. During blood draws/needle sticks, a First-Then board can help motivate your child to take part in an activity that is not enjoyable by clarifying a preferred activity that will occur after it is over.

To Create A First-Then Board:

- » **Decide what task you want your child to complete** first (what goes in the “First” box) and the preferred item or activity (what goes in the “Then” box) your child can have as soon as the “First” task is done.
- » **Put a visual on the board** for each “First” and “Then” activity. The board can refer to the general overall procedure (“First go to the doctor, Then playground”). The board can also refer to specific steps during the process that can each be paired with reinforcement. For example, “First sit in waiting room, Then lollipop.” Next, change the board to “First take temperature, Then sticker” and so forth through the blood draw.
- » **Show the board to your child** with a very brief statement (“First sit in waiting room, Then lollipop”) before starting the “First” task. If needed, refer to the board while your child is doing the task (“One more minute, Then lollipop”).
- » **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.



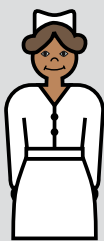
Visual Schedule

A visual schedule is a display of what is going to happen throughout the day or during an activity. A visual schedule is helpful during blood draws to decrease anxiety and difficulty with transitions by clearly letting your child know when certain activities will occur.

- » **Decide the activities that you will put on the schedule.** Try to mix in preferred activities with non-preferred ones.
- » Put the **visuals that stand for the activities that you have identified on a portable schedule** (on a binder or clipboard) and bring it to the visit. The schedule should be available to your child from the beginning of the first activity. It should continue to be visible through all of the activities.
- » **When it is time for an activity** on the schedule to occur, let your child know with a brief verbal instruction before the next activity begins. When that task is completed, tell your child to check the schedule again and transition to the next activity. Some children may respond best when each task during the procedure is broken down in a detailed way. If this makes your child more anxious, a more general schedule might be better.
- » **Provide praise and/or other rewards** for following the schedule and completing the activities. Put a preferred activity at the end of the schedule to give your child something positive to look forward to after completing all the items on the schedule.

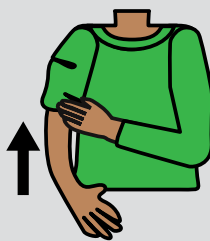
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Nurse



2

Push up sleeves



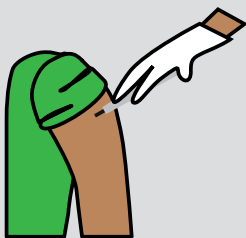
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Feel pinch



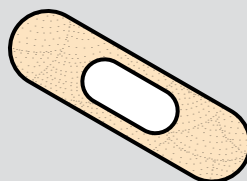
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Needle stick



5

Bandaid



6

Special activity



➤ Social Stories™ for Children with IDD

What Is A Social Story™?

Many people with IDD benefit from having a written guide for situations that may be new, scary, or confusing. A Social Story™ is a helpful way to provide this guide for blood draws/needle sticks. A Social Story™ helps your child understand the situation and decreases anxiety that may come from an unknown situation.

Tips For Writing A Social Story™

Accurately describe the situation in detail. Include both things your child may find difficult (for example, meeting new people, waiting, lights, smells) and things they may enjoy.

Focus on important social cues, events that might occur, reactions that might be expected, and why the event is occurring.

Write from your child's perspective ("I will go to the doctor. I will...") or third person ("Kevin is going to the doctor. He will...").

Use positive, concrete language by focusing on what you would like your child to do. For example, instead of saying "Do not scream or move your arm during the needle stick," you can say "I will try to stay calm and quiet in the chair while the nurse gives my vaccine."

Write the story specifically for your child and his or her experience with blood draws.

Some children may respond best to breaking down each task that will occur during the procedure in a detailed way. This may make other children more anxious and, for that child, a more general story might be better.



When To Read The Social Story™

If your child needs to know the details about the blood draw/needle stick ahead of time to relieve anxiety, then have your child read the story a few days prior to the visit. Use this as a time to briefly answer your child's questions about the visit.

If reading the story ahead of time will make your child more anxious, wait until before the visit (for example, in the car on the way) or when you are at the appointment in the waiting room. Have your child read the parts of the story that explain what is happening.

Social Stories™ were created by Carol Gray. For more information www.thegraycenter.org

➤ Reinforcement for Children With IDD

Why Does Reinforcement Matter?

Because of the differences mentioned above, these visits may be even harder or scarier for your child than another child. So, it is important to use specific reinforcers when asking your child with IDD to participate in blood draws/needle sticks and when practicing strategies, such as relaxation. Doing this will help your child with IDD connect these activities with other enjoyable things. This may make the process less stressful for your child and will let your child know that his or her hard work will be rewarded.

Tips for Using Reinforcement During Blood Draws or Needle Sticks

Choose a reward that your child does not always have available and is different enough to be motivating during something like a blood draw. This does not have to be something large or something new to buy each time. Instead, it can be access to something like their favorite video or a set of toys you put away and only bring out for doctor's visits.

If your child is undergoing several medical procedures, have a few different rewards so that your child remains motivated throughout the entire visit.

Give reinforcement as soon as you can. If this is not possible, provide some type of visual way to let your child know that the reward is coming soon (for example, a picture of the activity, a token).

Be clear about what the reward is and exactly what your child did to earn it (for example, sat still, walked in without help).

Always follow through with providing the reward you promised.

What If Challenging Behaviors Occur?

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

If you think challenging behaviors may occur, introduce your child to the strategies in this pamphlet before the visit and practice them during daily activities he or she enjoys.

➤ Resources

The tips presented here may be helpful for individuals of any age or with other conditions.

Want more tips for helping prepare your child with IDD for doctor's visits? Below are some links and resources that might be helpful. Visit vkc.vumc.org/vkc/resources/healthdevelopment/ for more detail, examples, and printable tools!

This publication was adopted in part from the toolkit for blood draws for children on the autism spectrum.

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