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The Impact of Social Isolation on Children with Autism, Developmental Delays, and their Families

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Developmental-Behavioral Pediatrician
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India Autism Center (IAC) is a state-of-the-art residential, vocational, and daycare center near Kolkata where individuals with autism spectrum disorder can find training, treatment, and boarding opportunities.

Future: inclusive school, marketplace, arts/music facility, sports facility, and research center.

IAC supports, connects, and cares for the global community beyond its borders.



Quarantine

- from the Latin, quadraginta, meaning "40"

During the bubonic plague pandemic of the 14th century, 40 days was used as the length of time in isolation that would prevent contamination.



When children are confined to their homes:

- less physically active
- much longer screen times
- irregular sleep patterns
- less favorable diets
- weight gain
- loss of cardiorespiratory fitness

Psychological stressors associated with pandemics:

- fear of infection
- frustration / boredom
- lack of face-to-face contact with peers
- lack of personal space
- worry about family financial troubles

Posttraumatic Stress Disorder in Parents and Youth After Health-Related Disasters

Ginny Sprang, PhD, and Miriam Silman, MSW

ABSTRACT

Objectives: This study investigated the psychosocial responses of children and their parents to pandemic disasters, specifically measuring traumatic stress responses in children and parents with varying disease-containment experiences.

Methods: A mixed-method approach using survey, focus groups, and interviews produced data from 398 parents. Adult respondents completed the University of California at Los Angeles Posttraumatic Stress Disorder Reaction Index (PTSD-RI) Parent Version and the PTSD Check List Civilian Version (PCL-C).

Results: Disease-containment measures such as quarantine and isolation can be traumatizing to a significant portion of children and parents. Criteria for PTSD was met in 30% of isolated or quarantined children based on parental reports, and 25% of quarantined or isolated parents (based on self-reports).

The incidence of posttraumatic stress disorder after pandemics:

- 2003 SARS pandemic in Canada, 28.9% (similar rate to that found after natural disasters and terrorism)
- 2009 H1N1 pandemic in US, 30% of quarantined or isolated children and 25% of quarantined or isolated parents

Autism Spectrum Disorder

- a disorder of social communication and restricted, repetitive behaviors (American Psychiatric Association, 2013).

Spectrum:

- used to classify something, or suggest that it can be classified, in terms of its position on a scale between two extreme or opposite points.



Autism Spectrum Disorder

- a disorder of social communication and restricted, repetitive behaviors (American Psychiatric Association, 2013).

Spectrum:

- entire range of wavelengths produced by separation of the components of light into colors, as seen in a rainbow.
- each color represents a different domain of function, including cognitive, emotional, adaptive, behavioral, social, sensory, etc.



Children with ASD and other developmental delays face additional challenges because of difficulties with communication, understanding abstract language, and insistence on sameness.

At least 50 - 60% of children with ASD exhibit clinically significant anxiety symptoms compared to about 8% of teens in the general population (van Steensel et al., 2011; Kirsch et al., 2019).

Is it anxiety?

- Excessive worrying or rumination
- Changes in sleep or eating patterns
- Increased self-soothing and/or repetitive behaviors such as rocking, wringing, or flapping hands
- Hitting others
- Pushing others
- Aggravates others physically
- Pulling others hair
- Kicking/hitting others
- Grabbing from others
- Throwing/kicking/pushing objects
- Banging on objects
- Ripping paper
- Head banging
- Poking self in eye
- Pinching/scratching self
- Pulling own hair
- Swallowing objects
- Screaming/yelling



Simons Foundation published results about COVID-related impacts.

Survey sent to participants in their SPARK (Simons Foundation Powering Autism Research for Knowledge) study:



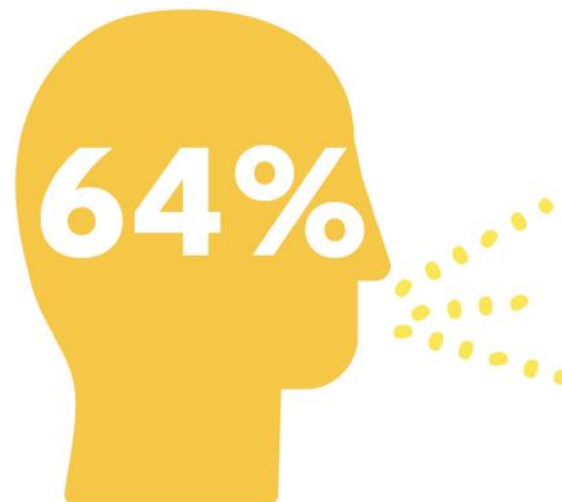
Sent to: **70,000 families**

Completed by: **8,000 families**

Results collected: **March 20, 2020 - March 30, 2020**

63%

of families report
severe disruptions in
services and therapies.



of families report
that speech therapy
is most disrupted.

Only 42% said that their children with autism could understand information about COVID-19 “moderately” or better.

More than 90% reported worsened behavioral, mood, and/or anxiety symptoms.

What's working?

- ✓ Social stories
- ✓ Breaks for rest and relaxation
- ✓ Telehealth appointments
- ✓ Pursuing hobbies
- ✓ Cooking for family
- ✓ Enjoying time with family in person and virtually

These suggestions are from comments that parents and guardians entered through an open-ended question in the survey.

Functional Behavior Assessment (FBA)

- analyze real-life situations that seem to generate tantrums
- what happens immediately before, during, and after the outbursts that might contribute to their happening again.

Contingency-Based Observation



Observation of the relationship between
behavior and environment

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Supporting Individuals with Autism through Uncertain Times

Kara Hume, Ph.D., UNC School of Education, & UNC FPG Autism Team



FRANK PORTER GRAHAM
CHILD DEVELOPMENT INSTITUTE



Support understanding



Offer opportunities for expression



Prioritize coping and calming skills



Maintain routines



Build new routines



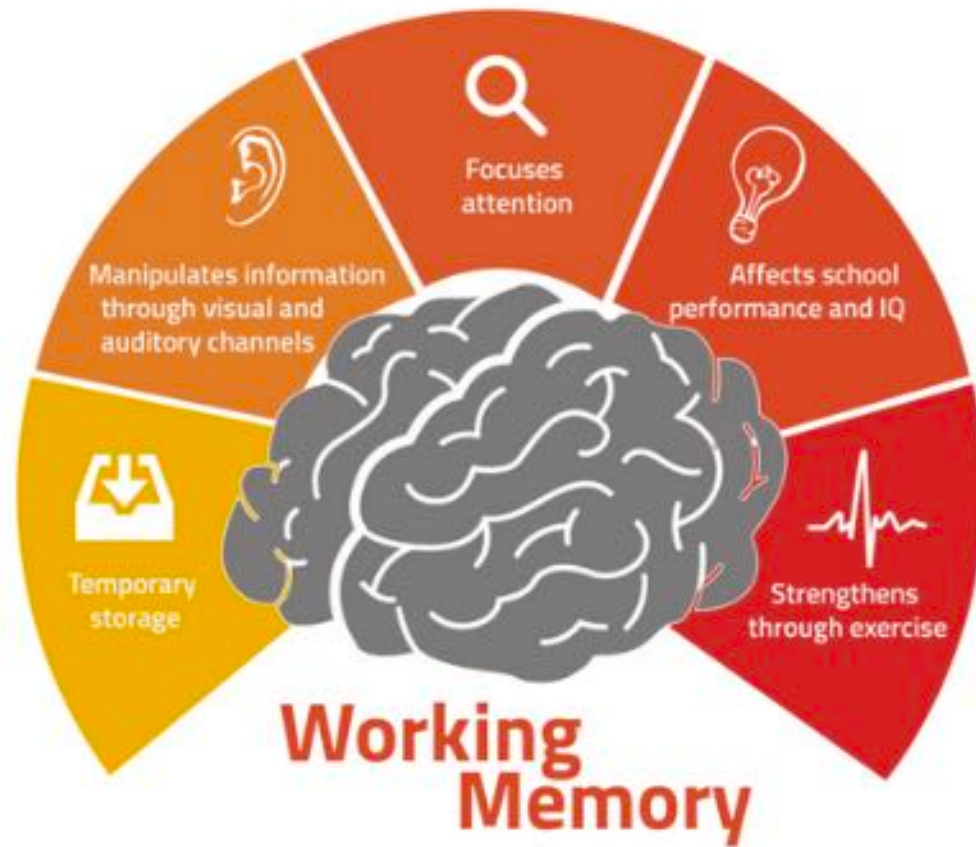
Foster connections (from a distance)

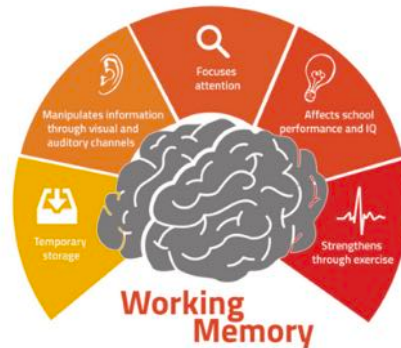


Be aware of changing behaviors

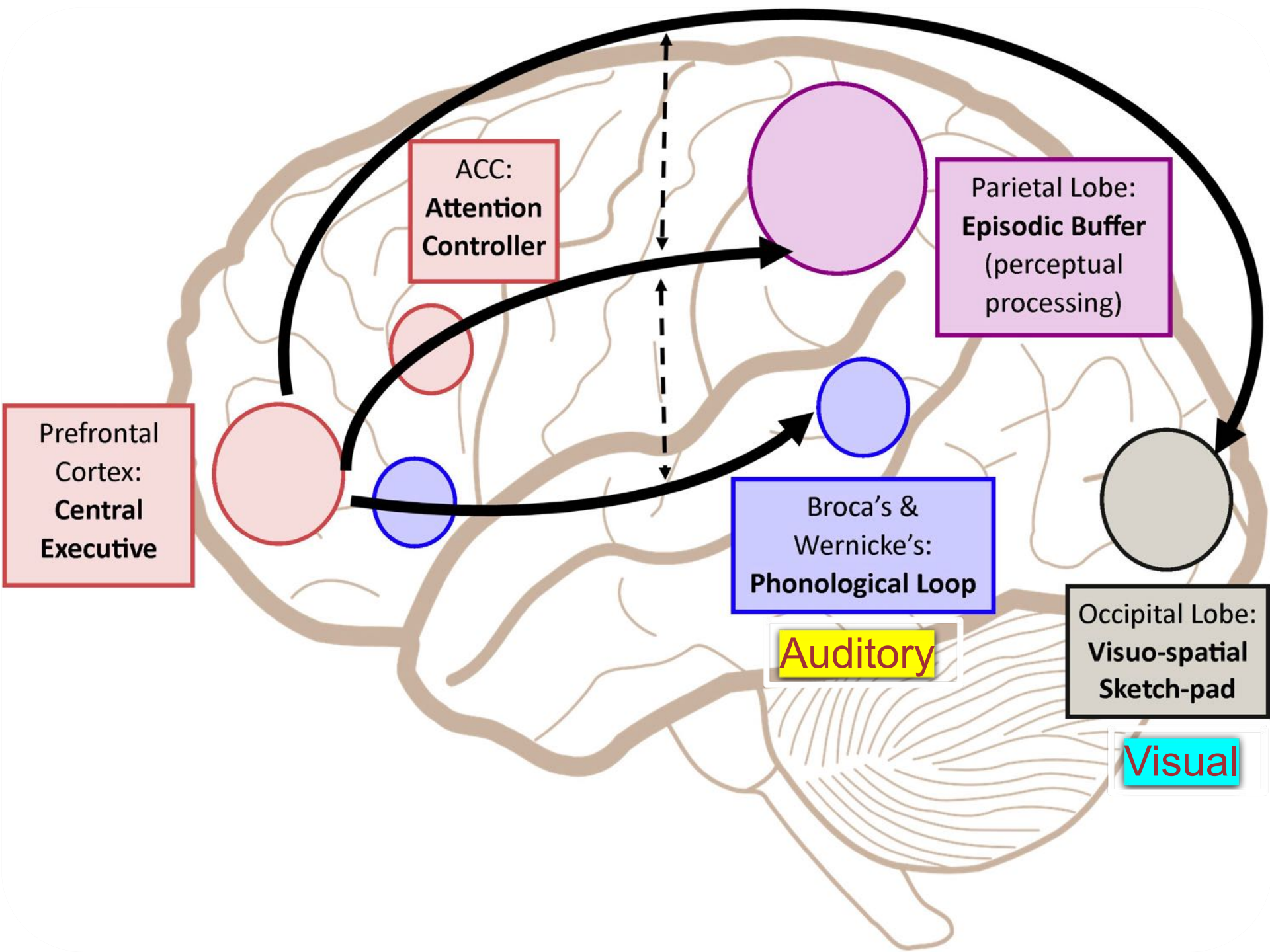
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- involves holding pieces of information active in your mind for a short period of time while you “work” on this information.
- closely linked with the ability to focus, organize, and problem solve.
- necessary for completing day-to-day tasks like following instructions, waiting your turn, making plans.
- allows us to make connections between new information and personal experiences



Two basic premises:

- Attention is limited
- Auditory working memory is limited
- Working memory is often the most impaired executive function in ASD
- Anxiety makes everything worse!

Supporting Individuals with Autism through Uncertain Times

Kara Hume, Ph.D., UNC School of Education, & UNC FPG Autism Team



- Watch your words and tone. Stay calm.
- Communicate using direct, clear, and concrete language while avoiding flowery or abstract phrasing:
 - *"The coronavirus is a germ. These germs are very tiny, and when they get inside your body, they can make you sick."*

Supporting Individuals with Autism through Uncertain Times

Kara Hume, Ph.D., UNC School of Education, & UNC FPG Autism Team



- Present information in multiple formats (visual tools):
 - multisensory strategies can help keep information in the mind long enough to use it.
- Keep messages brief and fact-based:
 - *"People get viruses all the time and are just fine, but we want to make sure not too many people get it all at once. That is why we are not going to school or work right now."*

Supporting Individuals with Autism through Uncertain Times

Kara Hume, Ph.D., UNC School of Education, & UNC FPG Autism Team



- Provide structure and routine.
- Create household rules.
 - *"I wash my hands every time I come inside."*
- Let them feel a sense of control:
 - *"I can avoid getting coronavirus by washing my hands with soap and water for 20 seconds and wiping down my devices."*

Visual Tools

- **Visual Supports**
- **Visual Timers**
- **Daily Schedules**
- **Daily Calendars**
- **Task Analysis**
- **Video Modeling***

Video Modeling and Other Visual Strategies for Children with ASD

Kathleen Bailey Stengel, CEO
Kaori Nepo, Ph.D., BCBA-D







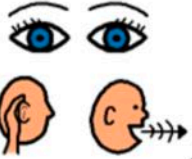
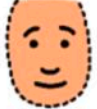

July 8, 2020

Visual Supports

- highlight specific actions and behaviors or break them down into steps



COVID-19 : CHAT BOARD







<p>questions</p>  <p>(turn over page for questions)</p>	<p>not</p> 	<p>wash hands</p> 	<p>OK</p> 	<p>home</p>  <p>(use AAC system for other places)</p>
<p>tell me more</p> 	<p>don't know</p> 	<p>touch</p> 	<p>worried/scared</p> 	<p>supplies</p>  <p>(turn over page for supplies)</p>
<p>I/me</p> 	<p>see, hear, talk</p> 	<p>soon</p> 	<p>sick</p>  <p>(turn over page for symptoms)</p>	<p>face</p>  <p>(use AAC system for other body parts)</p>
<p>you</p> 	<p>stay</p> 	<p>now</p> 	<p>COVID-19/ Coronavirus</p>	<p>I want to say something else</p>  <p>(get my AAC system)</p>

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We love to chat: twowaystreet.com.au

TWO WAY STREET

Visual Supports

 <p>First Then Visual Schedule</p> <p>\$9.99</p>	 <p>Pictello</p> <p>\$18.99</p>	 <p>iPrompts</p> <p>\$9.99</p>
 <p>iCreate</p> <p>Free (in-app \$)</p>	 <p>Social Story Creator & Library</p> <p>Free (in-app \$)</p>	 <p>First Then</p> <p>Free</p>



I wash my hands



1. Turn on water.



2. Wet hands.



3. Turn off water.



4. Get soap.



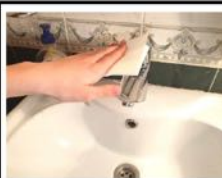
5. Scrub hands.



6. Turn on water.



7. Rinse hands.



8. Turn off water.



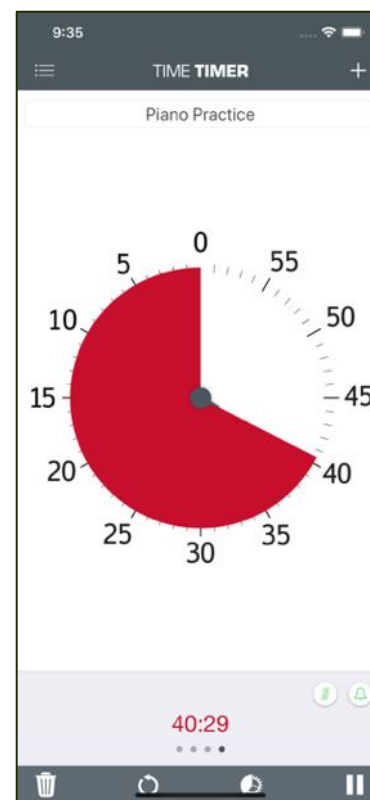
9. Dry hands.



10. Hands are clean.

Visual Timer

- Plan for screen time in the daily schedule.
- Help individuals with autism “see” how much time remains of screen time before they will be expected to transition off the device.



Time Timer



Daily Schedules

Daily Schedule Example

Task	Done
 Wake Up	
 Brush Teeth	
 Get Dressed	
 Eat Breakfast	
 Read (30 minutes)	
 Exercise (30 minutes)	

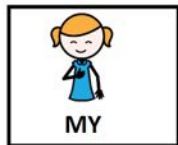
* Note: Icons from Microsoft Word Icons (Insert tab)

Daily Schedule Example

Task	To Be Done	Done
 Read (45 minutes)		
 Computer (30 minutes)		
 Eat lunch		
 Walk the dog		
 Complete homework		
 Eat snack		

Daily Calendars

- Aid in tracking time out of school
- "No School Calendar"



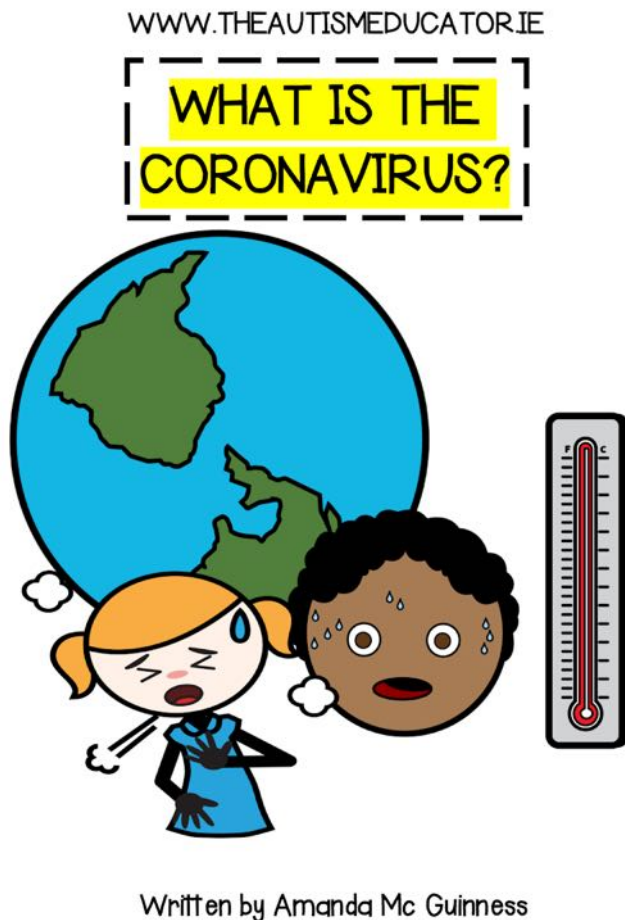
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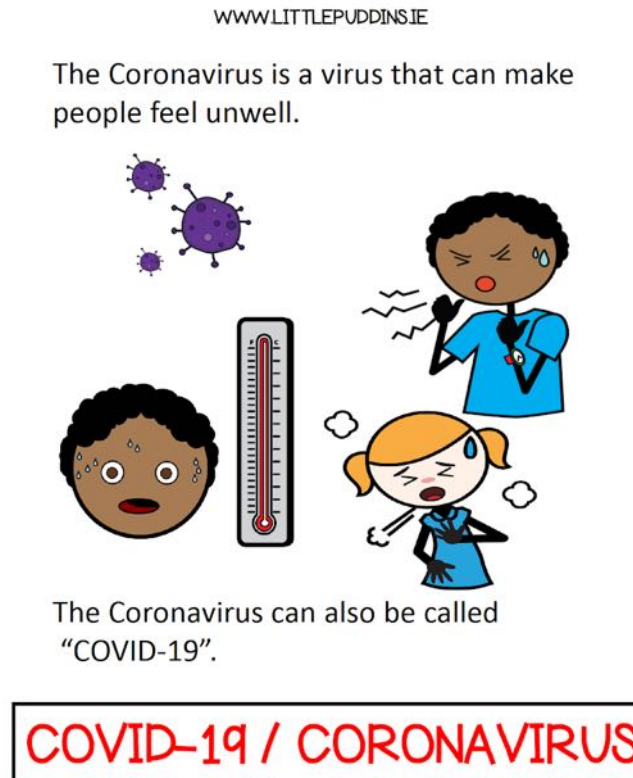
Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday

Social Narratives*

- Visual cues using modified text and photos:



<https://theautismeducator.ie/2020/03/11/corona-virus-social-story/>



Videos

What is a Virus?

This VCU-ACE COVID-19 resource was designed to help explain the meaning of a virus to individuals with ASD.



What Should I Do If Get Sick

This What Should I Do If Get Sick VCU-ACE COVID-19 resource is designed for individuals with ASD. This video explains the symptoms of COVID-19, helps individuals with ASD understand what to expect if they do get sick, and also discusses what they can do at home while getting better.



VCU Autism Center for Excellence

<https://vcuautismcenter.org/te/covid19.cfm#videos>

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- Exercise/physical activity is a proven strategy to reduce anxiety.
- Good sleep hygiene and maintain bedtime and waking routines.
- Educational and behavioral therapies are the primary treatment strategies for children with autism, while medicine is the second line.

Calming Routine

1. Take 4 deep breaths



2. Clench fists 4 times



3. Count to 10

1 2 3 4 5 6 7 8 9 10

4. Good job!



STRESS

2019, VOL. 22, NO. 3, 303–311

<https://doi.org/10.1080/10253890.2019.1572744>



Taylor & Francis
Taylor & Francis Group

ORIGINAL RESEARCH REPORT



Heart rate increase predicts challenging behavior episodes in preschoolers with autism

Heather J. Nuske^a, Emma Finkel^c, Darren Hedley^d, Valentina Parma^e, Liza Tomczuk^f, Melanie Pellecchia^a, John Herrington^b, Steven C. Marcus^a, David S. Mandell^a and Cheryl Dissanayake^d

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BioNomadix BioShirt

- children with autism showed ↑HR of around 20 bpm about one minute before the onset of challenging behavior, regardless of age, autism severity, expressive language ability, or overall developmental ability.



AUTISM RESEARCH INSTITUTE
Autism is Treatable

Webinars

- Coronavirus Impact – Basic Supports and Strategies to Get us Through and Keep us Sane.
- Anxiety and Autism: Tips For Coping At Home During The Coronavirus Outbreak.

<https://www.autism.org/>



AUCD

ASSOCIATION OF UNIVERSITY CENTERS ON DISABILITIES
Research, Education, Service

- Advice from People who have a Disability on Dealing with COVID-19
- Adaptations of CBT for people with ASD

<https://www.aucd.org/>

RUTGERS

Robert Wood Johnson
Medical School

THE BOGGS CENTER ON DEVELOPMENTAL DISABILITIES

Just In Time - Webinar Series Supporting People With Disabilities During The COVID-19 Pandemic

- Making it Meaningful at Home
- Maintaining Connections, Engagement, and Well-being while Social Distancing
- Self-Care Strategies for Direct Support Professionals
- Supporting Positive Behavior and Mental Health throughout the COVID-19 Pandemic

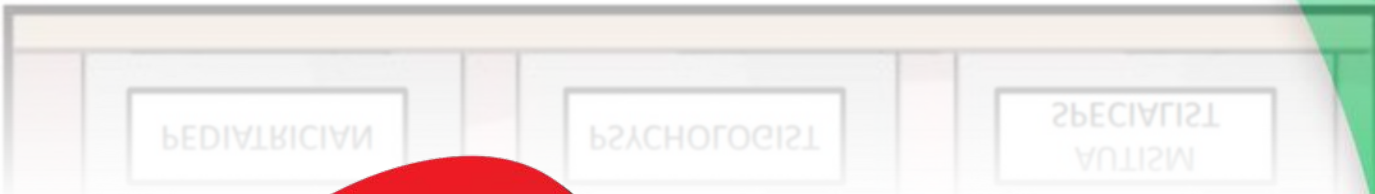
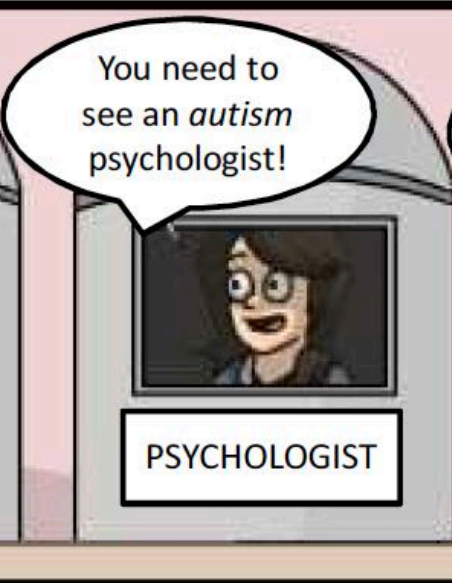
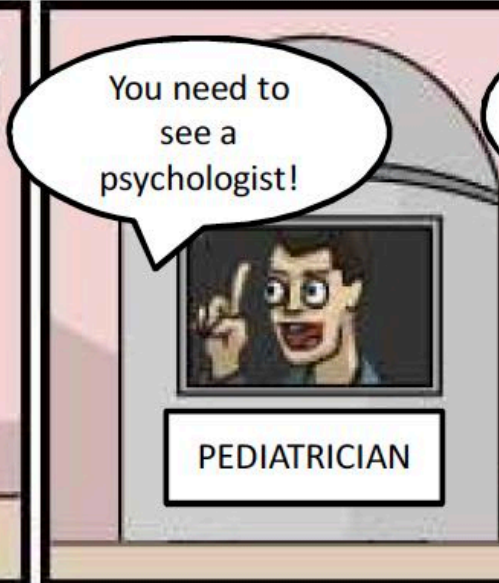
<https://boggscenterregistration.rwjms.rutgers.edu/index.php/event/training>

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In addition to telehealth, we have in-office appointments for patients with medical necessity that need to be seen in-person. Patients can visit our website to request an appointment or email info@neurabilities.com for assistance.

We are also sharing a lot of information on our Facebook page, so please consider following us there.



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