




## Changing landscape of autism care: perspectives from medical and mental health



Yamini Jagannath Howe, MD  
Jill Pineda, PhD  
Tuesday, September 27, 2022

**LURIE CENTER**


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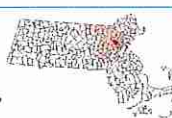
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## Introductions

- Dr. Jill Pineda, PhD
- Dr. Yamini Jagannath Howe, MD
- Lurie Center for Autism at MGH located in Lexington, MA
  - Telehealth has made our clinic more accessible for working families\*
- Disciplines at the Lurie Center:
  - Medical: Developmental Behavioral Pediatricians, Psychiatry, GI, Neurology, Primary Care
  - Psychological: Neuropsych testing, Early Diagnostic Clinic (Ages 4 and under), Therapy (Very Limited)
  - Family Support: Social Work
  - Research
  - Co-located with Spaulding Outpatient Center for Children (OT, Speech, AAC, Feeding/Nutrition)
  - Workshops offered for caregivers and freely available to anyone



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## Disclosures

None relevant

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## Objectives

1. Participants will gain knowledge of Autism Spectrum Disorder diagnostic criteria and review updates in terminology
2. Participants will further their knowledge of the co-occurring medical and psychological issues that are associated with autism, and gain an overview of medical and mental-health treatment options
3. Discuss how virtual care has impacted medical and mental health care for individuals with Autism Spectrum Disorder at a multidisciplinary autism center

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## Objective 1

Participants will gain knowledge of Autism Spectrum Disorder diagnostic criteria and review updates in terminology



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## Prevalence of Autism

### AUTISM QUICK STATS

1 in 44 kids identified with autism

241% higher than baseline stats in 2000

80% are 4x more likely to be diagnosed than girls

States with the highest rates: California 1/26, South Korea 1/39

Although autism can be diagnosed before a child reaches the age of five, most kids are diagnosed after the age of 4

40% are nonverbal, 44% have average or above average intelligence

25.3% of autism cases are 40x more likely to be diagnosed

• Over 5.4 million adults in US with autism\*

• In next 10 years ~1 million ASD teens will transition to adulthood\*\*

\*Centers for Disease Control 2020

\*\*Autism Speaks

Image from <https://www.upromise.com/articles/how-to-stay-focused-in-a-zoom-class-adults-and-children/>

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**Neurodiversity**

“The concept of neurodiversity provides a paradigm shift in how we think about mental functioning. Instead of regarding large portions of the American public as suffering from deficit, disease, or dysfunction in their mental processing, neurodiversity suggests that we instead speak about differences in cognitive functioning...The idea that there is one “normal” or “healthy” type of brain or mind is a culturally constructed fiction, no more valid than the idea that there is one “normal” ethnicity, gender or culture.” ~ Dr. Thomas Armstrong

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**Autism Spectrum Disorder (ASD)**

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**Autism Spectrum Disorder (ASD)**

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### Autism Spectrum Disorder (ASD)

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### Changes in the Diagnostic Criteria for Autism Spectrum Disorder

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### Autism Spectrum Disorder – DSM 5 Criteria

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### What is autism severity?

Autism is heterogeneous and requires personalized, evidence-based assessments and interventions, accessible and affordable to every person

Autismspeaks.org

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### Autism Spectrum Disorder Severity

**The Three Functional Levels of Autism**

**ASD Level 1**  
Requiring Support  
difficulty initiating social interactions  
organization and planning problems can hamper independence

**ASD Level 2**  
Requiring Substantial Support  
social interactions limited to narrow special interests  
frequent restricted/repetitive behaviors

**ASD Level 3**  
Requiring Very Substantial Support  
severe deficits in social and restricted social communication skills  
great difficulty with changing activities or focus

verywell

Image from from <https://www.verywellhealth.com/what-are-the-three-levels-of-autism-260233>

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### Autism and Communication

Modify Language to fit an Individual's needs and provide accessible communication

- ✓ Consider how the individual *expresses themselves and understands expectations* (these may be different)
- ✓ Make sure the individual has *access to their communication system*, if not spoken language (Spoken, Sign, Augmentative and Alternative Communication (AAC), Picture Exchange Communication System, Eye Gaze)
- ✓ *Do not make assumptions* about an individual's intellectual capacity based on their communication modality

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## Intellectual Disability

- Diagnostic criteria for intellectual disability are based on assessment of both **cognitive skills** and **adaptive functioning skills** (activities of daily living in the areas of communication, self-care, social skills)
- Criteria in DSM 5 are no longer based on specific IQ score (< 70)
- Students previously diagnosed with ID were later identified as having ASD without intellectual impairment
- 31% of Children with autism have an intellectual disability (Autism Speaks)

Over the course of the year, students with ID were re-evaluated and 10% of students (10,000) diagnosed with ID were found to have autism. This is a significant increase in the number of students with autism, which was previously 10% of the total student population. The increase in autism diagnoses is due to a combination of factors, including increased awareness, improved diagnostic tools, and a shift in diagnostic criteria. The increase in autism diagnoses is also reflected in the number of students with autism who are enrolled in college, which has increased from 10% to 15% over the same period.

<https://science.psu.edu/news/creating-progressive-education-for-students-with-disabilities>

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## Person-first versus Identity-first language

- The use of person-first and identity-first language will be used interchangeably today
- The Autism Self-Advocacy Network and our MGH Aspire faculty have strongly endorsed the use of 'identity first' language in autism
- Different for other disability groups; may not reflect everyone's individual preferences

See [autisticadvocacy.org](http://autisticadvocacy.org) for more info

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## Recent Media

**'As We See It' Is Not a Typical Portrayal of Autism**

More is being done to ensure that autism is portrayed accurately in the media. The Autism Self-Advocacy Network (ASAN) has released a guide to help the media portray autism accurately. The guide includes tips on how to interview autistic people, how to avoid stereotypes, and how to ensure that the portrayal of autism is respectful and accurate.

New York Times: By [Robert L. Thompson](#)  
Published Jan. 21, 2022 | Updated Jan. 25, 2022

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### Is there anything "wrong" about having autism?

• Neurodiversity to be celebrated



**Autistic Pride Day**  
June 18

<https://www.altogetherautism.org.nz/whats-the-deal-with-autistic-pride/>



**We're Not Broken**  
Changing the Autism Conversation  
ERIC GARCIA

<http://www.ericmgarcia.net/we-re-not-broken.html>

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### Sex differences in autism

- More common in biological males than biological females - 4:1
- Females with co-occurring ID more likely to get diagnosed
  - This is affected by ascertainment problems and differences in referral patterns
  - Female autism phenotype
- Unclear why underlying sex differences in risk as we understand it presently

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### Gender Diversity in Autism

- Individuals who are gender diverse are perhaps 3-6x as likely to be autistic as cisgender individuals
- Gender diverse people are also more likely to report autistic traits and question undiagnosed autism
- Warrier V. Et al. Nat. Commun. 2020

**A Disproportionate Number of Autistic Youth Are Transgender. Why?**



Slate.com

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### Ableism affects Autistic individuals and their families




- At least 78 million people worldwide have autism; the majority do not receive support from, or have access to, adequate health-care, education, and social care services (Lancet Commission 2022)




- Families caring for people with ASD are at greater risk for food insecurity (Karpur et al Autism 2021)



- Autistic individuals face limited housing options and lack of equitable job options



- Medical: difficulty with patient-provider communication, sensory sensitivities, executive functioning/planning (Mason et. al JADD 2019)



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## Objective 2

Participants will further their knowledge of the co-occurring medical and psychological issues that are associated with autism, and gain an overview of medical and mental-health treatment options

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### Common Co-occurring Medical issues



- Cognitive: Language, Learning/intellectual disabilities
- Psychiatric: ADHD, Anxiety, Irritability
- Neuro: Sleep, Seizure disorders (~20-30%) Mild motor discoordination
- GI: constipation, feeding and eating disorders (70%), may present as complex behavioral presentations
- Sleep onset, maintenance, and early morning awakening

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### Need for Specialists

- 98.9% of parents of children with ASD reported the need for at least one specialist
  - GI, neurology, PT/OT/speech, Dental, mental health and behavioral services
- Children with ASD require a greater number of visit to their primary care provider and sub specialists
- There is a great deal of need for behavioral support as well

(Todorow et al., 2018)

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### Goals of Follow-Up Care

- Monitor development
- Keep in mind early signs of co-existing conditions
- Psychopharm when appropriate
- Work collaboratively across disciplines
- Collaborate with educational and mental health providers

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### Treatments for Individuals with Autism

Behavior Programs

Education and Learning Programs

Medications

Other Treatments and Therapies

Image from <https://effectivehealthcare.ahrq.gov/products/autism-update/consumer>

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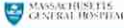
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**Intervention: Applied Behavior Analysis (ABA)** 

- Evidence-based intervention for Autism (decades of research)
- ABA is an intervention based on the science of *learning and behavior*; helps us to understand how our environment impacts our behavior
- ABA helps someone to:
  - Increase language/communication skills
  - Improve attention and pre-requisite skills for learning
  - Decrease problem behaviors (e.g. aggression)
  - Increase motivation for learning



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**Intervention: Applied Behavior Analysis (ABA)** 

- Especially important for teaching individuals with more severe ASD symptoms and/or Intellectual Disability (ID)
- Can be integrated in school programming & at home; Specialized school programs with integrated ABA may be necessary
- Challenge:** Wait lists can be years; high turn-over; not all service providers have the same level of experience
- Note: Not all patients with ASD may require ABA services




Image from <https://www.reiscollege.edu/academics/majors-and-programs/applied-behavior-analysis/>

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**Treatment: Systematic Desensitization (ABA)** 

- Evidence-based treatment based on ABA methodology
- Systematic Desensitization is the process of *gradual exposure* someone to a feared stimulus while *using relaxation tools* to help them tolerate a feared stimulus
- Can help someone to:
  - Overcome anxiety of specific fears/phobias
  - Help an individual learn to tolerate what scares them (e.g., dogs, medical care)
  - Decrease problematic behavior



Image from <https://www.usatoday.com/story/life/2015/04/15/fear-of-dogs-what-to-avoid-and-what-to-do-instead/235111700/>

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## Task Analysis – Needle Stick



BECTON Dickinson Syringe Glue Tip Needle and Cap - 10ml, 5ml, 3ml, 1ml Syringes 14ga 16ga 18ga 20ga 22ga Needles - Oil or Glue Applicator (Pack of 10)

BECTON Dickinson Syringe Glue Tip Needle and Cap - 10ml, 5ml, 3ml, 1ml Syringes 14ga 16ga 18ga 20ga 22ga Needles - Oil or Glue Applicator (Pack of 10)

Can Use  
Varied Sized  
Mock Needles



Walk into room
Sit in chair and begin watching video
Place arm in syringe
Adjust clothing to expose site
Put on gloves
Touch/probe site
Apply alcohol
Prepare mock needle
Apply mock needle
<ul style="list-style-type: none"> <li>- Black cap, no needle</li> <li>- Black cap, small needle</li> <li>- Green cap, longer needle</li> </ul>
Needle in place for 5 seconds
Needle in place for 10 seconds
Band Aid/Cotton

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*A **visual task analysis** can be helpful in showing the steps of a medical procedure to help individuals with ASD/DD understand and anticipate what will happen*

***Social stories** can also help individuals to understand expectations, anticipate what may happen, and remind them of effective coping strategies*

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## Intervention: Cognitive Behavioral Therapy (CBT)



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- Evidence-based therapy which *helps people learn to identify and change maladaptive thought patterns* that have a negative influence on their behavior or emotions; helps to change maladaptive behaviors
- Found to be helpful in treating:
  - Anxiety
  - Depression
  - Panic Attacks
  - Addiction
  - Eating Disorders
  - Phobias
- Typically delivered by a psychologist/mental health counselor
- **Challenge:** Wait lists are long; traditional CBT intended for individuals with Average language/cognition (but some modified CBT programs do exist)



The diagram illustrates the CBT model as a cycle of three interconnected components: **THOUGHTS** (What we think affects how we feel and act), **EMOTIONS** (What we feel affects how we think and act), and **BEHAVIORS** (What we do affects how we think and feel). These three components are arranged in a triangle, with double-headed arrows connecting each pair, indicating that they all influence each other. In the center of this cycle is the acronym **CBT**.

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### Educational Programming

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#### IEP vs. 504 Plan

- Students have the right to a **Free and Appropriate Education (FAPE)** in their **Least Restrictive Environment**
- Parent Consultation/Communication is critical to help students with ASD **generalize skills** across settings
- An **educational advocate** may be **necessary** to help parents make change in school programs

Image from <https://thispost.com/obtaining-understanding-and-managing-the-504-plan/>

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### Other Therapies

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- Speech-Language Therapy
- Occupational Therapy
- Augmentative and Alternative Communication (AAC)
- Physical Therapy
- Feeding Therapy
- Social Skills Programming
- There are many more...

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### Autism Care Questionnaire (ACQ)

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- A brief survey completed by a patient/caregiver prior to a medical visit
- Addresses non-medical needs of a patient with ASD:
  - Communication
  - Environmental Accommodations
  - Sensory Needs
- For Children and Adults
- Can be printed and shared with medical providers and/or uploaded into medical record

Link to ACQ:  
<https://www.massgeneral.org/children/autism/lurie-center/autism-care-questionnaire>

Image from <https://www.massgeneral.org/children/autism/lurie-center>

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Patient Accommodations Care Plan	
<b>Patient Accommodations Care Plan (Communication Section)</b> <ul style="list-style-type: none"> <li>Non-medical accommodations needs located in an accessible location in the electronic medical record</li> </ul>	
<b>Communication</b> <b>Speech</b> <input type="checkbox"/> Verbal <input type="checkbox"/> Minimally verbal <input type="checkbox"/> Non-verbal <b>Comments:</b>	
<b>Communication partner required</b> (trusted individual who understands and facilitates the patient's communication) <input type="checkbox"/> For functional interactions <input type="checkbox"/> For medical interactions <input type="checkbox"/> When requested by patient <input type="checkbox"/> When patient is in pain, ill or anxious <input type="checkbox"/> For interpretation of patient's unique mode of expression <b>Comments:</b>	
<b>Self Expression</b> Expresses a basic/functional need (hunger, thirst, bathroom, comfort)	

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Patient Accommodations Care Plan: Communication	
<b>Speech</b> <input type="checkbox"/> Verbal <input type="checkbox"/> Minimally verbal <input type="checkbox"/> Non-verbal  <b>Communication partner required</b> (trusted individual who understands and facilitates the patient's communication) <input type="checkbox"/> For functional interactions <input type="checkbox"/> For medical interactions <input type="checkbox"/> When requested by patient <input type="checkbox"/> When patient is in pain, ill or anxious <input type="checkbox"/> For interpretation of patient's unique mode of expression	<b>Self Expression: How does the person</b> 1. Express a basic/functional need (hunger, thirst, bathroom, comfort item) 2. Initiate questions, clarification, and/or confirmation 3. Express yes/no 4. Express a preference or choice  <input type="checkbox"/> Verbal <input type="checkbox"/> Alternative and augmentative communication <input type="checkbox"/> Gestures/Sign language <input type="checkbox"/> Other: <input type="checkbox"/> Communication partner required <input type="checkbox"/> Does not express <input type="checkbox"/> Is only understood in familiar context

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Patient Accommodations Care Plan	
<b>Patient Accommodations Care Plan</b> <ul style="list-style-type: none"> <li>Immediate Needs and Accommodations</li> <li>Communication</li> <li>Pain</li> <li>Safety               <ul style="list-style-type: none"> <li>Stressors</li> <li>Comforts</li> </ul> </li> <li>Accommodations in the Medical Setting</li> <li>Daily Activities in Medical Settings</li> <li>Other Disabilities</li> </ul>	
<b>Accommodations in Medical Settings</b> <b>Appointment/Arrival Time/Waiting for Appointment/Procedure/Discharge</b> <input type="checkbox"/> No accommodation needed <input type="checkbox"/> Needs accommodation(s) and support <input type="checkbox"/> Does not tolerate even with accommodations/support  <b>Accommodation(s):</b> <input type="checkbox"/> Schedule for early appointment/procedure/urgency if waiting or delay <input type="checkbox"/> Allow arrival time as close to appointment/procedure as possible	
<b>Expected Anxiety/Waiting Room</b> <input type="checkbox"/> No accommodation(s) needed <input type="checkbox"/> Needs accommodation(s) and support <input type="checkbox"/> Does not tolerate even with accommodations/support  <b>Accommodation(s):</b> <input type="checkbox"/> Quiet/private entrance into office or hospital <input type="checkbox"/> Quiet/private space to wait <input type="checkbox"/> Allow patient to think up and down end waiting room (e.g. hallway) until ready to be seen <input type="checkbox"/> Reduced number of transactions (e.g. postal waiting room to meet nurse or lab, etc.)	
<b>Hospital Room and Stay</b> <input type="checkbox"/> No accommodation(s) needed <input type="checkbox"/> Needs accommodation(s) and support <input type="checkbox"/> Does not tolerate even with accommodations/support	

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## Objective 3

*Discuss how virtual care has impacted medical and mental health care for individuals with Autism Spectrum Disorder at a multidisciplinary autism center*



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### Questions Raised During the Covid-19 Pandemic



- What is the validity of making an ASD diagnosis virtually?
- How much physical examination do I need to do in person?
- How do we assess non-verbal communication in a virtual format?
- What is the validity of neuropsychological testing?
- What are the barriers families will experience for virtual visits?
- How can we ensure the content of our visits remain confidential?
- How will patients engage in a virtual format (e.g., remain on screen)?

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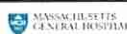
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### Statistics on Virtual Appointments at Lurie



- The Lurie Center/MGH response to the Covid-19 pandemic:
  - Stopped in-person visits March 2020
  - Began virtual visits shortly afterwards
  - Masks have been required by all individuals who enter the Lurie Center since 2020; this is a broader MGB policy
    - Clinician's families may make exceptions based on patient/provider need
  - Shift in provider's expectations to be on site vs. remote

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### Statistics on Virtual Appointments at Lurie



- Virtual care is here to stay!
- In 2022, 75% of Lurie Center appointments were virtual in 2022; 2.2% of visits were conducted via phone
- There are not large differences in percent of virtual visits by race/ethnicity (limited data to date)



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### Medical Care: Benefits of Virtual Care



- More comfortable to wait at home rather than waiting room
- Serve larger geographic region in MA
- Parents are more free to talk with child in separate room or playing with their own toys
- Ability to have meetings from school, group home, etc.
- Parents or caregivers can be on zoom from multiple locations (child at school, parent at work)
- BCBAs, teachers sometimes able to join as well
- Interpreters available for video over zoom



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### Medical Care: Challenges of Virtual Care



- Subtle nonverbal signals from patient may be missed
- Some patients are more frightened of being on camera than in person
- Parents sometimes need to see the Lurie Center and feel supported in person
- Cannot collect vital signs easily on pedi patients or complete good physical exams online – though can ask patient to see school nurse or visit PCP, if needed

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### Mental Health: Benefits of Virtual Care

- Efficacy of virtual-care for psychiatric services appear to have similar outcomes to in person care
- Increased access to healthcare for clients/families
- Sustained mental health services despite disrupted in-person care
- Reduced missed/cancelled appointments
- Provides insight into home and day-to-day activities

(Carpenter et al., 2018; Hersch et al., 2006; Uscher-Pines et al., 2020)



source from <https://www.unomise.com/articles/how-to-stay-focused-in-a-zoom-class-adults-and-children/>

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### Parent Training – Desensitization for Medical Care

- Due to challenge of patients receiving Covid-19 vaccine and limited in-person care, a *3-session parent training* was developed to teach parents skills to help their children/young adults tolerate medical care (e.g. vaccines, blood draw)
- Included individual follow up with caregivers
- Benefits:
  - Reached more people
  - Parents connected with one another
  - Empowered and coached parents to teach skills at home



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### William Syndrome - Modified CBT Group

- William Syndrome is a rare genetic condition associated with mild-to- moderate Intellectual Disability and Anxiety
- Lurie Center *psychiatrist & psychologist* developed and *virtually-delivered a modified Cognitive Behavioral Therapy (CBT) group for adults with William Syndrome and Anxiety*
- Benefits:
  - Participants met other people with WS for the first time
  - Increased access to care with support from caregivers as needed
  - Joined from varied locations (group home; home)
  - Resulted in a significant reduction in clinician-rated anxiety

(Thom et al., 2022)



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**Mental Health: Challenges to Virtual Care** 

- Reduced ability to observe non-verbal cues
- Distractions in the patient's environment
- Compromised patient privacy
- Unreliable internet
- Lack of available norms for remote testing of cognitive functioning
- Working with an interpreter can be more challenging than in-person care
- Can be more challenging for younger children and individuals with limited language abilities or more dysregulated behavior
- "Zoom Fatigue"

(Romanchych et al., 2021; Uscher-Pines et al., 2020)


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**Lurie Center Resources**

<https://www.massgeneral.org/children/autism/lurie-center>

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**Caregiver Workshops/Training (Virtual)** 

**Coffee Convo**

- Free virtual training for families from providers

**Monthly Caregivers Workshops**  
(Ranges from Free to 75\$/family)

- New diagnosis & Next Steps
- Behavior Basics (ABA)
- Transition Planning
- Guardianship
- Medical Desensitization

**Workshop, September 22**  
 "The Impact of Chronic Coughing Cycles - Information and Strategies for Parents and Caregivers"  
 Presenter: Sylvia Fogel, MD

**Workshop, October 20**  
 "Empowering Parents and Families in ADO Research"  
 Presenter: Sarah Hagan, PhD

**Workshop, November 17**  
 "Skills for Pediatric Training: Research and Clinical"  
 Presenters: Gillian E. Porges, PhD and Nathan Houser, MD

**Workshop, December 8**  
 "ADO Best Practices: Finding Community Opportunities"  
 Presenter: Jessica Williams, M.S., QOOC, ELP

**Workshop, January 26**  
 "The Story of a Neurodivergent Gender Fluid Child - A Family's Personal Journey"  
 Presenters: Kira Duff, MEd and Brad Sullivan

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### Social Stories for Medical Care

Use our social narratives to help prepare for a medical appointment or procedure:


Introduce With a Memo.pdf  
 COVID-19 Social Narrative.pdf  
 COVID-19 Social Narrative.pdf  
 COVID-19 Social Narrative.pdf  
 COVID-19 Social Narrative.pdf

- COVID-19 Detailed COVID-19 Coronavirus Test.pdf
- COVID-19 Simple COVID-19 Coronavirus Test.pdf

EMERGENCY COVID-19 Coronavirus Test.pdf

- EMERGENCY COVID-19 Detailed COVID-19 Coronavirus Test.pdf
- EMERGENCY COVID-19 Simple COVID-19 Coronavirus Test.pdf

C.T. Scan/CT Scan.pdf  
 CT Scan/CT Scan.pdf  
 CT Scan/CT Scan.pdf  
 CT Scan/CT Scan.pdf



1. When you get the shot, you should try to sit very still.

2. If you wait, you can look away from your arm or close your eyes.

3. You can listen to music or sing a song, or hold someone's hand.

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### Lurie Center for Autism

- More information can be found at:  
<https://www.massgeneral.org/children/autism/lurie-center>
- Patient Resources can be found at  
<https://www.massgeneral.org/children/autism/lurie-center/autism-patient-resources>
  - Autism 101
  - Information about related medical, psychological, and behavioral treatments
  - Tip sheets (supporting siblings, vaccine tips, water safety, therapy)
  - Transition services and supports

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### Questions?

Thank you!



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Mass General Hospital for Children

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