Life in Quarantine with a Severely Affected Individual

Michelle Gorenstein, PsyD
Pilar Trelles, MD
Beth Brown, LCSW-R

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Agenda

- Introductions
  - Michelle Gorenstein, PsyD
  - Pilar Trelles, MD
  - Beth Brown, LCSW-R

- Behavior as a Form of Communication
- Safety/Proactive Strategies
- The Role of Medication
- Resources
- Question and Answer
Behavior

- Behavior is often a form of communication
- Behaviors serve a function and/or produce an outcome
  - Obtain a desired outcome
  - Escape a task or situation
  - Get attention (either positive or negative)
  - Attempt to self-regulate (sensory input)
  - Sensory avoidance
  - Attempt to gain control over a situation

Siper, P. (2019)
Questions you can ask yourself- Be a Detective

- Did this behavior start suddenly?
- Is there an underlying medical concern or condition that is making him/her reactive?
- What is my child attempting to gain from this behavior?
- What is he/she trying to tell me?
- Does it happen in certain places, with specific people or in specific conditions?
- What happens before this behavior?
- What happens after the behavior occurs?
- What do I typically do to get my child to stop engaging in a behavior?

What is behavior management?

- A process which guides people to change their actions within a specific context.
- Behavioral strategies can be used proactively to prevent challenging behavior and in the moment to manage problematic behavior.
- Both positive and negative reinforcement increase the likelihood that a specific behavior will occur again.

Image credit: www.thoughtco.com

Siper, P. (2019)
Offer choices to promote task completion

- Offering choices involves the other person in the decision making process, providing a sense of control that promotes task compliance.
- Give two or three choices rather than unlimited (open-ended) options.
- Asking which of two undesired tasks a person wants to engage in often increases compliance.

Image credit: www.madisonhouseautism.com

Siper, P. (2019)
Use planned ignoring to decrease attention to unwanted behavior

- Minimizing attention to unwanted behavior will decrease the frequency of the behavior.
- Attention can still be given to appropriate behavior during planned ignoring.
- An increase in problematic behavior may be observed prior to extinction of the behavior. Consistency is key.
- Exception: Planned ignoring should not be used if there are safety concerns.
Adapt the Environment

• Organize and provide structure
  • Visual schedules
• Prepare for transitions and changes
  • Timers
  • Social Stories
  • Schedules
• Use visual supports
  • If-then boards
  • Schedules
  • Social Stories
• Remove or minimize distracting or upsetting stimuli
**Visuals**

**First Then Board**

<table>
<thead>
<tr>
<th>FIRST</th>
<th>THEN</th>
</tr>
</thead>
<tbody>
<tr>
<td>Say &quot;hi&quot;</td>
<td>Play with cars</td>
</tr>
</tbody>
</table>

**Token Boards**

<table>
<thead>
<tr>
<th>FIRST</th>
<th>THEN</th>
</tr>
</thead>
<tbody>
<tr>
<td>Eat lunch</td>
<td>Playground</td>
</tr>
</tbody>
</table>

**Visual Supports**

**Visual Schedule**

- wash
- toilet
- pajamas
- get dressed
- milk
- brekfast
- story
- brush teeth
- bedtime

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Image credit: Autism Speaks Visual Supports Toolkit

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Creating a Safe Space

- Your family should have a safety plan to follow should a behavioral crisis arise.
  - Two family members should be present to support each other

- Create a safe space in your home (remove any items that could cause harm, use pillows, preferred items, bean bag chairs)

- Home modifications- if possible remove items around the house that could break easily, put furniture in front of windows, make sharp edges dull, etc. Do not make too many changes to the home environment.

- Be mindful of clothing and accessories. If your child pulls hair or other clothing items, avoid wearing hanging jewelry and keep your hair pulled back.

From Autism NJ-Managing Severe Challenging Behavior in the Home during the COVID-19 Crisis
Proactive Strategies

• Think about reinforcers. What worked for your child in his/her school or day program? What does your child enjoy. You might consider increasing the frequency of reinforcers during this time.

• Plan and engage in preferred activities. This is not the time to begin working on new skills or adding additional stress to your child’s schedule. Make sure to schedule preferred activities daily.
The Role of Medications: ASD as an Example

Deficits in social communication

Repetitive and restrictive behaviors

AUTISM SPECTRUM DISORDER
The Role of Medications: Symptom domain approach

- Irritability
- Anxiety
- ADHD
- Sleep
- Aggression
- Mood changes
The Role of Medications: When to treat

- When symptoms cause severe impairment of functioning
- When symptoms can be targeted with medications
- When behavioral interventions have failed
- Risk to self and others
- Balance: treating vs not treating
- Outcome: improve quality life
COVID-19 Resources
COVID-19 Resources For Severely Affected Individuals

How to Get Through COVID-19: A PAAL Guide
https://drive.google.com/file/d/1UzIJdvvIljCXY3tb84M68NX8INR2fsN3/view

Supporting Individuals with Autism Through Uncertain Times, Autism Focused Intervention Resources & Modules
https://afirm.fpg.unc.edu/supporting-individuals-autism-through-uncertain-times
Community Agencies with COVID 19 Resources:
They will send you invites to their online workshops, support groups, and online events.

- **Include NYC:**
  - On-line workshops and support group.
  - Educational advocacy.
  - Special events.
  - Excellent listings for general and COVID-19 resources.
  - Contacts: www.includenyc.org
  - Helpline: 212-677-4660 (English); 212-677-4668 (Spanish)

- **Sinergia – Metropolitan Parent Center:**
  - On-line workshops and support group.
  - Autism initiative – ages 3-13- learning social skills through the arts
  - Listings for general and COVID-19 resources.
  - Adult service programs, respite, community habilitation, housing help, educational advocacy…
  - Contacts: information@sinergiany.org
  - Telephone: 212-643-2840 Ext:336
Community Agencies with COVID 19 Resources:

- **YAI – Young Adult Institute:**
  - Programs for people with Developmental Disabilities from birth through geriatric years (educational programs – Manhattan Star Academy, iHOPE Academy, Recreation Programs, Medical Services, Group Homes…)
  - On-line workshops and support group (Project Grow is now on-line)
  - Excellent listings for general and COVID-19 resources.
  - Go on their website and download a copy of the Family Resource Guide for people with developmental disabilities in your borough.
  - YAI LINK – Information line – 212-2736182
  - Contacts: www.yai.org

- **O.P.W.D.D. (Office for People with Developmental Disabilities):**
  - If you have not already applied for OPWDD eligibility for your child you should begin the process now! Begin by calling your Front Door Office and they will walk you through the process.
  - Manhattan – 646-766-3220
  - Bronx – 718-430-0757
  - Brooklyn – 718-642-8576
  - Queens – 718-217-6485
  - Staten Island – 718-982-1913
  - Westchester County – 914-332-8960
  - Orange/Sullivan County – 845-695-7330
  - Rockland County – 845-947-6390
  - Taconic County – 844-880-2151
  - Long Island – 631-434-6000
  - For N.J. call the Dept. of Human Services – Division of Developmental Disabilities Office in your county.
  - COVID-19 resources on their website- opwdd.ny.gov
Favorite COVID -19 Resources

- National Geographic Kids – kids.nationalgeographic.com
- Georgia Aquarium Web Cams – Georgia aquarium.org
- Children’s Museum of the Arts – cmany.org
- Food Network Cooking with Kids- foodnetwork.com
- PBS Kids – pbskids.org
- JumpStart – jumpstart.com/parents/activities
- The Spanish Experiment – theSpanishexperiment.com/stories
- Audible – stories.audible.com
- Scholastic- Interactivestorybook-scholastic.com
- Teach your monster to read – Teachyourmonstertoread.com
- Learning Ally – Learningally.org
- Hands in Autism – Hands in Autism.iupui.edu
- Interactive social story about Corona virus – https://www.flipsnack.com/keshetChicago/Coronavirus-social-story/
- Sprout Flix – sproutflix.org
- Yale Child Study Center Guide and Resources – Covid.yale.edu/resources
- United Federation of teachers Homework Helpline – dialateacher.org – 212-777-3380
- Advocates for Children Dept. of Education updates – advocates for children.org
Important COVID-19 Services
Counseling – Medical – NYC services

- NYC Well – 24/7 confidential helpline and psychotherapy referral – nycwell.cityofnewyork.us – English, Spanish & other languages -1800-NYC-WELL/ 888-692-9355
- Thrive NYC – thrivenyc.cityofnewyork.us mental health support via phone or online.
- UFT Free Mental Health Hotline – general mental health support for NYC public school students and their families – 212-709-3222
- American Red Cross Virtual Family Assistance Center – Crisis counselors are available to provide emotional support and guidance when someone has lost a loved one. 585-957-8187 – www.redcross.org
- Free COVID – 19 Medical Infoline for NYC residents: if you have symptoms or questions about COVID 19 call: 1-844-692-4692 – 9am-9pm
- NYC COVID-19 Resources Directory – obtain resources for accessing food(1-866-888-8777), rental assistance, domestic violence (1-800-621-HOPE), etc. –go to: www1.nyc.gov
Please feel free to contact me should you have any questions at:

Beth Brown, LCSW-R
Mount Sinai West
Developmental Disabilities Center & Pediatric Neurology
212-523-6278
Questions & Answers

• Thank you for your attention and participation!
• Please write questions into chat feature and let us know of additional topics you would like covered
• For copies of slides, please email:
  audrey.rouhandeh@mssm.edu or bari.britvan@mssm.edu