



Mass General Brigham
for Children

LURIE CENTER FOR AUTISM

Healthcare Access for All: Improving Medical Experiences for Individuals with Autism and Intellectual and Developmental Disabilities (ASD/IDD)

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LTSS & Health Equity Subcommittee

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How We Can Help

We help patients and their families with medical conditions by teaching them how to manage pain, anxiety, and depression, and how to adhere to prescribed medical care. Examples include:

- Taking medicine
- Behavioral management of pain and anxiety
- Breathing treatments and respiratory assistance
- Tracheostomy care
- Restricted diet
- Exercise programs
- Wearing glasses or hearing aids
- Wound care
- Dressing changes
- Repeated blood tests
- Spinal taps
- Intravenous catheter insertion
- Chemotherapy
- Transfusions
- Radiation therapy
- Dialysis
- Bowel and bladder management
- Stoma care
- Self-catheterization

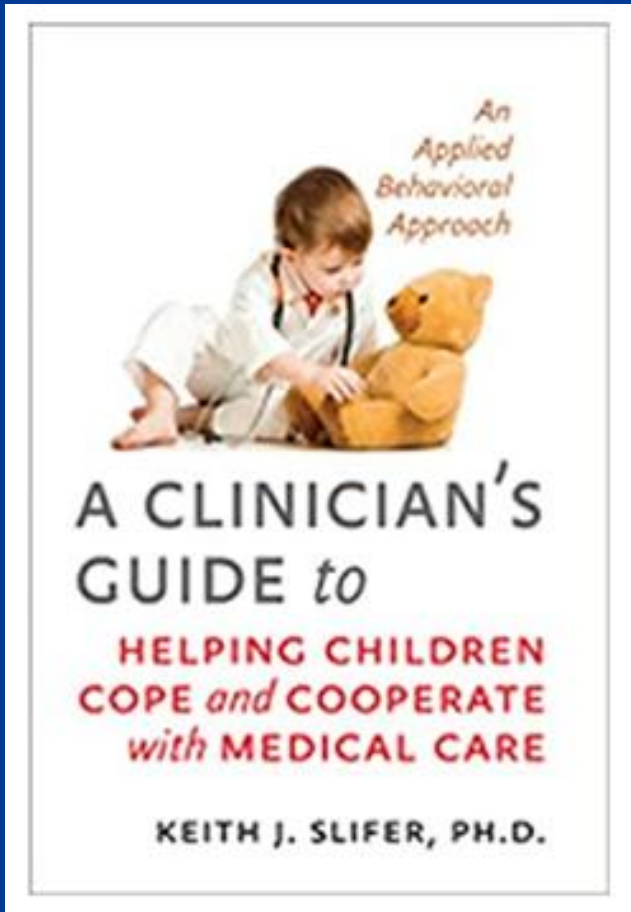


Agenda

- Understanding Barriers to Healthcare for Individuals with ASD/IDD
- Preparing for Medical Visits
 - Steps to Decrease Anxiety
 - Social Stories
 - Desensitization
- Collaborating with Medical Providers
- Resources
- Questions/Discussion



Strategies reviewed have been found to be effective in individuals who are typically/developing and individuals with ASD and Neurodevelopmental Disabilities, however...



Treatment approaches must be ***Individualized based on each individual's preferences, cognitive profile, communication, and lived experiences***

Understanding Barriers to Healthcare



Understanding Healthcare Access Challenges

Individuals with disabilities can become overwhelmed in busy clinic settings and may experience:

- Communication challenges
- Sensory sensitivities
- Disrupted routine/unfamiliar environments
- Difficulty tolerating physical exams, medical procedures, and preventative health screenings
- Emotional and behavioral melt-downs



Understand Healthcare Access Challenges

Impact on Healthcare Outcomes:

- Difficulty adhering to recommendations
- Delays in care
- Cancelled or incomplete care
- Negative medical experiences



Barriers to Medical Care

Individuals with autism spectrum disorder (ASD) experience:

- ***Greater number of medical visits*** than typically developing peers.
- Length of visit is almost ***2 times longer***
- Experience a ***poorer quality of health care***

Noncompliance with medical care is a widespread problem, particularly for individuals with disabilities

- Sometimes results in **restraint, sedation, or anesthesia**, which can alter test results and cause unnecessary stress to the individual
- Can also result in delays or incomplete care



(Gurney et al., 2006; Liptak et al., 2006; Zuckerman, Lindly, Bethell, & Kuhlthau, 2014; Bultas, McMillin, & Zand, 2016)

TABLE 1. Perceived barriers during the health care encounter for children with autism

Health care providers (49 responses)			Parents (45 responses)		
Challenge	No. of respondents*	%	Challenge (theme)	No. of comments†	%
Child behavior during encounter	38	78	Provider/staff doesn't understand impact of ASD	19	42
Uncooperative, unable to completely examine	35	71	Child behavior during encounter	11	24
Child fears about the examination	33	67	Environmental issues (e.g., waiting, lights, noise)	11	24
Difficulty communicating with child	27	55	Face pace of office	8	18
Parent overwhelmed during encounter	26	53	Child communication deficits	5	11
Child fears about the provider	23	47	Need case management for child	4	9
Parent distracted by child	22	45	Parent distracted during encounter	3	7
Family dynamics	17	35			
Parent beliefs about health care	13	27			
Office environment	11	22			

Note. ASD, autism spectrum disorder.

*Respondents were able to choose more than one.

†Respondents may have provided more than one comment.

Medical Trauma

- **Medical trauma** is “a set of psychological and physiological responses to pain, injury, serious illness, medical procedures and frightening treatment experiences”
- People with Intellectual Disability are **3-4 times more likely** than those without ID to experience adverse events such as abuse, neglect, and medical trauma.
- **A negative experience can have long-lasting effects.**



(Brenner et al., 2018; Daveney et al., 2019; Haruvi-Lamdan et al., 2018; International Society for Traumatic Stress Studies, 2025)



Trauma Informed Care Model

People with autism spectrum disorder and intellectual/ developmental disabilities **require trauma-informed care.**

Some core principles:

- Safety and Trust
- Empowerment and Choice
- Trauma-Sensitive Communication
- Proactive Care Planning



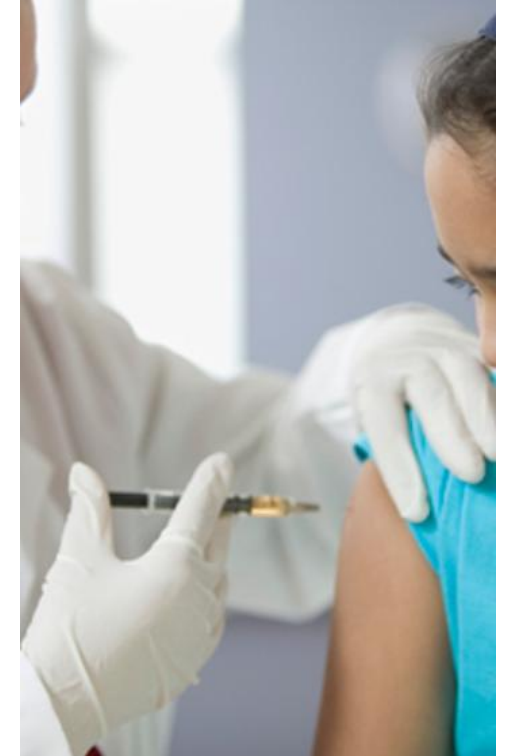
(Houck, E. J. & Dracobly, J. D., 2022)

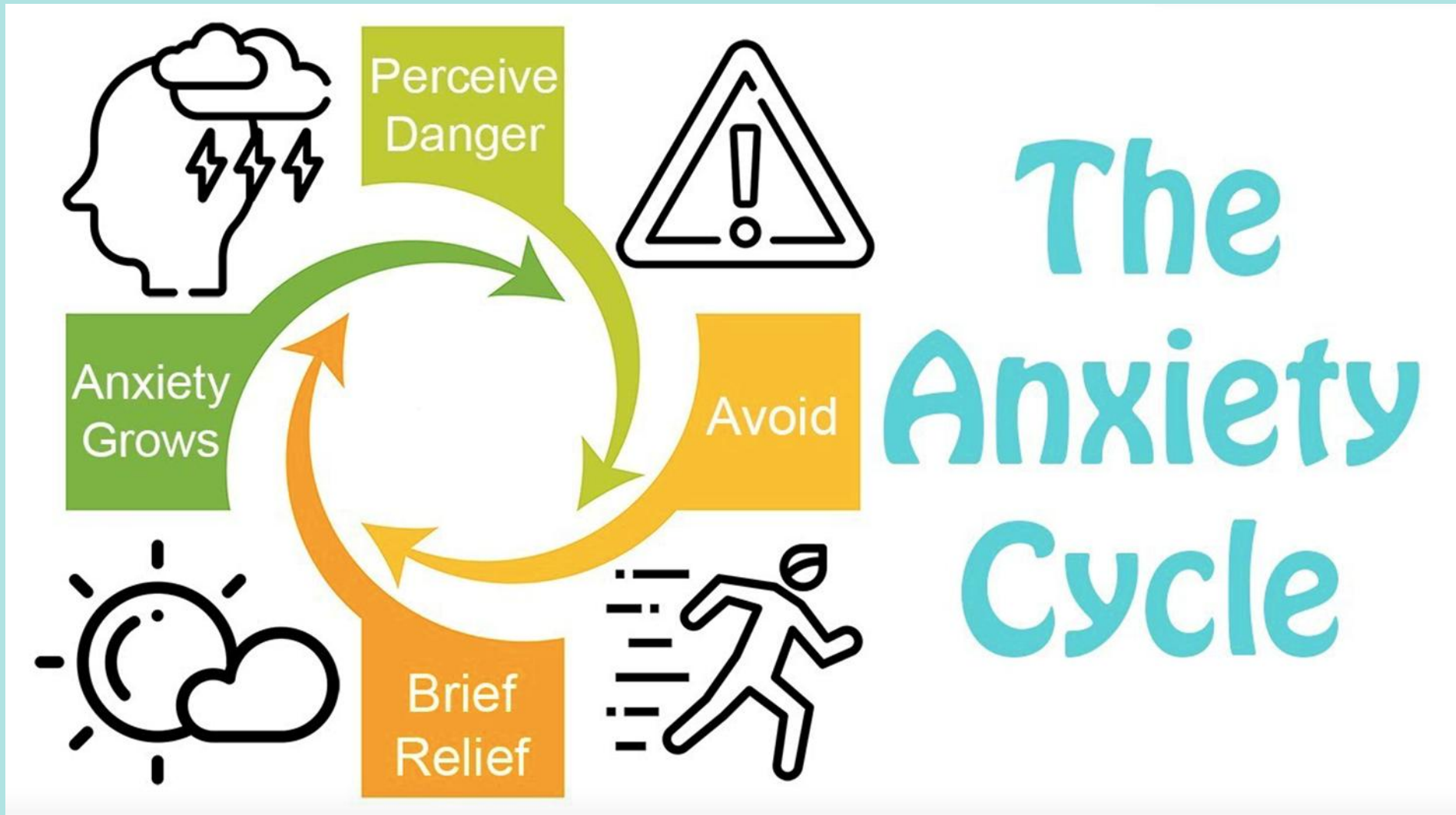
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Preparing for Medical Visits



Examples apply to needle sticks, but can apply to many different types of procedures





Step 1: Talk About It!

Talking about the vaccine (blood draws/procedures) & why it is important

- What is a vaccine? (describe in language familiar to the individual)
- Talk about benefits of getting a vaccine: Protects you from getting very sick, allows you to see friends/family, do activities you enjoy
- Talk about risks of not getting a vaccine: you could get very sick, it may not be as safe for you to see friends/family, do activities you enjoy
- Be honest about what to expect (you will feel a brief pinch/pain, your arm may be sore...)



Step 2: Read a Social Story/Look at Pictures

- **Read a social story/ look at pictures** of what may happen during a procedure
- Match the **individual's communication skills; modify existing resources**
- **Personalize** – Add support person, coping strategies, preferred interests, familiar language

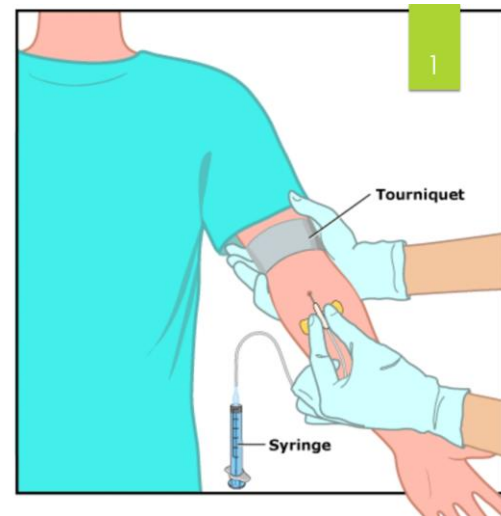
Getting a COVID-19 Vaccine

 COVID-19 is a virus that has made many people very sick. Some people have died.	 Now there is a vaccine. The vaccine is in a shot.	 The vaccine shot puts medicine in my body to keep me from getting COVID-19.
 When it's my turn, I can get the COVID-19 shot to stay healthy.	 I will go to a doctor's office or the drug store to get my shot.	 I will check in when I arrive, sit, and wait for the nurse to call my name.
 I will roll up my sleeve. The nurse will rub a cold wipe on my arm. It might smell funny.	 Then the nurse will give me the vaccine shot. It will feel like a pinch or a prick. I will sit very still.	 The nurse will put a band-aid on my arm.

**Blood Draw :
What I need
to know**

HEALTHCARE ACCESS FOR
AUTISM PROJECT
MADE POSSIBLE BY THE C.J.L.
FOUNDATION

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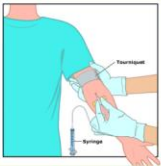


I may feel nervous, but it's okay because my family member/caregiver will go with me. I will not be alone.

First, I will get my blood drawn, then I will go home.



_____ will come with me

FIRST BLOOD DRAW	THEN HOME OR _____ (insert preferred activity)
	



Visual Steps of a Blood Draw



Sit in Chair



**Place Arm on
Arm Rest**



**Nurse feels
arm/veins**



**Tourniquet gives
a tight squeeze**



**Clean with
Alcohol Wipe**



**Needle goes in;
brief pinch**



**Hold still for a
few minutes**



**Tube collects
blood**



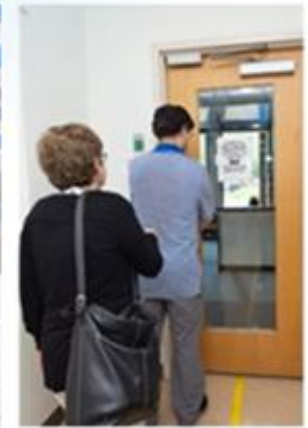
**Needle comes
out**



Gauze on arm



**Adhesive wrap
on arm**



**All done –
Time to Go!**

Step 3: Watch videos of someone completing a procedure

- Identify example of individuals who do not show aversive reactions
- When possible, accompany caregiver/family member to model (e.g. blood draw, vaccines)



Step 4: Become Familiar with the place you will complete the procedure

- Look at pictures or videos
- Make a visit ahead of time with no expectations
- Think of unsuccessful visits as an “exposure” to the setting



Step 5: Practice the Steps of a Procedure

- You may **model for your loved one** (they can be the doctor”, you can be the “patient”)
- **Practice on a stuffed animal**
- **Practice the steps with the individual**



Systematic Desensitization



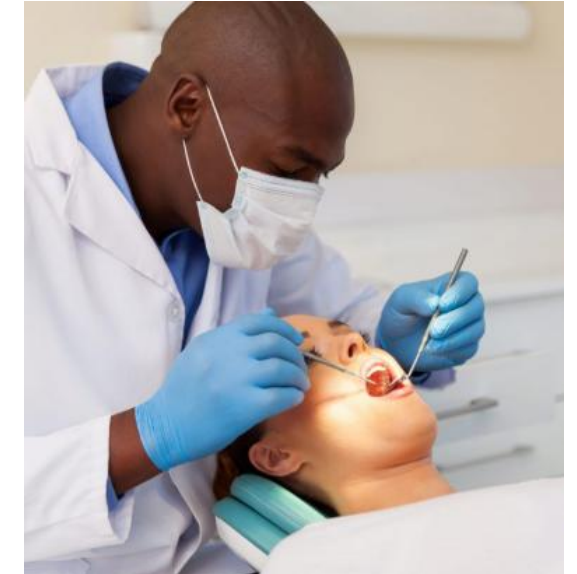
Systematic Desensitization



**Gradually & Systematically
Increase Exposure to Feared
Stimuli**



***Combines exposures with
reinforcement & relaxation
strategies***



Can Apply To Many Procedures:
Needle Sticks, EEG, MRI, Dental Care,
CPAP, Hearing Aids, Glasses, etc.

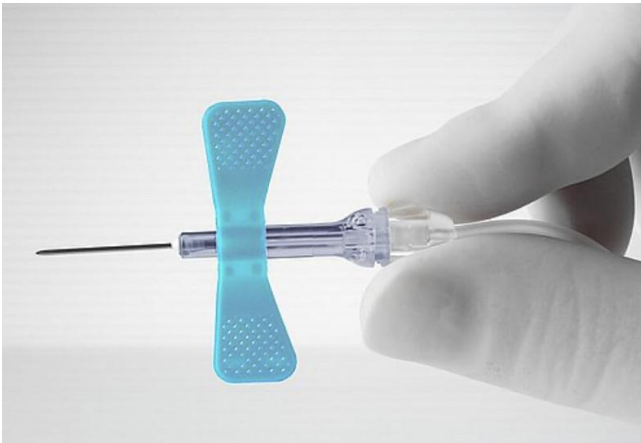


Hierarchy of exposures

Patient-Led, Data Driven

Support Communication

Accommodate



Example Task Analysis for Blood Draw (Slifer et al., 2011)

- ☐ Walk into room
- ☐ Sit in chair and begin watching DVD
- ☐ Place arm in position
- ☐ Adjust clothing to expose site
- ☐ Put on gloves
- ☐ Touch/probe site
- ☐ Tie tourniquet on upper arm
- ☐ Apply alcohol
- ☐ Prepare mock needle (0/4, 1/4, 2/4, 3/4, 4/4 needle size)
- ☐ Apply mock needle (0/4, 1/4, 2/4, 3/4, 4/4 needle size)
- ☐ Manipulate tubing/vial with needle in place
- ☐ Needle in place for 5 seconds
- ☐ Needle in place for 10 seconds
- ☐ Needle in place for 30 seconds
- ☐ Needle in place for 1 minute
- ☐ Needle in place for 1.5 minutes
- ☐ Needle in place for 2 minutes
- ☐ Manipulate tubing/vial with needle in place (if actual needle, qualified medical staff only)
- ☐ Perform needle stick with real needle (qualified medical staff only)



Sit in Chair



**Place Arm on
Arm Rest**



**Nurse feels
arm/veins**



**Tourniquet gives
a tight squeeze**



**Clean with
Alcohol Wipe**



**Needle goes in;
brief pinch**



**Hold still for a
few minutes**



**Tube collects
blood**



**Needle comes
out**



Gauze on arm



**Adhesive wrap
on arm**

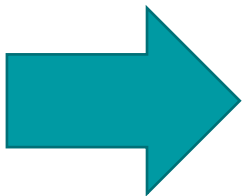


**All done –
Time to Go!**

Desensitization – Vaccines



Can Use
Varied Sized
Mock Needles



BSTEAN Syringe Blunt Tip Needle and Cap - 10ml, 5ml, 3ml, 1ml Syringes 14ga 16ga 18ga 20ga Blunt Needles - Oil or Glue Applicator (Pack of 10)

\$7.89

Get Fast, Free Shipping
Amazon Prime
& FREE Returns

Walk into room
Sit in chair and begin watching video
Place arm in position
Adjust clothing to expose site
Put on gloves
Touch/probe site
Apply alcohol
Prepare mock needle
Apply mock needle
- Black cap, no needle - Black cap, small needle - Green cap, longer needle
Needle in place for 5 seconds
Needle in place for 10 seconds
Band Aid/Cotton

- Black cap, no needle
- Black cap, small needle
- Green cap, longer needle



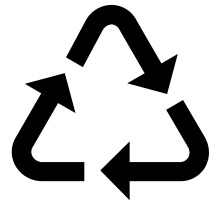
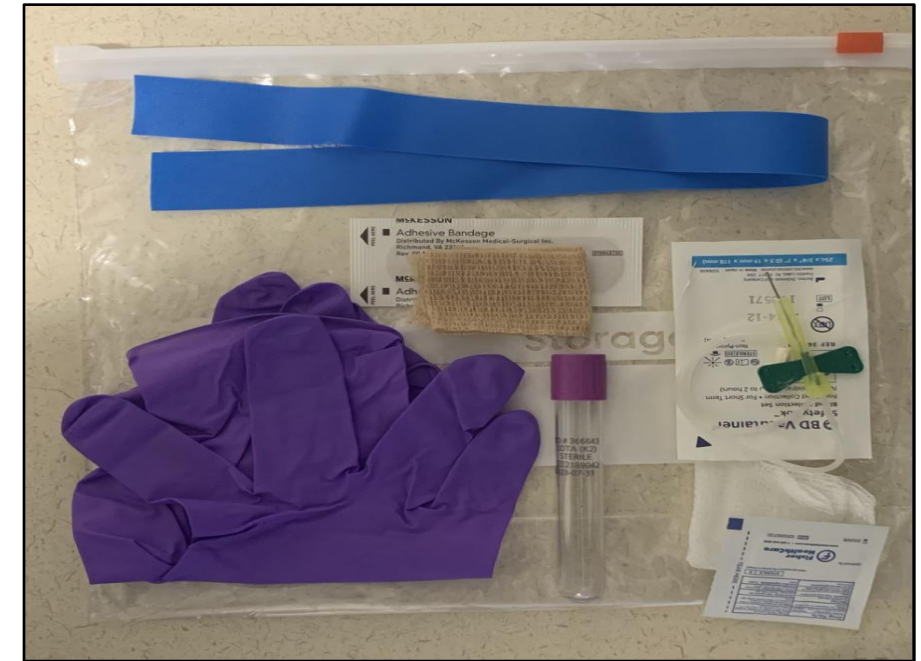
Desensitization – Who Can Help?

- **Parents/Caregivers**
- **Board Certified Behavior Analysts (BCBAs) and Related Professionals**
- **Psychologists**
- **Child Life Specialists**
- **Lived Experiences!**
 - A “failed attempt” may be a steppingstone to future success.
 - End on a good note and try again later.
 - Consider regular or more frequent visits (e.g. dental cleanings/visits)



Lurie Center Blood Draw Toolkit

- Launched in September 2024
- Given to patients with fear/anxiety around blood draws or history of unsuccessful blood draw
- Includes:
 1. Social story on blood draws
 2. Caregiver tip sheet to prepare
 3. Physical toolkit with materials to practice at home; paperclip in lieu of a needle
- Families have reported success in using the toolkit to complete blood draws, or decrease anxiety



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Collaborating with Medical Providers



Advocacy and Communication with the Clinic



Caregivers are experts on their loved one or client and are valuable partners to clinic providers and staff.

Proactive communication between families/caregivers and clinic leadership is key.

Recommended staff to speak with:

- Practice manager
- Nurse
- Social Worker

Key components could include:

- Discussing disability accommodations and if pre-medication is needed
- Discussing what tasks are planned and who will be involved in the visit
- Sharing resources (e.g., Social stories)



Strategies and Accommodations for Common Triggers

Triggers	Strategies
Transportation and Transitions	Transportation safety equipment, visuals, arrive early/allow extra time, patience, clustered care in room. Telehealth, when possible
Waiting	First appt of day/after lunch, bring snacks/activities, call ahead to confirm if physician running on time, entry/exit plans, movement breaks
Crowded or loud waiting room	Wait in car/outside, request separate room, headphones, expedite to exam room
Unfamiliar people or routines	Social story/visual, online photos, pre-visit for familiarization
Being touched	Preview, practice, model, ask for permission, minimize
Vitals	Social story/visual, model, choices, skip(!)
Needles (including fear of)	Prepare, motivate, reassure when not occurring, vibration tools, topical numbing agents



Accommodation Plans: Proactive Care Planning

Healthcare Passports or Accommodation Care Plans are highly effective tools **when visible** to healthcare staff

MGH: MGH Patient Accommodations Care Questionnaire and Plan

- Completed in collaboration with family. Viewable from highly visible locations in Electronic Medical Record. Provides key info about communication, safety, and accommodations for common healthcare tasks.



The screenshot shows the header of the MGH Patient Accommodations Care Plan form. It includes the Massachusetts General Hospital logo and name, followed by the title 'MGH Patient Accommodations Care Plan' and a subtitle 'For patients who are Autistic, on the Autism Spectrum, or with Intellectual/Developmental Disabilities'. The form explains that it outlines how to best support and provide accommodations for the patient and their family, and that the completed plan is placed in the electronic medical record. It also includes fields for 'Patient Name' and 'Date of Birth' with instructions to click or tap to enter text.

AASPIRE Autism Healthcare Accommodations Tool: Creates a personalized letter outlining accommodation needs

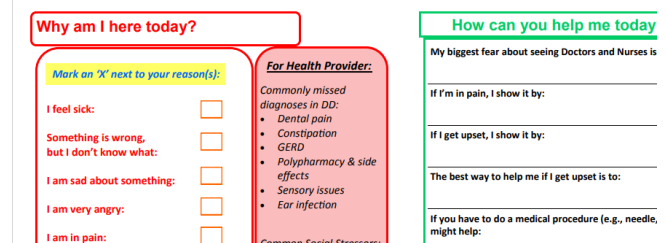
- www.researchautism.org/healthcaretoolkit



The screenshot shows the homepage of the AASPIRE Autism Healthcare Accommodation Tool. It features the 25th Anniversary logo for the Organization for Autism Research (OAR) and a navigation bar with links for Families, Self-Advocates, Educators, Researchers, Get Involved, and About Us. A prominent orange 'DONATE' button is also visible. Below the navigation bar, the title 'AASPIRE Autism Healthcare Accommodation Tool' is displayed in a teal banner, followed by the section 'Personalized Accommodation Reports'.

H-CARDD (Canada): Resources and toolkits for providers, caregivers, and people with I/DD. Checklist patients or caregivers complete.

- H-CARDD: Health Care Resources - | CAMH



The screenshot shows a portion of the H-CARDD checklist form. It is divided into two main sections: 'Why am I here today?' and 'How can you help me today?'. The 'Why am I here today?' section includes a list of reasons for the visit, such as 'I feel sick', 'Something is wrong, but I don't know what', 'I am sad about something', 'I am very angry', and 'I am in pain', each with a checkbox. The 'How can you help me today?' section includes questions about the patient's biggest fear, how they show pain or upset, the best way to help them if they are upset, and how to help them with medical procedures. It also includes a section for 'Common Social Stressors'.

Patient Navigator for Autism and Developmental Disabilities



Karen Turner, MS, OTR/L

Works with providers to enhance understanding of unique communication, sensory, and behavioral needs

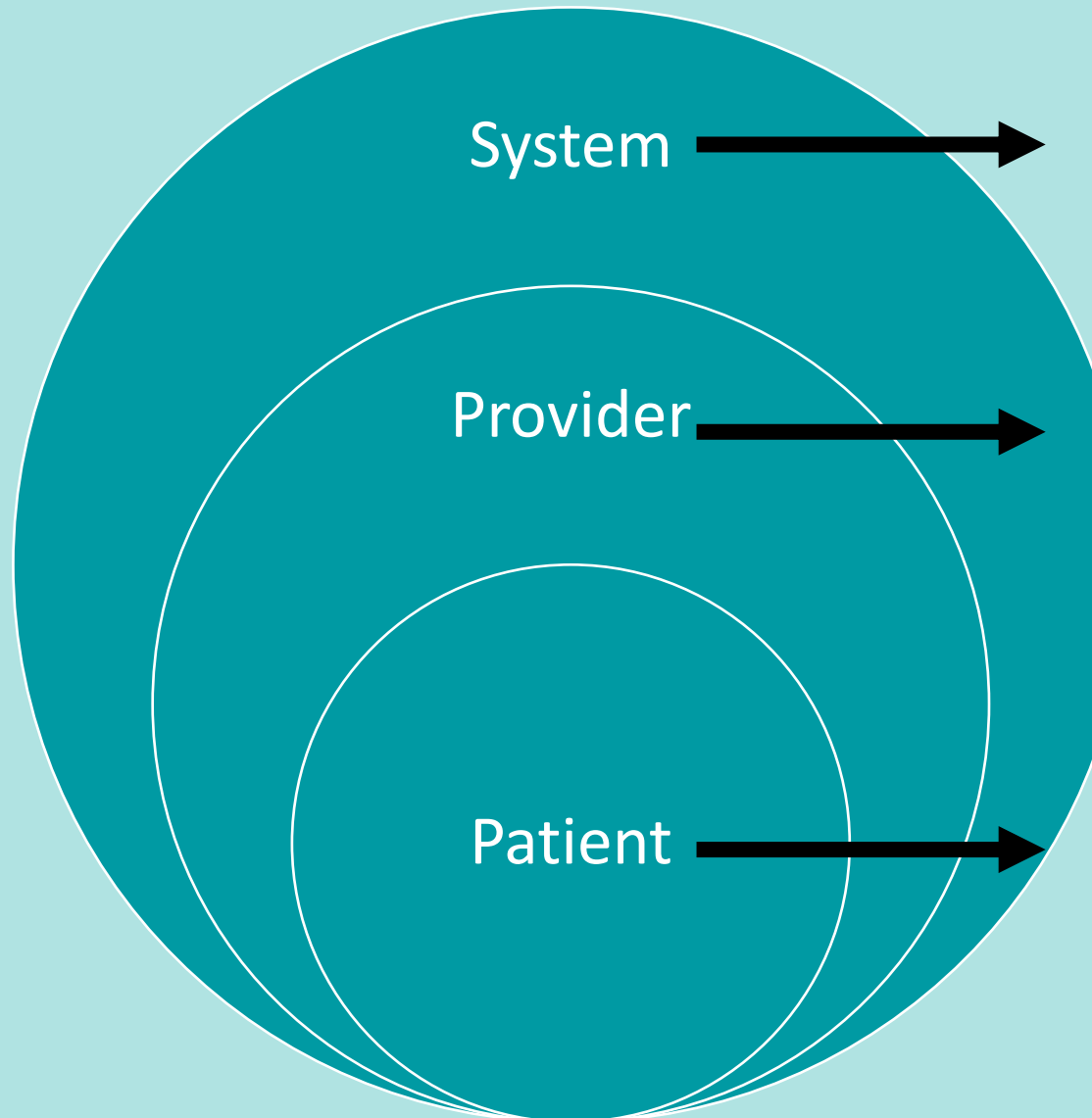
Helpful to consult for inpatient procedures or procedures with increased complexity. Outside of MGH, you may want to consult child life professionals or staff familiar with ASD/DD

Helps to create Patient Care Plan for Autism/IDD at MGB

Information regarding Karen Turner's Role:
<https://www.massgeneral.org/children/autism/lurie-center/karen-turner>



Collaboration



How can the larger system support patient experiences?

- Train providers to become familiar and comfortable with conducting procedures with ASD/IDD populations
- Support Patient-Centered Care through support from Patient Navigator*

What can a provider do to support a patient?

- Discuss urgency of results
- Inform family of strategies
- Consider Accommodations
 - Reduce wait times
 - Alternatives that may make the procedure easier
 - Ordering topical Analgesics/Medication

What can a family and patient do to prepare?

- Set Expectations/Talk about it
- Practice Procedure
- Prepare (e.g., drink fluid, medication if needed, apply topical analgesic, bring items for distraction, choose optimal clothing such as short sleeves)



Resources



Social Story Resources

Boston Medical Center Social Stories;

<https://bmcautismfriendly.github.io/socialstories/>

Rady Children's Health – Healthcare Social Stories

<https://www.rchsd.org/autism-friendly-health-system-initiative/healthcare-social-stories/>

Boston Children's Hospital

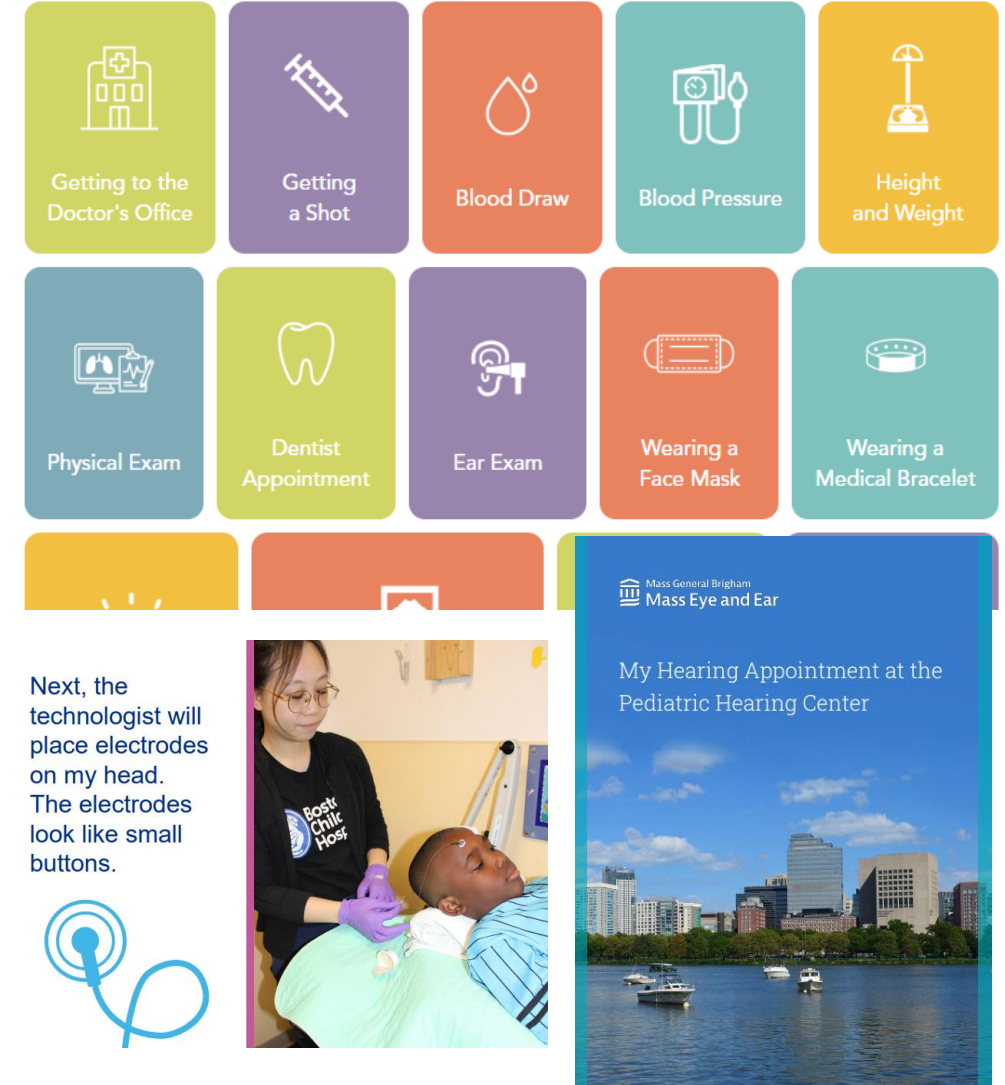
<https://www.childrenshospital.org/patients-families/you-arrive/your-visit/my-hospital-story>

Mass Eye and Ear – Hearing Appointment

<https://www.masseyeandear.org/assets/MEE/pdfs/ent/pediatric-hearing-center-visitor-handbook.pdf>



Autism Friendly Social Stories



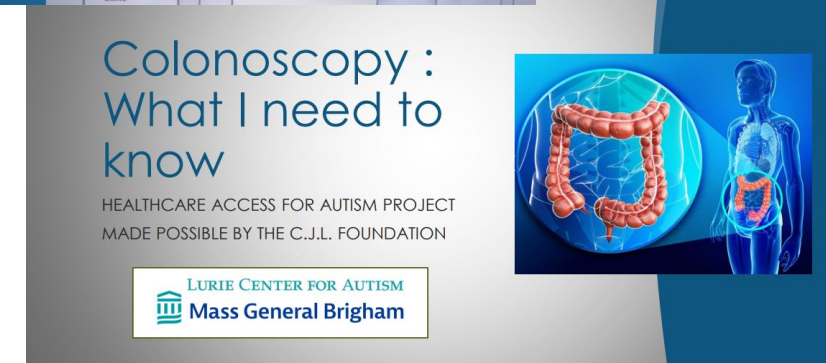
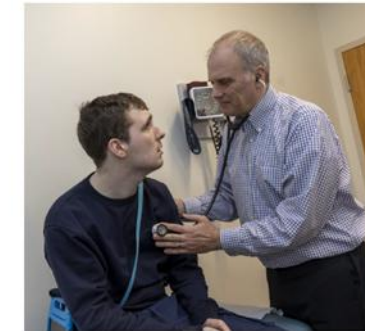
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Healthcare Access for Autism

- Thanks to the generous support of the C.J.L. Foundation
- Goals:
 - Creating social stories for preventative care procedures
 - Provide training to healthcare providers
 - Focused on adult care
- Blood Draws
- Vaccines
- Primary Care Visits
- GYN exams
- Colon cancer screening
- Breast cancer screening
- Hearing & Vision Tests
- And more...



Scan for Preventative
Care Resources & More



Blood Draw Toolkit



- Website:** [Blood Draw Toolkit Link](#)

37



Virtual Workshops for Parents/Caregivers



Parent and Caregiver Workshops

Lurie Center for Autism invites parents, guardians, and families to participate in our Parent and Caregiver Workshops.

All workshops are held virtually and open to the public. Registration is required.

To register, click [Workshop Registration](#) at the bottom of each page.



Need to access a digital copy? Scan here

www.luriecenter.org | LurieCenter@mgb.org | 781-860-1700.

REV. 01.2026.2

Virtual workshops open to ALL

Medical Care Topics:

- Pill Swallowing
- Fear of Needles
- **Desensitization Workshop**



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Adult Autism Health Resources

- Information about Autism Competent Care
- Health Care Rights
- Navigating health insurance for autistic adults
- Caregiver checklist
- The Language of Autism
- Information about transition to adulthood

GETTING STARTED

AAHR Health Care Toolkit

Guiding caregivers and autistic adults through health care resources and information across the lifespan.

There are many critical junctures in the lifespan of an autistic adult. We've assembled information and resources about how to find and advocate for good care.



References

- Ames J, Morgan E, Onaiwu M, Qian Y, Massolo M, Croen L. Racial/ethnic differences in psychiatric and medical diagnoses among autistic adults. *Autism Adulthood*. 2022;4(4):290–305. doi:10.1089/aut.2021.0083.
- Doherty M, McCowan S, Shaw SC. Autistic SPACE: a novel framework for meeting the needs of autistic people in healthcare settings. *Br J Hosp Med (Lond)*. 2023;84(4):1–9. doi:10.12968/hmed.2023.0006.
- Stein Duker, L. I., Giffin, W., Taylor, E. E., Shkhyan, L., Pomponio Davidson, A., & Mosqueda, L. (2025). Barriers and facilitators to primary healthcare encounters as reported by autistic adults: a qualitative study. *Frontiers in medicine*, 12, 1481953. <https://doi.org/10.3389/fmed.2025.1481953>
- Gilmore D, Harris L, Longo A, Hand B. Health status of Medicare-enrolled autistic older adults with and without co-occurring intellectual disability: an analysis of inpatient and institutional outpatient medical claims. *Autism*. 2021;25(1):266–274. doi:10.1177/1362361320955109.
- Houck, E. J., & Dracobly, J. D. (2022). Trauma-Informed Care for Individuals with Intellectual and Developmental Disabilities: From Disparity to Policies for Effective Action. *Perspectives on behavior science*, 46(1), 67–87. <https://doi.org/10.1007/s40614-022-00359-6>
- Schott W, Tao S, Shea L. Co-occurring conditions and racial-ethnic disparities: Medicaid-enrolled adults on the autism spectrum. *Autism Res*. 2022;15(1):70–85. doi:10.1002/aur.2644.



Questions/Discussion

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