

**Autism & Hospital Visits:
How to prepare your child or support your staff to improve outcomes**

**Improving Hospital Visits for Children with Autism:
Preparing the Child and Supporting the Staff to Improve Outcomes**



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Autism & Hospital Visits: How to prepare your child or support your staff to improve outcomes

This guide is designed to support the hospital visit experience for patients with autism spectrum disorder (ASD) and the hospital staff that provides services to these patients and their families. The information in this guide is derived from evidence based methodology that has been effective for individuals with ASD. Designed for use by caregivers and hospital staff through collaboration with nurses, doctors, social workers, developmental therapists, teachers, behavioral specialists and clinical psychologists, this guide includes resources for caregivers and staff working in the hospital environment.

Caregivers:

- ✚ Tips to prepare your child before a hospital visit
- ✚ Ideas for supporting your child during the visit including printable resources
- ✚ Suggestions to guide you when challenges arise

Hospital staff:

- ✚ Materials to support basic training
- ✚ Resources to print and use during visits
- ✚ Guidelines for using basic behavior support strategies to improve overall outcomes

The guide is organized in sections for easy use. For quick reference use the links within the guide to move to the section you need.

Overview of Autism Spectrum Disorders

Autism Spectrum Disorder (ASD) is a behavioral-developmental disorder that affects many areas of functioning. Each individual with ASD presents with a range of skills and deficits making it a “spectrum” disorder. ASD includes a variety of traits and each individual will present with a unique collection of skills and deficits related to:

- ✚ Social communication and social interactions
- ✚ Repetitive or restricted interests/patterns of behavior

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Typically, these challenges present early in life and risk for ASD can be identified before a child turns two. Children with ASD usually don't meet developmental milestones in the expected timeframes and this affects development across domains.

- ✚ ASD is one of the most common childhood disorders; research reports prevalence to be as high as 1 in 68 children and as high as 1 in 48 boys
- ✚ Research shows that ASD is 4.5 times more common in boys than in girls
- ✚ Prevalence rates for ASD are the same across regions, cultures, and nationalities

For staff working in a hospital, it is very likely a child with ASD will come in for a range of procedures throughout their lifespan as the ASD population exists in every city, every country and every culture throughout the world.

To learn more about basic concepts related to emotional intelligence, diagnostic terminology and the significant sensory based challenges that some children experience, use the links below:

- ✚ [ASD and emotion](#)
- ✚ [Other names for ASD](#)
- ✚ [Sensory challenges](#)

What can I expect?



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ASD: What can I expect?

Deficits: Social skills

Children with ASD usually present with significant social challenges including, but not limited to:

- ✚ Difficulty with eye contact
- ✚ Difficulty developing friendships with same age peers and interacting socially with unfamiliar people
- ✚ Trouble responding to or recognizing social cues such as facial expressions, voice volume, physical proximity, or invisible social expectations (e.g., being respectful of others feelings, speaking quietly in a waiting room, etc.)
- ✚ Challenges with joining in activities or routines with others

Deficits: Communication Skills

Most children with ASD present with communication challenges in early childhood and some experience these challenges throughout the lifespan including, but not limited to:

- ✚ Delayed speech (e.g., four years old functioning at level of 18 month old)
- ✚ Odd and repetitive speech patterns (e.g., script phrases from television programs, repeating phrases they have heard in context to meet their needs)
- ✚ Limited nonverbal communication, including limited use of gestures, voice inflection, eye contact and other forms of nonverbal communication
- ✚ Difficulty reading facial expressions, responding to changes in vocal tone and/or struggle with processing language in general (e.g., no reaction when parent raises voice or appears upset, delayed response to verbal language)

In contrast, some children with ASD have exceptional oral language skills. In these cases, proceed with caution as they may have more difficulty understanding spoken language than using it.

When communicating with children with ASD:

- ✚ Simplify your language & break it into small parts
- ✚ [Show them what you tell them](#) with pictures or actions
 - This strategy is recommended to set expectations that are clear and developmentally appropriate and can be useful with ALL young children!

Deficits: Repetitive/Stereotypical Behaviors

Stereotypic and repetitive behavior refers to atypical repetitive or restricted interests, movements and play that can interfere with social communication and impact the child's ability to attend and participate in social situations or follow simple instructions.

Not every child with ASD engages in repetitive behaviors but many have difficulty with changes in routines and unfamiliar situations. This can have a direct impact on the hospital visit experience as their expectations may not align with what needs to happen in this unfamiliar setting and this disruption to their world can trigger behavior difficulties.

Stereotypic and repetitive behaviors may include sensory issues, repetitive speech, play and behavior as well as restricted interests:

- ✚ Sensory Issues:
 - Looking at items/objects from different angles
 - Peering out of the side of the eyes
 - Walking on tip toes or "toe walking"
- ✚ Repetitive speech:
 - Repeating phrases or words over and over
 - Quoting from television or media
 - Repeating what others' say (this is referred to as echolalia)
- ✚ Repetitive behavior:
 - Flapping hands or arms including full body movements or jerking motions
- ✚ Repetitive play:
 - Repeating the same action with a toy over and over and not using it the way it was intended to be used (e.g., lining up toy cars in a row instead of driving with them)
 - Repetitive movement with objects (e.g. rolling wheels near eyes repetitively)
- ✚ Restricted Interests:
 - Heightened interest in parts of objects (e.g. opening and closing doors repetitively due to interest in hinges)

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Repetitive behaviors may be warning signs for problem behaviors as the child is likely feeling scared or overwhelmed, but can also be viewed as coping mechanisms in stressful situations.

- ✚ Allow the child to take a break to regulate and calm down
- ✚ Use the [first/then card](#) provided in this guide to help him/her understand that after the break they will come back and finish their appointment



Now that you are prepared to look for core traits and understand the deficits that children with ASD experience; let's move on to setting the child up for success. The next section includes ideas for preparation before a hospital visit in addition to suggestions related to strategies that can be effective in the hospital setting and finally recommendations for helping the child de-escalate if s/he does become upset.

With aims to capture the variety of experiences that exist in the hospital setting, this guide includes supports intended for use in situations ranging from routine checkups to developmental screenings in addition to visits involving specialist procedures and overnight hospital stays.

Before the visit: Be Proactive!



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Before the visit: Be Proactive!

There are many ways to prepare any child with or without ASD for a new place or experience. These techniques are called antecedent or preventative strategies.

Antecedent strategies are effective because they are applied **before** a problem behavior occurs, effectively avoiding the issue before it starts. These strategies should be of primary focus, as *prevention* is the most effective behavior management strategy out there!

- ✚ Talk about it:
 - Children with higher cognitive ability and communication skills will benefit from discussing details of the hospital visit before they experience it.
 - Let them ask questions about their fears.
 - Emphasize the positive outcomes (e.g., “The doctor is going to take care of you to help you grow big and strong like mommy and daddy”)
- ✚ Pretend play with doctor materials:
 - Children with limited communication skills will benefit from learning about the hospital visit through play.
 - Use real materials and model actions in play with dolls and babies before the real procedure.
 - For some children, using what they learn at home in a new place may be challenging- this is called generalization. Practice won't hurt but it may benefit some children more than others.

The way a child uses language indicates the level of understanding they have. For example, if a four year old child is using 1-2 word phrases, it is likely they can understand simple 1-2 word demands and less likely that they are able to follow complex instructions. Differentiating between chronological age and where the child is developmentally will help make your interactions with the child more successful.

Begin by gathering important information to help staff understand your child.

[Information Gathering: The Basics](#)

Role Playing

An effective & creative way to help a young child understand what a new situation will be like. Use your acting skills and demonstrate through role playing!

During the Visit



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During the visit

The hospital experience can create a high level of anxiety and worry for any family, particularly for families with children that require special accommodations or children with limited communication skills. During the visit, don't make assumptions about the child or the staff.



Rather than assuming the child will be comfortable or that staff has specialized training to work with children with ASD; hospital staff and caregivers can use this acronym as a simple reminder of important points:

- A**sk the right questions
- S**peak in simple, short phrases
- S**peak to an autism expert in your area if needed
- U**ncover invisible rules and set clear expectations
- M**otivate the child with rewards for compliance
- E**xpect the child to have a hard time so you are prepared



Caregivers:

Ask about doing a walk through before the day of your appointment to introduce your child to the setting. This would be a good time to take pictures of equipment and exam areas (if hospital policy permits!) to show your child before the day of your appointment.

Hospital staff:

Children with ASD benefit from repeated exposure to novel or scary experiences. Think of creative ways to introduce them gradually to things that may be frightening or anxiety provoking (e.g., machines, sounds, painful procedures, etc.)

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During the Visit: Communication Support

Children with ASD usually have delayed communication skills, especially during early stages of development (e.g., age 0-5.) These children may not talk or use eye contact; they may not show their emotions through facial expressions and/or they may pay minimal attention to others.

In most cases, the ability to understand spoken language is even more limited in times of distress. One of the most effective supports, visual supports, is an easy way to help the child understand and is supported by a wealth of research.

Visual supports clarify auditory information and shape the child's expectations.

An effective strategy used to:

- ✚ Avoid problematic behaviors before they occur
- ✚ Help the child understand the expectations
- ✚ Set clear boundaries for a child of any age
- ✚ Manage problem behavior
- ✚ Support the sensory challenges of a child with an ASD

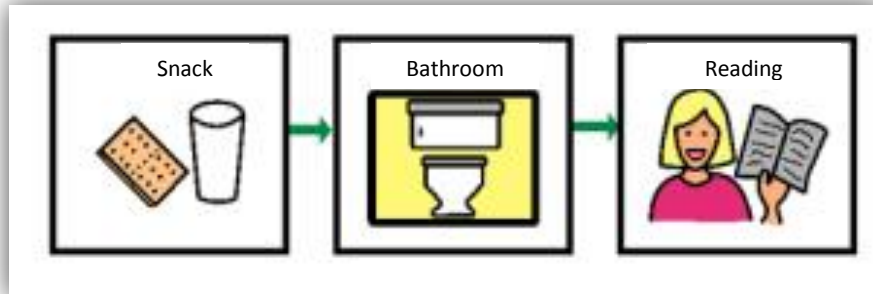
Visual support strategies include [pictures](#), [social stories™](#), schedules, and [first then boards](#), each of which is described in more detail below.



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Communication Support: Pictures

Caregivers, teachers, and therapists often use pictures of common items to teach children with ASD spoken language and also to improve expressive and receptive communication abilities.



“My brain works like google images, I pictures”

-Temple Grandin (Successful author and professor with ASD)

[Pictures](#) of common procedural events are provided for your use in this guide. When real pictures are not available or applicable, it is effective to use any visual representation (e.g., tangible items, labels from containers, gestures, modeling of actions/words, videos, etc.)

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Communication Support: Social Stories™

Social Stories™ are a highly effective proactive method supported by research. A concept developed by Carol Grey (info@carolgraysocialstories.com), social stories are used to prepare children with ASD (and without!) for new and unexpected experiences and can also be effective for teaching complex social skills across multiple environments.

Social Stories™ are used to teach social concepts such as “sharing toys with friends” or introduce new experiences such as “going on vacation.”

Social Stories™ can be effective for children with varying levels of ability however, this requires that the child is able to attend to pictures and process sequential language and behavioral contingencies.

For some children, **social stories™** will include a lot of descriptive text with minimal pictures to represent the concepts. For children with communication challenges, the **social story™** does not need to include any words because pictures can represent all steps in the sequence. **Social stories™** should be tailored to the child’s cognitive capacity and be developmentally appropriate.

It is most effective to review the **social story™** for several days before the stressful event; additionally, the story can be a resource during the experience to help them move through the sequence step by step.

Creating your own story:

- Include an introduction, body, and conclusion
- Answer “wh” and “how” questions (who, what, when, where, how)
- Write in first person (as if the child is the one describing the event/concept)
- Use positive language to describe responses and behaviors
- Make sure it is literal and accurate
- Use concrete, understandable words and use visual supports when possible
- Illustrations will clarify and enhance the meaning of text
- Use a style and format that is motivating -- this will help maintain attention to the story (e.g., include a favorite character to increase the child’s level of interest)

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Use the links below to view and print sample social stories included in this guide; you can modify these stories or use them to create your own.

- ✚ [Social Story: Audiology](#)
- ✚ [Social Story: Speech and Language Therapy Evaluation](#)
- ✚ [Social Story: Angiogram/Cardiology](#)
- ✚ [Social Story: EEG](#)
- ✚ [Social Story: Surgery](#)
- ✚ [Social Story: Radiology/X-Ray](#)
- ✚ [Social Story: Ultrasound](#)

Visual Schedules

Visual schedules are a great tool for communicating expectations and setting boundaries for children who have a difficult time following instructions, transitioning between activities, attending and/or participating in new and unfamiliar situations. This is a flexible and easy method for supporting communication and behavioral challenges for a child with ASD.

Visual schedules

- ✚ Can include [pictures](#), written words, tangible objects, labels, or drawings
- ✚ Should be used to let the child know what is coming in addition to spoken language, not to replace it
- ✚ Are an effective method for increasing a child's compliance by creating a sequence that ends in something highly preferred (e.g. getting a sticker, a favorite snack or simply getting to leave and go home)

Displaying the sequence allows the child to see what needs to happen before s/he gets a reward; this is likely to increase motivation, in turn, increasing compliance to complete less desirable tasks.

- ✚ [Printable visuals](#) are included in this guide for use by caregivers and hospital staff

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- Very young children with ASD or those who are not yet using words or phrases will not be able to follow a visual schedule; in these cases the [first/then card](#) will be more effective.

Caregivers:

Be prepared- print the visuals in this guide and bring them with you just in case!

Hospital Staff:

Create supports that are easily accessible in your exam rooms. It may be easier to have a white board or chalk board available for easy use!

First/Then

The first/then concept is a behavioral strategy used to clarify expectations and increase compliance in children with limited communication skills and/or behavioral challenges.

Hospital staff should assess the child's abilities and challenges during the [information gathering](#) phase. If the child is preverbal or struggles to use words independently, use pictures to show them:

"First (non-preferred), Then (preferred)"



"First ear doctor, then lollipop"

The second item should always be something the child likes!

Use the "first, then" method only when you can follow through with immediate reinforcement and pair difficult tasks with easy tasks (e.g., first medicine then break.)

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Hospital Visit Grab and Go Bag

It is recommended that both families and hospital staff prepare a “grab and go” bag to support hospital visits for children with ASD.

This is often something parents do for children to keep them busy in the grocery store or maintain sanity in the care or at Disneyland; why not prepare for the stressful hospital visit experience to eliminate unnecessary stress for all involved?

- ✚ Grab and Go bags are intended for proactive use when possible such as to develop a visual way of communicating the schedule.
 - Alternatively, staff and caregivers can offer the materials to the child if s/he gets agitated in an effort to soothe or redirect their frustration.
- ✚ Remember, the child with ASD is still a child with unique personality traits and preferences and will use verbal and nonverbal cues to communicate their likes and dislikes to others.
 - If you are having a difficult time reading their cues, don't be afraid to ask a caregiver or significant other to interpret for you!

The items included in the grab n go bag might include: sensory materials, supports to develop visuals in the moment, busy work, as well as items that will inhibit aggression or other fear responses (e.g., biting.)

The list below provides specific suggestions including:

1. Squishy farm critters: can be used to release stress by squeezing, stimulate the child and keep them occupied while waiting between activities, or motivate them during difficult times
2. Folder game: simple, familiar and repetitive. This type of activity can be soothing and keep a child occupied for longer periods of time when necessary.
3. Writing materials: can be used to create visual supports (e.g., quickly draw first/then pictures or write out schedule for child to cross off steps during visit.)
4. Milkshake straws: Something for the child to chew on. This can meet sensory needs, buffer anxious responses and stop a nervous child from biting during a visit if they become frightened.

The following list is provided to assist you with development of your very own grab n go hospital visit bag to support a child with ASD!

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Suggested Item or Similar	Suggested Vendor or Similar	Price Per Item in California as of Nov. 2014
Squishy Farm Critters 	Amazon	1.58
Getting Ready for School File Folder Game 	Amazon	2.25
Crayola 8ct washable bold board markers 	Amazon	.61
Perforated Writing Pads, 8 ½ x 11 ¾ Legal Ruled 	Office Depot	.40
Board Dudes Double-sided Dry Erase Lap Board 9x12 Item #325939 	Office Depot	5.59
Milkshake Straws 	Big Lots	.01



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De-escalation: Reactive Strategies

Sometimes we put forth our best effort to prepare a child with ASD or soothe them during a stressful experience and they still become distressed and sometimes even combative. Don't forget to use communication supports as the distressed child will have a hard time processing language.

Suggestions for caregivers:

- ✚ Use strategies that work at home- familiarity is comforting
 - This might include taking deep breaths, counting, or any other familiar routine
- ✚ Do not let them escape the situation unless it is a safety risk to keep them in the exam room, once they leave the room it may be difficult to get them back in
- ✚ Stay calm and use a soft voice to model the behavior you would like your child to imitate
- ✚ Incentivize good behavior by offering them a reward for compliance during the visit (e.g. proactive strategy)- remind the child what they are working for to motivate them to calm down
- ✚ Demonstrate trust and respect toward the staff so your child sees that your expectations align

Suggestions for staff:

- ✚ Do not crowd; give the child space with consideration of safety
- ✚ Use minimal speech (1-3 words is a good rule of thumb)
- ✚ Stay calm, and let this be reflected in your tone of voice and body posturing
- ✚ Provide clear, simple directions using pictures or written words whenever possible
- ✚ Allow the patient to make a choice between 2-3 options
- ✚ Limit bright lights and loud noises to provide a sensory conducive environment
- ✚ Try to redirect with highly preferred activities (i.e. bubbles, music, picture of caregiver or favorite character)
- ✚ Use the "first, then" approach to explain what is expected of the child.
- ✚ Be aware of the child's non-verbal cues and know when to seek help to avoid putting yourself or the child at risk

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Positive Behavior Support

Positive behavior support (PBS) refers to a collection of strategies used to determine why a behavior occurs and how to change it or prevent it from occurring. There are many technical terms clinicians use to describe these processes, but it comes down to prevention and control in a way that allows the child to feel empowered and learn socially acceptable ways to meet their needs.

PBS involves:

- ✚ Environmental modifications
- ✚ Real time support including reinforcing items, activities, and people
- ✚ Increase motivation and compliance using proactive support systems and assistance (e.g., verbal instructions, using visuals or physical touch to get a child to do/say something)
- ✚ Development of a plan to provide consistency for the child and others involved in their care

Use the links below for brief descriptions of specific strategies to use PBS during a hospital visit:

[Say-Show-Do](#)

[Repeated Exposure](#)

[Sensory Strategies](#)

[Contingencies](#)

Overview of Autism Spectrum Disorders

ASD & Emotion:

ASD impacts a child's ability to understand and express emotion and this can influence a hospital visit in a number of ways. Like any other child, a child with ASD experiences fear of the unknown and this can exacerbate communication challenges and regulatory problems.

To address these challenges, children with ASD often require individualized intervention in their home and school environments to teach new concepts or desensitize them to novel experiences.

Other Names for ASD:

Our understanding of the common features and course of ASD throughout the lifespan continues to expand each year as we learn more about causation and evidence based treatment modalities through research and early intervention (e.g. treatment for children under age five). ASD may also be referred to as:

- ✚ Asperger's Disorder
- ✚ Autistic Disorder
- ✚ Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS)

All of these diagnoses refer to ASD and can be treated with the resources and tips provided in this guide.

Sensory Challenges:

Many children with ASD have trouble with regulation; what they see, touch, feel, and hear can be very different from what others' experience in similar situations. A child with ASD:

- ✚ May respond aversely to bright lights or loud noises or become upset when exposed to sudden noises or other unexpected events
- ✚ May *not* respond readily to sound, touch or pain or may be much more sensitive to and bothered by touch, pain or sound
- ✚ Caregivers and staff should use the [sample intake form](#) to inform staff of potential challenges a child may have

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ASD: What can I expect? Deficits: Communication Skills

Example of using picture supports during a hospital visit to deliver three-step instruction:

Sit down



Open Mouth



Stick out Tongue



Before the visit: Be Proactive!

Information Gathering: The Basics:

To begin the information gathering phase for hospital staff, a special accommodations intake form should be filled out prior to the visit to inform the staff of communication level, anticipated challenges, sensory sensitivities or aversions and preferences.

This information is very important to be shared **before** the visit.

- ✚ The [sample intake form](#) can be modified for use by either caregivers or hospital staff to include important information specific to the child and/or the procedure.

Caregivers:

Be thorough when filling out these forms and remember, you are responsible for bringing communication materials including picture exchange systems and AAC (assistive augmentative communication)

Hospital staff:

Ask questions that relate to the environment and use the intake form as a guide.

- ✚ Modify the environment
- ✚ Limit wait time when possible
- ✚ Inform front desk staff of special accommodations

Environmental modifications may include dimming florescent lighting, limiting high pitch sounds or sudden movements, limiting how many chairs are in the room if the child needs to sit down in a specific place, creating a visual of rules in the exam room to keep the child on task, etc.

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During the visit

Caregivers:

- ✚ Stay calm
- ✚ Share your tips and tricks with staff
- ✚ Don't assume the staff have been trained to work with children with ASD
- ✚ Be patient

Hospital Staff:

- ✚ Use visuals
- ✚ Speak in short, simple phrases
- ✚ Provide incentives/rewards
- ✚ Model behavior/actions through role playing
- ✚ Be patient

As adults, we often forget that children have their own set of expectations and when those expectations do not align with reality, it can be very upsetting.

If your child likes McDonalds and passes it when walking through the doors of the doctor's office, s/he may think that is where you're headed unless you explain "first doctor, then McDonalds."

It can be difficult to identify the triggers for problem behaviors in a new environment and the behavior of children will not always make sense to others. Be patient and remember to soothe them with familiarity. Bring comfort items from home and offer them during times of distress to redirect their nervous energy.

For nonverbal children:

- ✚ Think of creative ways to prepare the child for expected and unexpected events
- ✚ Ask hospital staff to allow for a short **tour before the day of the procedure** to work on desensitizing the child to the environment. Exposure to a new setting can buffer stress during the actual appointment.
- ✚ **Use pictures** to create a **social story**. Most doctors have pictures on the website of their organization that can be printed; if not, ask the staff if they can help gather photos relevant to the procedure.
- ✚ **Prime through play**. Priming is a concept that relates to introducing a concept before a child actually experiences it. For example, if a child is going to get a shot, it would be helpful for them to see doctor toys days before the actual experience. This can be done effectively through play materials.
 - For children that are not talking yet, playing with real materials or pretend materials before the visit can help prepare them for what will happen.
 - Some children may have a difficult time generalizing this to the doctor's office, in these cases pretending in the actual exam room just before the real procedure might also be helpful

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Staff: Grab n Go Bag

- + Visual supports (pictures, first/then card, visual schedule board)
- + Resource pages for continued education and staff support- these may be pages from this guide!
- + Special accommodations forms
- + Fidget toys
- + Drawing/writing materials (e.g., paper, white board, coloring book, etc.)
- + Simple familiar and fun game
- + Reinforcers (stickers, markers, glitter ball, etc.)
- + Chewy tubes (disposable milk shake straws are a nice alternative)
 - o This can meet sensory needs and void others things going in the mouth!
- + These items will be useful during a visit to
 - o Keep the child busy
 - o Create shared interest and commonality (i.e. by playing a game together the patient may trust the practitioner more and demonstrate increased compliance)
 - o Reinforce desired behavior (i.e. first sit on the bed then you can use the markers)
 - o Create a positive experience overall for the patient and staff

Caregivers: Grab n Go Bag

- + Favorite comfort item
- + Communication supports (it is the family's responsibility to bring communication support used in other settings to hospital visits, this may include picture exchange communication systems (PECs) or assistive augmentative communication devices (AAC))
- + Edible treats
 - o ONLY if the procedure allows for ingestion of food. If not, use the food as reinforcement after the procedure is over
- + Prime through play with a pretend doctor set using a syringe or stethoscope and bring these items with you to help your child comply with the doctor's requests
 - o Some children may need to play with real materials to grasp the concept
- + Bring 1-2 copies of the special accommodations form with you to the visit
- + Family photos- looking at pictures of significant others can help keep a child calm
- + Novelties (special toys that your child does not play with often)
 - o It may be a good idea to keep a new toy in the grab n go bag so it is motivating!

Click [here](#) for a list of suggested materials and vendors.

Positive Behavior Supports

Say-show-do

This is a simple concept to remember when interacting with a child with ASD; it is particularly useful when placing a demand or delivering an instruction.

The following example describes the strategy:

- ✚ **Say:** "sit down"
- ✚ **Show:** model the action by sitting down or show them a picture of sitting down
- ✚ **Do:** after 3-5 seconds, help the child sit down with physical assistance and quickly praise them for it
 - Some children will respond better to significant others giving them instructions. Be sure to use the intake form to determine if it will be beneficial to have caregiver instruct child during the visit.

Sensory strategies

Many children with ASD experience sensory processing challenges such as:

- ✚ Hyper-sensitivity to sensory input
 - Evidenced by behavioral changes in noisy or over stimulating environments.
- ✚ Hypo-sensitivity to sensory input
 - Evidenced by under responsiveness to sensory input such as touch or pain.

Caregivers should use the [intake form](#) to report sensory challenges. If you know your child has a difficult time around mechanical sounds (e.g., machines beeping, phones ringing, etc.) or bright lights it is very important to inform the staff so they can make accommodations to avoid unnecessary stress for your child.

- ✚ Informing staff will not always result in them being able to eliminate all environmental stressors but it will allow them to be sensitive to those elements of the visit and limit exposure for the child.
- ✚ Minor environmental modifications such as dimming florescent lighting or removing chairs from the exam room can result in calmer, more compliant behavior from a child with ASD.

Repeated Exposure

Like most children, a child with ASD will benefit from repeated exposure to uncomfortable or novel experiences.

- ✚ Prime through play
 - Use play doctor materials at home to pretend giving shots to babies and animals.
 - Gradually introduce the child to a “pretend shot” on their own skin and talk about the upcoming doctor’s appointment.
 - Pair this with a social story to help prepare the child for the real event and include a sentence about the “pinch” they will feel when the doctor gives them a shot. Remember to emphasize the positive parts of the event (e.g., “after the pinch it will be all done. Everyone will be so proud of me for being brave; I will get to watch my favorite movie after my shots.”)
 - For preverbal children and children with limited cognitive skill it may be challenging to understand play from home relates to a new place/experience; in these cases, it will be best to use real materials in the hospital setting before the procedure to help the child link the actions with the actual procedure.
- ✚ Tour the setting: Go to the doctor’s office when you do not have an appointment and talk to your child about the aspects that are not scary. Sometimes it will be possible to tour the actual exam room, other times it will not. Do your best to expose the child and know that even a little bit of exposure is more effective than none to ease the stress of the overall experience.

Contingencies

A contingency is like a contract (if you go to work, you will receive a paycheck after a pre-determined amount of time.)

Behavioral contingencies exist throughout most aspects of our day. Clear and developmentally appropriate contingencies usually include an “if/then” clause and are extremely effective with children with ASD to increase motivation for non-preferred activities.

- ✚ Contingencies create significant changes in behavioral responses
- ✚ Behavioral contingencies allow us to create dynamic reinforcement relationships to increase the likelihood of behaviors we want to see more of and decrease the problem behaviors.
- ✚ Use behavior contingencies to shape the child’s behavior before and during the hospital visit using visual supports (first non- preferred, then preferred) and motivating activities to work toward.

Patient Intake Form – Special Accommodations

Patient Demographics

Patient Name: _____
DOB: _____ **Diagnosis:** _____
Parent/Guardian: _____ **Phone #:** _____

Communication

My child:

- Speaks in full sentences Speaks in short phrases Speaks 1-2 word responses
 Non-verbal Uses a communication device: _____

My child communicates best using:

- Spoken language Pictures Written words

Behavioral

My child's specific interests or favorite objects include:

- 1) _____
2) _____
3) _____

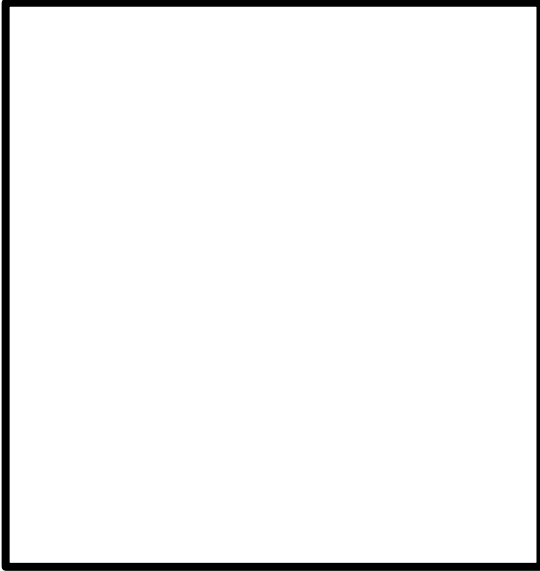
My child's dislikes or things that upset my child include:

- 1) _____
2) _____
3) _____

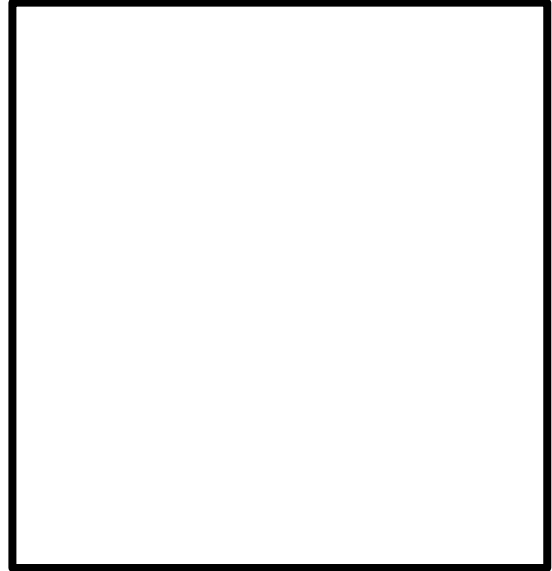
Suggestions for my child

- Use simple, direct language Allow time for processing questions or instructions
 Provide 2-3 choices when offering items/ activities Give '2 minute' warning before changes/transitions
 Keep lights dimmed Keep noise levels low
 Model any necessary procedures Create a visual schedule of necessary procedures
 Create a written schedule of necessary procedures
 Earn a reinforcer at the end of the visit _____
 Other: _____ Other: _____

1. First

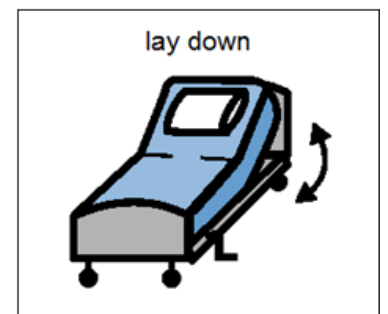
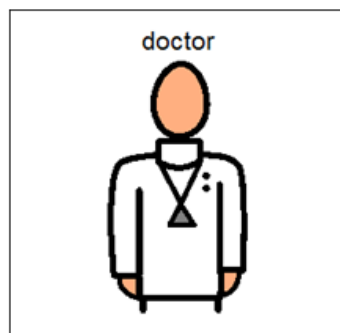
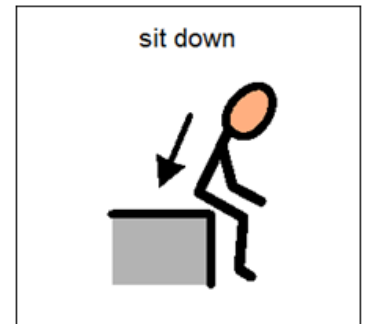
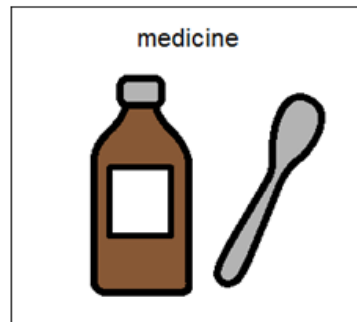
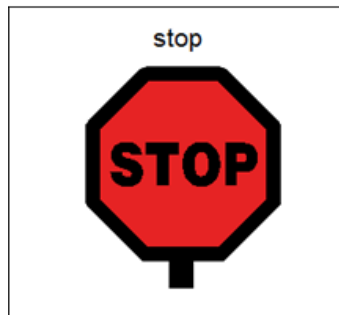
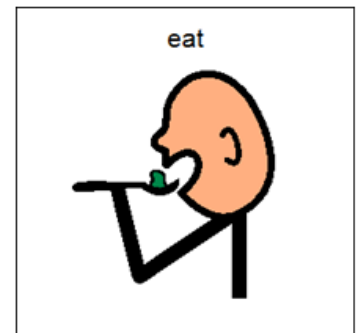
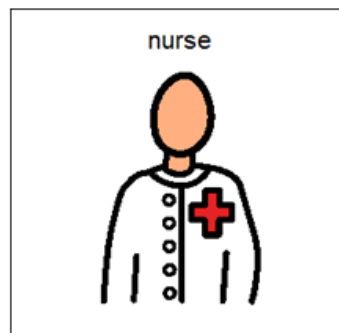
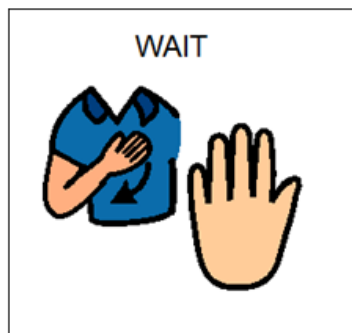
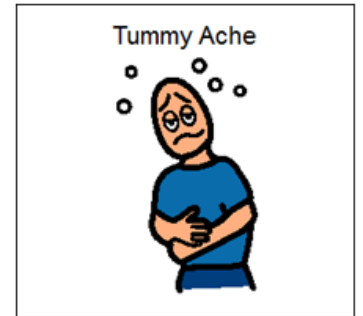
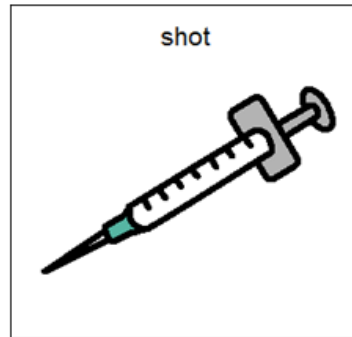
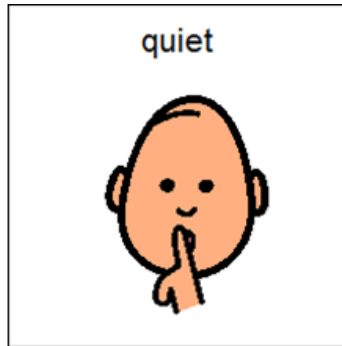


2. Then



Autism & Hospital Visits: How to prepare your child or support your staff to improve outcomes

Communication Support: Pictures



Autism & Hospital Visits:
How to prepare your child or support your staff to improve outcomes

bathroom



wash hands



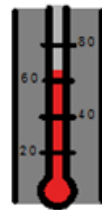
sad



hold hands



temperature



walk



open mouth



put in trash



TV



all done



happy



open eyes



Autism & Hospital Visits: How to prepare your child or support your staff to improve outcomes

Social Story: Audiology Appointment



I am going to see the ear doctor.



The doctor's office is in a big building on the 4th floor.



There will be chairs in the waiting room I can sit on.



We will check in to let the doctor know we're here.



We can take the elevator to the 4th floor.



When we get off the elevator we will walk to the doctor's office.



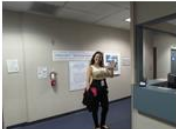
I can play with toys in the waiting room.



I can play with toys while I wait for the doctor.

Page 1

Page 2



The doctor will call my name when it's my turn.



We will go into the exam room.



I can touch the machine if I ask nicely.



The doctor will look in my ear; it won't hurt.



The doctor is nice and has toys in the room.



My parents can stay with me in the exam room.



It might feel cold and tickle my ears a little.



Next we will go into a special room with a window so the doctor can test my ears.

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Page 4



I will sit down at the table and get soap to clean my hands.



If I'm a good listener, I get to play with toys in the special room.



The doctor will help me put the headphones on to test my ears.



The headphones will be tight on my head but it won't hurt.



It's fun playing with toys in the special room.



I can't touch the wires of headphones until the doctor helps me.



Next I will try tiny earphones. I can touch them if I follow directions.



The doctor will put one in each of my ears.

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Autism & Hospital Visits: How to prepare your child or support your staff to improve outcomes



The doctor will help me put the headphones on to test my ears.



The headphones will be tight on my head but it won't hurt.



I will look like a silly bug with the tiny earphones in my ears.



The doctor will ask me questions and I will be a good listener.



Next I will try tiny earphones. I can touch them if I follow directions.



The doctor will put one in each of my ears.



The doctor will sit outside the window and look at me.



We will have to close the door, turn off the lights for a few seconds to check my ears.

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Page 8



Then I can take a break and walk to another room with more toys!

Ear mold Procedure Starts here



I can sit on mom or dad's lap while the doctor gets the tools ready.



I like the doctor's tools.



If I ask nicely the doctor will let me wear gloves too!



I can touch the tools to see that they don't hurt.



The tools won't hurt my hands or my ears.



Now it's time to look in my ears; it might feel cold and tickle a little.



It makes the doctor happy when I am a good listener.

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The doctor will use the tools to protect my ear with gauze and string. It might tickle.



The doctor will mix clay to put in my ear.



Soon it will be time to pull the clay out.



If I ask nicely, I can make a rubber bouncy ball with the left over clay!



It will feel cold when the clay goes in my ear; it won't hurt.



I can play with the toys while the clay in my ear dries.



Everyone will be proud of me for being brave at the ear doctor!



I might get a sticker or a treat from the dell downstairs when we are all done.

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Autism & Hospital Visits: How to prepare your child or support your staff to improve outcomes

Social Story: Speech and Language Therapy Evaluation Appointment



I am going to see the speech therapist.



The speech therapist's office is in a big building on the 3rd floor.



We will wait in line to check in.



After we check in, I can play in the waiting room.



We can take the elevator to the 3rd floor.



We will get off the elevator and go check in.



I need to stay close to my parents and follow directions in the waiting room.



I can sit in a chair and look out the windows in the waiting room.

Page 1

Page 2



We will wait in line to check in.



After we check in, I can play in the waiting room.



The speech therapist will call my name when it's my turn to go play.



I will follow directions and walk with the therapist down the hallway.



I need to stay close to my parents and follow directions in the waiting room.



I can sit in a chair and look out the windows in the waiting room.



We will clean our hands and sit down to play.



It's so fun to follow directions and play with the speech therapist!

Page 3

Page 4



The therapist might ask me to make funny faces in the mirror.



The therapist might ask to touch my lounge with a soft sponge.



If I am good listener, I can play iPad games too!



I will wait for my turn and follow directions.



If I follow directions, I will get to play with more toys!



We will talk about pictures while we play.



I can have a lot of fun with the speech therapist.



I will follow directions and show them I can use my words.

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We might walk to another room to play.



I might visit the group room and sing songs.



There's a swing in the gym. I will be a good listener in the gym.



There is a tunnel in the gym as well. Tunnels are fun.



If we go to the gym, I will take my shoes off. I can ask for help.



I will wait and follow directions before I play in the gym.



I will follow directions in the gym and I will have fun!



When I am done playing in the gym I will put my shoes back on. I can ask for help.

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Page 8



We will walk down a long hallway back to the office.



I can pick a sticker to take home for being such a good listener with my speech therapist.



Everyone will be proud of me. It's fun to play with the speech therapist!



It's time to leave. We will say goodbye and I leave the speech therapists office.

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Autism & Hospital Visits: How to prepare your child or support your staff to improve outcomes

Social Story: Cardiology/Angiogram



I am going to see the doctor today!



After we park the car, we will walk into the hospital. It's a big building where the doctor works.



When it's my turn to see the doctor, they will call my name and I will walk with them to see how big I am!



I will take my shoes off before I the nurse checks how big and tall I am.



We will wait in the heart center for them to call my name. I can sit in the big chairs.



We will wait for them to call my name, I can play quietly in the waiting room.



I will show the nurse I am big and strong. I will stand still so the nurse can weigh me and measure me.



Then we will walk down the hallway to the exam room. My parents can come with me!

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Page 2



There are machines with lights and sounds in the exam room. There is a TV too!



I won't touch the machines but I can watch the TV!



Now it's time to get started! The nurse will put cold wet stuff on the machine to check my heart.



I will lift my shirt up. It will feel cold and wet on my skin. Its won't hurt.



The nurse will get things ready to check my heart. I will watch TV and wait quietly.



I will lay down and my parents can stay with me and hold my hand.



When it touches my skin, the computer will show pictures of my heart!



I can look at the pictures of my heart or I can watch TV. I need to lay down and be still.

Page 3

Page 4



It doesn't hurt when the doctor looks at my heart. I can hold hands with my parents if I'm scared.



I might get to change into a dressing gown or I might stay in my own clothes.



Sometimes the doctor has stickers for doing a good job!



There is a McDonald's by the doctor's office that I can visit after my appointment.



Soon I will be all done and I can sit up.



Give fives for being so brave at the heart doctor! It wasn't scary and it didn't hurt!



There is a gift shop that I can visit after my doctor's visit.



Then it will be time to go back to the car and go home!

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Autism & Hospital Visits: How to prepare your child or support your staff to improve outcomes

Social Story: EEG



I am going to see the doctor.



First we will park the car.



I can stand on the feet while I wait.



I can look at the fish tank while I wait.



The big white doors will open so we can walk in.



There will be a desk with lots of colors and bright lights.



We will check in so they know I am here.



We will walk down long hallways together. I will not be alone.

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Page 2



When I get to my room there will be a bed and a computer.



The nurse will show me cool rainbow wires before we start. I can touch them if I want!



When it's time to lay down I can hold the pinwheel.



The nurse will squeeze some stuff onto a towel by my head.



The nurse will let me play with a pinwheel before we start!



We can pretend the wires are scoops to dip in a bowl of ice cream!



The nurse will be gentle and put the jelly on my hair.



Then the nurse will scoop the "ice cream" out while I lay down and relax.

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Page 4



My job is lay still while the nurse puts jelly on my hair.



The nurse will put the ice cream scoops on my head while I look at my toy.



I get to relax and blow the pinwheel.



Next the nurse will turn on a flashing light! It looks cool and helps them make sure I am not sick.



It tickles and makes kids smile when they get ice cream scoops on their head!



The nurse will wrap my head with gauze to make sure my wires don't fall off.



The nurse is nice and will help me take the ice cream scoops off when I am done.



They will wash my hair and wrap it to keep me warm!

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Autism & Hospital Visits: How to prepare your child or support your staff to improve outcomes



Sometimes the doctor has stickers for doing a good job!



There is a gift shop that I can visit after my visit.



There is a McDonald's by the doctor's office that I can visit after my appointment.



Then it will be time to go back to the car and go home!

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Social Story: Surgery



I am going to see the doctor.



First we will park the car.



I can stand on the feet while I wait.



I will wait with my parents until they are ready. I can watch TV and play with my favorite toy.



The big white doors will open so we can walk in.



There will be a desk with lots of colors and bright lights.



I can also play in the activity room while I wait for the staff to call my name.



The nurses and doctors are here to help me grow big and strong!

Page 1

Page 2



I will stand on the scale so they can see how big and tall I am growing!



The nurse's aide will connect my finger to the computer to check on me. It won't hurt.



I will feel so brave with the wires on my finger, my chest and my arm!



The nurse's aide will wait with me while the machines tell them I'm healthy!



The nurse's aide will want to hear my heart beat too! It won't hurt.



After my heart, the nurse's aide will place a wrap on my arm. It will be tight for a short time. It won't hurt.



There will be machines and cool stuff to look at while the nurse's aide checks me. It won't hurt.



We will take the wires off and put a gown on to get ready for surgery.

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Autism & Hospital Visits: How to prepare your child or support your staff to improve outcomes



I get my own mask! First we have to make sure it fits me.



We'll use lip gloss that smells really good!



The nurse will show me what to do and keep me safe while I am with the doctors.



I will say bye to my parents and walk with the nurse. The nurse will help me if I am scared.



I can help put the lip gloss in the mask.



It fits! I'm all set.



I will lay down and they will put seat belts on me to keep me safe.



The nurse will take my temperature and put straps on my hands. It won't hurt.

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Page 6



Then it's time to go meet my doctor. It's fun to lay down while my bed moves.



The doctor will put my special mask on that fits just right and I will fall asleep for a while. It won't hurt.



I can get presents for being brave at the doctor!



I even get a yummy popsicle when I am all done.



When I wake up, I can watch TV and see my parents!



Everyone will be proud of me for being brave and strong.



The nurses will give me stickers for doing a good job!



Later, I can look at the train set and eat my popsicle!

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There is a McDonald's by the doctor's office that I can visit after my appointment.



There is a gift shop that I can check out after my visit.



Soon it will be time to go to the car and go home!

Page 9

Autism & Hospital Visits: How to prepare your child or support your staff to improve outcomes

Social Story: Radiology/X-Ray



I am going to see the doctor.



First we will park the car.



I can stand on the feet while I wait.



I can look at the fish tank while I wait.



The big white doors will open so we can walk in.



There will be a desk with lots of colors and bright lights.



We will check in so they know I am here.



A nurse will call my name when it is time to go get my x-ray.

Page 1

Page 2



We will walk down long hallways together.



When we get to the room it will be dark.



When I lay down the nurse will strap me in like a seat belt.



Then the nurse will put a heavy blanket on me.



The lights have to be off for the special machine that takes my x-ray.



My mommy or daddy will stay with me in the x-ray room.



My Mommy or Daddy has to wear a silly shirt and will be next to me during my x-ray.



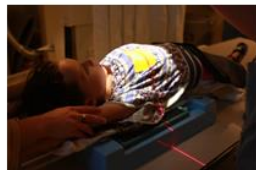
Then I have to put my arms up so they can take my picture.

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Page 4



My Mommy or Daddy can hold my arms to help me keep them up.



Then the nurse will take my picture with the big machine.



After my x-ray, I get to look at the train!



I might even get a sticker for good listening during my doctor's visit.



That was easy! The x-ray is all done.



Everyone will be so proud of me for being brave!



Maybe I can visit McDonald's or the gift shop when I am done!



Then it will be time to go back to the car and go home!

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Page 6

Autism & Hospital Visits: How to prepare your child or support your staff to improve outcomes

Social Story: Ultrasound



I am going to see the doctor.



First we will park the car.



I can stand on the feet while I wait.



I can look at the fish tank while I wait.



The big white doors will open so we can walk in.



There will be a desk with lots of colors and bright lights.



We will check in so they know I am here.



A nurse will call my name when it is time to look at my tummy.

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Page 2



The room will be dark when I walk in because the machines are sleeping.



I can look at the machines while I wait to get started.



The nurse will show me what it's like before it touches me.



It won't hurt when the nurse touches my tummy.



The nurse will tell me what is going to happen.



The nurse will put gooey stuff on the machine first.



But it will feel cold because it comes out of the fridge!



The nurse will lift my shirt and touch my tummy with the cold wet stuff. It won't hurt.

Page 3

Page 4



After they see my tummy, I can look at the train!



I might even get a sticker for good listening during my doctor's visit.



Maybe I can visit McDonald's or the gift shop when I am done!



Soon it will be time to go home!

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Acknowledgements

The creation of this toolkit was made possible by Autism Speaks. The content was written and designed by Chelsea McCawley, MSc, BCBA with support from Christina Corsello, PhD, Clinical Director of the Autism Discovery Institute, Kristin Gist, MA, Director of Developmental Services and Linda Martin, MME, MT- BC, Certified Neurologic Music Therapist. Collaborative efforts included lecture based trainings throughout hospital departments and valuable feedback received from hospital staff and family members of children with ASD within the local community. The children featured in the toolkit are valued contributors and the staff working across the hospital departments that are featured in the social stories made this project possible.

The Autism Discovery Institute at Rady Children's Hospital, San Diego serves children of all ages with ASD and their significant others through intensive parent training, social skills groups, cognitive behavioral therapy as well as diagnostics and consultation. The ADI also has an in-house inclusion school for children with ASD ages 18 months to five years old where social skills are the focus on intensive behavioral intervention. Continual liaison with the population served in the clinic and school served as a guide for the material that is included in the toolkit.

Our aim is to share this resource with people across the nation to support children, families and service providers in hospital settings and contribute to improved outcomes for patients with ASD and their families.

