

Autism Spectrum Disorder Part II: Medical Home Care for Children with ASD and Other Developmental Disabilities



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Learning Objectives



At the end of this educational activity, participants should be able to:

- Describe medical home care for children with ASD.
- Implement counseling strategies for parents, caregivers and family members on effective ASD management strategies.
- Identify community resources available for families.
- Describe autism-sensitive care in the office, emergency department and hospital.

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Medical Home Care

Medical Home Care for the Child with Autism Spectrum Disorder



- 2009-2010 National Survey of CYSHCN:
 - Prevalence = 13.9%
 - Less than 50% had access to a medical home
- Children with ASD – least access to a medical home
- PCPs report:
 - Overall lower competency,
 - Greater need for primary care improvement, and;
 - Greater desire for education regarding ASD.
- Family-centered care

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A medical home is not a building or place

7 Key Components:

- Access to care
- Family-centered care
- Cultural responsiveness
- Continuity of care
- Comprehensive care
- Compassionate care
- Coordination of care

(AAP, 2004)

With the help of a medical home approach, **PCP and Parent** are able to coordinate **all aspects of care** – eliminating the difficulties of navigation and fragmented care



Medical Home Care Assorted Medical Conditions



Care of a child with ASD is 24 / 7 / 52

- **GI:** 9-70% – chronic constipation / diarrhea, recurrent abdominal pain, celiac, GER, eating and feeding challenges
- **Seizures:** 20-33%
- **Sleep problems:** up to 86%
- **Common childhood illnesses:** Ear infections, headaches, allergies, asthma, dental
- **Not so common:** Diabetes, juvenile rheumatoid arthritis (JRA), leukemia
- **Behavioral Health:** ADHD, anxiety, depression

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Medical Home Care Nutrition / Feeding problems



- Emily only ate Lorna Doone cookies and milk
- Jimmy's mom was a genius
- Underweight and / or nutrient deficiencies: iron, vitamin D, protein
- Pica
- Casein-free and gluten-free diet

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What About Sleep?



- Sleep problems may include:
 - Sleep onset delay
 - Frequent and prolonged night waking
 - Early rising
 - Less sleep overall
- Monitor for obstructive sleep apnea (OSA), restless legs, seizures and anxiety
- Results in daytime learning, attention & behavior problems
- Studies find genetic mutations, less REM sleep
- Parents have chronic stress

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Children with ASD May Have Sensory Processing Problems



- High pain tolerance or unusual response
- Tactile hypersensitivity
 - Become upset if touched
 - Band-Aids, other adhesives
 - Examine slowly
- Expect the unexpected
 - Ingestions
- Wrap in blanket with arms inside

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Medical Home Care Challenging Behaviors



- Aggression – hitting, biting, pinching
- Disruptive – screaming, tantrums
- Self-injurious – head-banging, self-punching, slamming into desks
- Self-stimulatory – rocking, masturbating, self-spinning

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Questions to Consider



- Significance of behavior?
- Pain, upset, or self-soothing?
- Level of cognitive, verbal, social interaction abilities?
- Best way to communicate / interact with this child?
- What calms and soothes the child?
 - What has the opposite effect?
- How to facilitate the medical care of the child?

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The Case of Ryan



Meet Ryan



- 5 years old, nonverbal, autism
- New onset self-injurious behavior – slamming into tables, desks
- No other changes in family, school, social life
- No signs or symptoms of illness
- Independent in dressing, toileting, eating

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The Case of David



Meet David

- Mild to moderate autism, verbal
- He presents with a 2-month history of unexplained aggressive outbursts
- He could not explain the outbursts of rage
- Examination is unremarkable



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The Case of Eduardo



Meet Eduardo

- 15 years old, severe autism, non-verbal
- On Risperdal® (risperidone) per psychiatrist
- New onset self-injurious behavior – punching his left cheek repeatedly
- No changes in family, school, social life
- Bruising and swelling of his left cheek



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The Case of Joey



Meet Joey



- Moderate to severe autism
- Presents to the ED with sudden onset self injurious behavior (SIB) and destructive behavior
- Various neuroleptics for increasing agitation and sleep problems, with no success over the past year
- Multiple respiratory infections
- Frequently coughs and this keeps him up at night

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What to do if the Child is Carrying Out Undesired Behaviors?



- Investigate reason for behavior
- Give no reaction, praise, or reinforcement when a request is refused or when an inappropriate behavior is exhibited (REALLY HARD!)
- Instead of stating “No,” “Stop,” or “Don’t” direct the child to what you want them to do
 - Then reward when the action is carried out
- Minimize the use of restraints

Souders et al., 2003

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The Needs of the Child with ASD in the Hospital / ED / Office



- Increased anxiety and distress due to novel sounds, smells, visual stimuli and tactile experiences
- Pragmatic assessment of the communication strategies and sensory differences unique to each individual is essential in the development of an appropriate inpatient care plan
- Consult with the Expert – THE PARENT

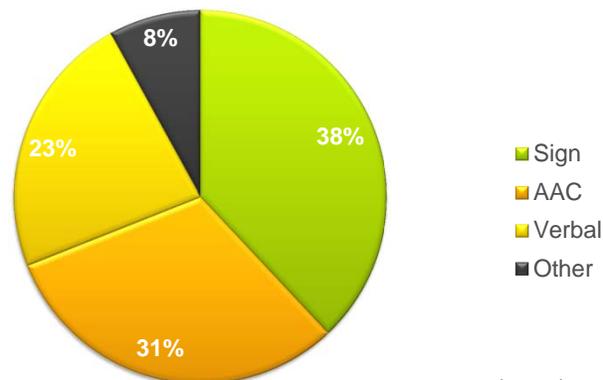
Kopeccky, et al, 2013, Mass General

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Expressive Communication



Modes of communication are variant, but all express needs or desires



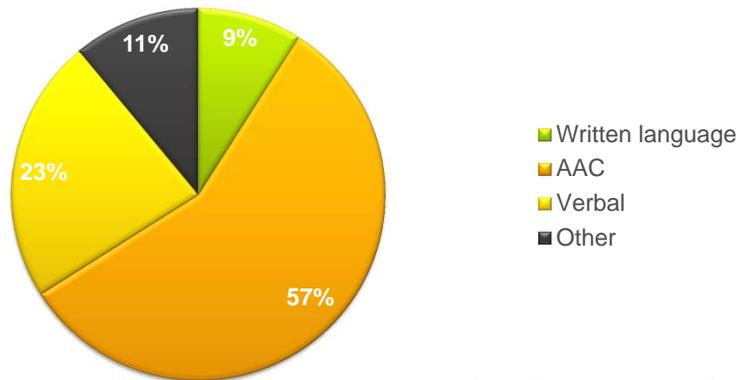
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Receptive Communication



Modes of receiving new information are variant, but all support understanding



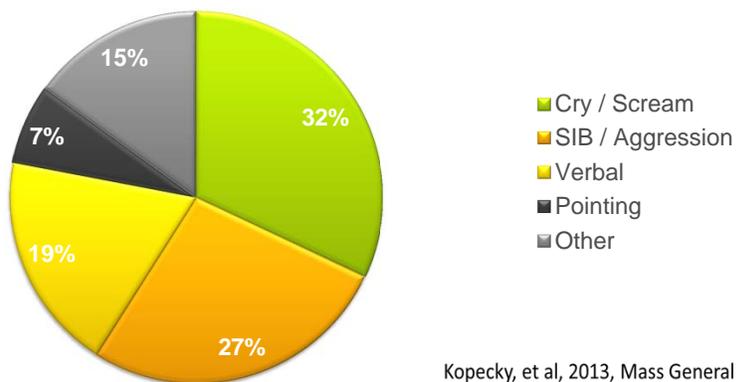
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Expression of Pain



Being able to recognize pain indicators is critical to care and security



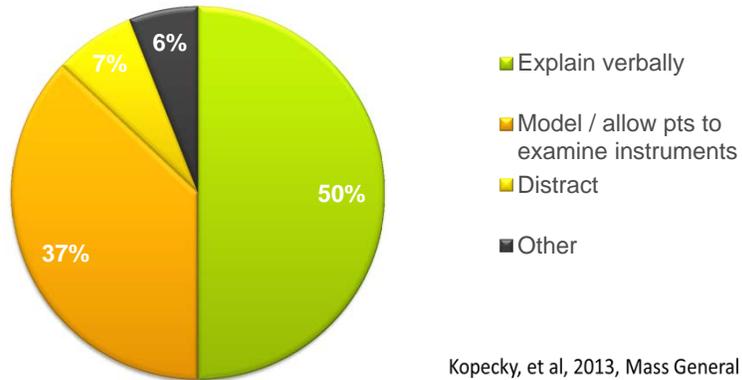
Kopecky, et al, 2013, Mass General

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Best Way to Examine a Child with ASD



It is easier to examine a child who is calm, than one who is distressed



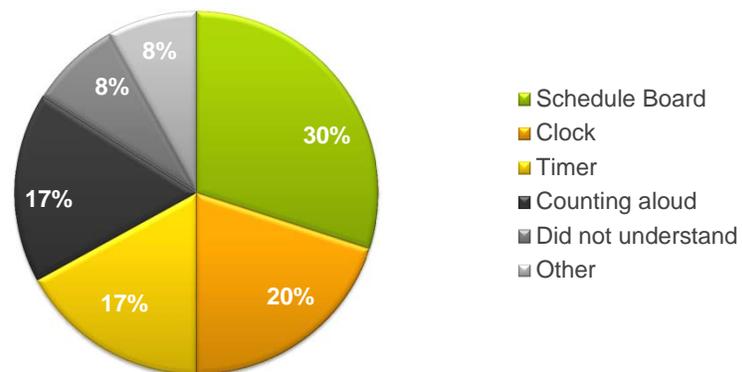
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Understand Passage of Time



Helping the child understand passage of time can help decrease stress and anxiety



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In the Office What to Do / Suggestions for Care



- Decrease environmental stimuli: light, noise, chaos
- Use Visual Communication Systems
- Provide as much consistency as possible
- Have family members present as much as possible
- Transition planning / designated breaks
- Behavioral techniques
 - Avoid things that are known to agitate
 - Offer choices
- OT Supports – Sensory Integration

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In the Office What to Do / Suggestions for Care



- Consult with the Expert – THE PARENT
- Develop ASD-sensitive care
- Understand that the most common problem when a child is sick is increased anxiety, sensory processing and communication
- Understand the spectrum of ASD

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Parents Know Best!



- Family-centered care
 - Collaborate with family members to develop optimal plan of care for the child
- Strategies to prevent challenging behaviors of the hospitalized child may lead to:
 - Improved safety
 - Decreased cost of care
 - A more satisfactory experience for parents, child, and staff

Scarpinato, et al. 2010

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Parents Know Best!

Health care professionals (HCPs) should consider asking:

- How does your child tolerate new faces?
- How does he/she react to other children? To adults?
- Is he/she sensitive to anything?
- What is the best way to approach him/her?
- How does he/she communicate?
- How does he/she report or express pain?

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Parents Know Best!

HCPs should consider asking:

- Are there any items of fixation for your child? If so, how does the family manage these?
- What are some things that agitate him/her?
- What early warning signs may indicate that he/she is agitated?
- When he/she becomes agitated or overstimulated, what interventions work best?

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Parents Know Best!

HCPs should consider asking:

- What is this child's schedule at home?
- How much can the hospital's routine mirror his/her home schedule?
- How can I best prepare him/her for upcoming transitions?
- What is his/her developmental level?

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Complementary and Alternative Medicine

Medical Home Care Fielding Tough Questions



- Alternative therapies and interventions
 - Very little to no evidence of benefit
 - 95% of parents use some type of CAM therapy
 - Levy and Hyman, Child Adol Psychiatr Clin N Am. 2008 October
 - <http://www.autismspeaks.org/what-autism/treatment/complementary-treatments-autism>

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Medical Home Care - CAM <http://nccam.nih.gov/>



Diet / Supplements

- Gluten- and/or casein-free diets
- Essential fatty acids
- Probiotics
- Digestive enzymes
- Carnitine

Other CAM Therapy

- Sensory integration
- Chiropractor
- Vaccination delay, separation, or refusal

Biological Treatment

- Antifungal
- Melatonin
- Homeopathy
- Antibiotics
- Secretin
- Chelation

Other CAM Therapy

- Hippotherapy
- Massage
- Prisms, vision therapy
- Auditory Integration Therapy

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Medical Home Care Fielding Tough Questions



- The role of immunizations, thimerosal
 - No evidence of an association
 - <https://healthychildren.org/English/safety-prevention/immunizations/Pages/Vaccine-Safety-The-Facts.aspx>
 - <http://www.cdc.gov/vaccinesafety/Concerns/thimerosal/index.html>

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Mercury Poisoning vs ASD



FINDING	MERCURY POISONING	AUTISM
Motor	Ataxia	Repetitive behavior
Vision	Bilat. visual field constrict	No problems
Speech	Dysarthria	Delayed speech, echolalia
Sensory	Peripheral neuropathy, paresthesias	Decreased pain response, hyperacusis, hypersensitive to sensory stimuli
Psychiatric	Toxic psychosis; mild nonspecific depression, anx, irritability	Socially aloof, insistence on sameness
Head size	Small	Large
Other	Chronic mercury toxicity: HTN, skin eruption, thrombocytopenia	Seldom seen

Community Resources

Medical Home Care Investigate Resources in Your Community



- Early Intervention
- School Services
- State Services
- Parent Support Services / Respite
- Community Organizations
- What therapies are available and from where?

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Autism Treatment Early Intervention and School



- Early Intervention
- School District / Individual Education Plan (IEP)
 - 3-5 yo: Special Needs Preschool
 - 5-22 yo: Elementary, Middle, High School
- Individual Transition Plan
 - 18-22 yo
 - Start planning at 14 or 16 yo

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Other Treatment

Autism Treatment Behavioral Interventions



- Applied Behavioral Analysis
- Floor time Relationship Development Intervention (RDI)
- Eclectic models
 - Early Start Denver Model
 - Project Impact
- See ASD Part IV – September 11, 2018

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Autism Treatment Medical Interventions



- Sleep – restless, insomnia, OSA
- GI – selective eating, nutrition, constipation
- Seizures – use anticonvulsants with mood stabilizing qualities
- Psych – anxiety, ADHD, irritability, aggression
- <https://www.autismspeaks.org/family-services/tool-kits>

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Autism Speaks Resources



[ATN/AIR-P Guides to Pica for Parents and Professionals](#)



Pica, the repeated eating of non-food items, is the eating disorder most often displayed by children with autism. In published literature, the most common definition of pica is the placing of non-edible items past the plane of the lips. For example, a child [More...](#)

[ATN/AIR-P Medication Decision Aid](#)



Many families of children with autism spectrum disorder (ASD) are faced with the option of using medicines to help treat their child's challenging behaviors. This is a tough medical decision and there is no one right answer. Though many children [More...](#)

[ATN/AIR-P Melatonin and Sleep Problems: A Guide for Parents](#)

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What Else Can We Do?



- Picture schedules
- Social Stories Priming
- Story boards
- First-then boards
- Video-modeling
- Practice with toy doctor's equipment
- Reward Charts

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Social Stories / Picture Schedules / Medical Priming



Use of pictures or a verbal story can:

- Help prepare the child for an upcoming event
- Help the child understand what an appropriate response to a situation may be

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Preparing for Procedures



Look at Me Now! LLC



- Pay a small fee for access to:
 - First-then boards
 - Story boards
 - Social story priming
 - Video-modeling

Search: Look at Me Now Autism Videos

Consider having your child watch a sibling go through similar experiences

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Preparing for Procedures



Autism Speaks Family Toolkits

<https://www.autismspeaks.org/family-services/tool-kits>



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Resources – Autism Speaks



- [FAMILIES & ADULTS](#)
- [RESEARCH](#)
- [ADVOCATE](#)
- [GET INVOLVED](#)

ATN/AIR-P Blood Draw Tool Kit

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Blood Draw Tool Kit for Parents



Has your child with ASD had a negative experience during a doctor's visit that has left him or her feeling anxious? Does the prospect of having your child's blood drawn make you anxious as well? Perhaps this anxiety has even prevented you from seeking needed tests and treatments. This toolkit was designed with you and your child in mind. It provides a variety of tools to help you and your child to prepare for future medical visits and reduce the stress and worry that may come with blood draws. Inside, you will find strategies easing your child's medical appointments, particularly those involving blood work. The kit's resources include ready-made visual supports, social stories, relaxation and distraction techniques, and tips designed specifically for children with ASD. Although "Taking the Work Out of Blood Work" focuses on phlebotomy, the information and techniques presented here also apply to other aspects of a clinic visit, such as measuring vital signs, undergoing physical exams and tolerating those inevitable wait times. A medical provider version of this toolkit is also available. Send a

Autism Treatment Network

- [What is the ATN?](#)
- [Find/Become an ATN Member](#)
- [ATN Information for Researchers](#)
- [ATN Tool Kits](#)
- [News and Stories](#)
- [AIR-P Oversight & Partnerships](#)
- [Publications](#)

Resources – Visual Supports



Visual Supports and Autism Spectrum Disorders

Introduction

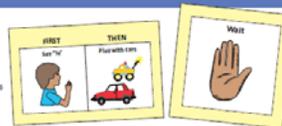
What are visual supports? A visual support refers to using a picture or other visual item to communicate with a child who has difficulty understanding or using language. Visual supports can be photographs, drawings, objects, written words, or lists. Research has shown that visual supports work well as a way to communicate.

Visual supports are used with children who have autism spectrum disorders (ASD) for two main purposes. They help parents communicate better with their child, and they help their child communicate better with others.

This brochure introduces parents, caregivers, and professionals to visual supports and provides instruction on how to use them effectively. Visual supports can be used with persons of any age, although this brochure refers to children. Also, visual supports can be used by caregivers other than parents.

Why are visual supports important? The main features of ASD are challenges in interacting socially, using language, and having limited interests or repetitive behaviors. Visual supports help in all three areas.

First, children with ASD may not understand social cues as they interact with others in daily activities. They may not grasp social

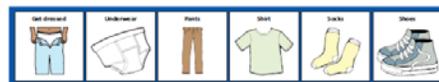


expectations, like how to start a conversation, how to respond when others make social approaches, or how to change behavior based on unspoken social rules. Visual supports can help teach social skills and help children with ASD use them on their own in social situations.

Second, children with ASD often find it difficult to understand and follow spoken instructions. They may not be able to express what they want or need. Visuals can help parents communicate what they expect. This decreases frustration and may help decrease problem behaviors that result from difficulty communicating. Visuals can promote appropriate, positive ways to communicate.

Finally, some children with ASD are anxious or act out when their routines change or they are in unfamiliar situations. Visuals can help them understand what to expect and will happen next and also reduce anxiety. Visuals can help them pay attention to important details and help them cope with change.

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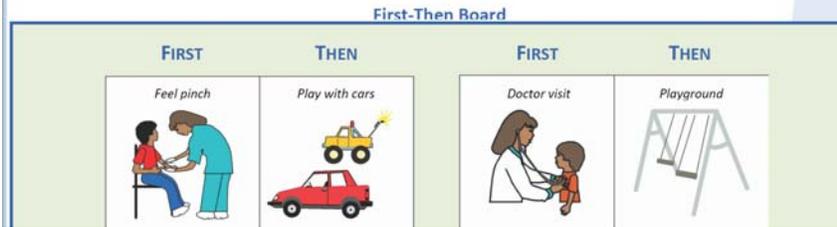


Resources – First Then Boards



What Is A First-Then Board?

A First-Then board is a visual display that motivates patients to engage in medical procedures that are not preferred by clarifying the preferred items/activities that will be available after it is over.



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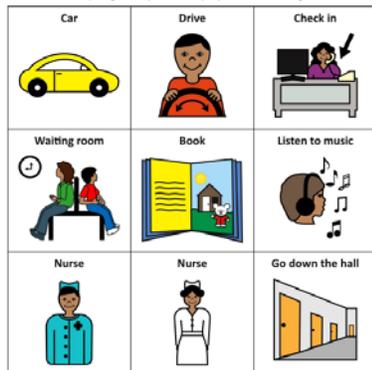
Visual Supports for Phlebotomy



Phlebotomy Toolkit for Providers Treating Children with Autism

Appendix F: Visual Supports

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



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Phlebotomy Toolkit for Providers Treating Children with Autism



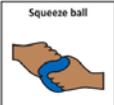
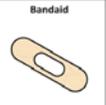
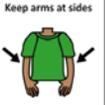
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Visual Supports for Phlebotomy

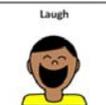
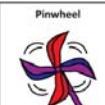
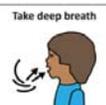
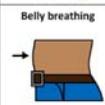
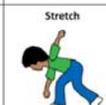
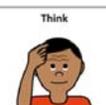
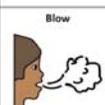
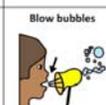


Phlebotomy Toolkit for Providers Treating Children with Autism

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

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Phlebotomy Toolkit for Providers Treating Children with Autism

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

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Resources – Autism Speaks



Phlebotomy Toolkit for Providers Treating Children with Autism

APPENDIX B: DEEP BREATHING

Belly Breathing Instructions for Children with ASD:

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

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

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

Blowing Bubbles

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

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

Pinwheel

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

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Resources – Autism Speaks



Phlebotomy Toolkit for Providers Treating Children with Autism

APPENDIX C: MUSCLE RELAXING TRAINING SCRIPT

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



Hands and Arms: Squeeze a Lemon

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



Arms and Shoulders: Stretch Like a Cat

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



Shoulders and Neck: Hide in Your Shell

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



Back: Swing up High

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

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Summary

People First Language Essential for Family-Centered Care

A disability descriptor is simply a medical diagnosis.

People First Language respectfully puts the person before the disability.

**A person with a disability is
more *like* people without disabilities
than different!**

- **NOT** the Downs Kid – The child with Down syndrome
- **NOT** the Autistic Kid – The child with Autism
- **NOT** the Retarded Kid – The child with an intellectual disability

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In Summary Best Practice Recommendations



- **Provide Medical Home / Family-centered Care**
- **Use People First Language**
- **Collaboration** of providers and staff with family members and their caregivers is crucial
- **Empower the parent**

**Listen to parents' concerns.
Remember – Parents are the Experts!**

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Resources and References

Resources and References Autism



- **Autism Society of America**
 - www.autism-society.org
- **Autism Speaks**
 - www.autismspeaks.org
 - <https://www.autismspeaks.org/family-services/tool-kits>
- **National Institutes of Health**
 - <https://www.nimh.nih.gov/health/topics/autism-spectrum-disorders-asd/index.shtml>
- **First Signs (public awareness)**
 - www.firstsigns.org
- **CDC/AAP (Act Early)**
 - www.cdc.gov/actearly

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Resources and References Medical Home

- <https://www.medicalhomeportal.org/clinical-practice>
- **American Academy of Pediatrics**
 - <https://www.aap.org/en-us/professional-resources/practice-transformation/medicalhome/Pages/home.aspx>
- <https://www.aap.org/en-us/professional-resources/practice-transformation/medicalhome/Pages/home.aspx>
- <http://www.ncqa.org/programs/recognition/practices/patient-centered-medical-home-pcmh>
- <https://medicalhomeinfo.aap.org/Pages/default.aspx>

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Resources and References Other



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- Souders M, et al. Caring for children and adolescents with autism who require challenging procedures. *Pediatric Nursing*, 28(6), 2002.
- Birth to Five: Watch me Thrive
 - https://www.acf.hhs.gov/sites/default/files/ecd/pcp_screening_guid_e_march2014.pdf

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What's Next?

SNI / OHE Collaboration ASD Webinar Series



- **Part I: Overview**
Available on-demand:
optumhealtheducation.com/autism-part-I-2018
- **Part III: Genetics and ASD**
Registration open:
optumhealtheducation.com/autism-part-III-2018-reg
- **Part IV: Treatment Strategies**
- **Part V: Dual Diagnosis of Down syndrome and ASD**
- **Part VI: Transition to Adult Care**

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Thank you

Q&A