Virtual House Call:
Supporting Children with Developmental Disabilities During the COVID-19 Pandemic

April 28, 2020
10:00-11:00am
Disclaimer

New and updated information on COVID-19 is being published on a near constant basis

The best websites for up to date information include the CDC and WHO

- Centers for Disease Control and Prevention (CDC):
- The World Health Organization (WHO)
  www.who.int/emergencies/diseases/novel-coronavirus-2019
Our Speakers

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Communicating About COVID-19
What do families of children with developmental disabilities need to know about COVID-19? Is my child with a developmental disability at higher risk for severe illness from COVID-19?

People with COVID-19 have had a wide range of symptoms reported — ranging from mild symptoms to severe illness.

These symptoms may appear 2-14 days after exposure to the virus:

- Fever
- Cough
- Shortness of breath or difficulty breathing
- Chills
- Repeated shaking with chills
- Muscle pain
- Headache
- Sore throat
- New loss of taste or smell

https://covid19.nj.gov/
What should I tell my child with developmental disabilities about Coronavirus? How can I help my child understand what's going on around them?

News of the coronavirus COVID-19 is everywhere. Be sure to use reliable resources and then:

1. Talk to your child in a way that is simple to understand. Be clear, direct, and honest.

2. Go over important rules:
   - **Wash hands** well and often (for at least 20 seconds).
   - Try not to touch their nose, mouth, and eyes.
   - Practice **social distancing**, keeping at least 6 feet away from other people.
   - Wear a cloth face covering or face mask in public places.

3. Find out what your child already knows.

4. Offer comfort and honesty.

5. **Speak calmly and reassuringly.**
Adjusting to New Routines
What can I do if my child has difficulties adjusting to new routines and following recommendations? How can I help my child adjust?

Here are 8 Key things you can do to help your child with follow directions:

◦ Make sure your child is paying attention. (close proximity, eye contact).
◦ Be specific. ("hands down")
◦ Give short and simple directions. ("walking feet", "stay with me")
◦ Give one direction at a time. ("stand-up", "hold my hand")
◦ State the direction in a positive manner. (instead of "no hitting", try "nice hands")
◦ Give extra assistance. (repeat the directions, show pictures, and repeat often depending on child’s developmental level)
◦ Tell, do not ask. ("time to go potty", "all finished"; Not "do you need to go potty?" "Are you finished?")
◦ Repeat, practice, and praise – make it a habit (stand-up, take my hand, walk with me, sit down, "great job!")
How can my family cope with added stress during these uncertain times?

People everywhere are feeling stressed about the coronavirus, you are not alone.

Anxiety is a normal emotion and serves as a signal to pay attention so we can protect ourselves.

1) Follow the advice of experts.

2) Make a conscious decision to stay calm.

3) Focus on the positives.

4) Establish and maintain a visual schedule.

5) Stay connected to the school or EIP team.

6) Be aware of your children’s mental health.
Are there strategies that you would suggest for managing increased aggressiveness, especially self-injurious behaviors, during this time?

**Safety First**

Proactive strategies
- Routines
- Reinforcers
- Preferred activities
- Home modifications
- Create a safe, calm space

Safety Strategy
- Protective Equipment
- Personal Apparel
- Safety Plan

If a parent only has five minutes a day to take care of their own well-being, what should they do? In other words, how can parents be supported in their own self-care?

Put your own oxygen mask on first!

Here are Six 5-minute self-care activities that sound simple, but will help you feel good:

1) Shower
2) Face Mask (facial)
3) Skin Care Routine/Put on Make-up
4) Exercise/stretch/yoga
5) Read
6) Relax: Breath!
Treatment for COVID-19
What should I do if my child with a developmental disability is sick with symptoms of COVID-19?

Most people have mild illness and are able to recover at home.

- Stay in touch with your doctor.
- Stay home. (except to get medical care)
- Take care of yourself: Get rest and stay hydrated.
- Monitor symptoms: fever, able to eat, weakness.
- Avoid public transportation,

When to Seek Immediate Medical Attention:

If you have any of these emergency warning signs* for COVID-19 get medical attention immediately:

- Trouble breathing
- Persistent pain or pressure in the chest
- New confusion or inability to arouse
- Bluish lips or face

*This list is not all inclusive. Please consult your medical provider for any other symptoms that are severe or concerning to you.

Call 911 if you have a medical emergency: Notify the operator that you have, or think you might have, COVID-19. If possible, put on a cloth face covering before medical help arrives.
What would happen if my child with a developmental disability needed to be hospitalized with COVID-19? How can I help them cope with an inpatient stay? How can I explain their needs to the staff?

My Health Passport: If you are a health care professional who will be helping me, PLEASE READ THIS before you try to help me with my care or treatment.

If I get upset or distressed, the best way you can help is by:

If I am in pain, I show it by:

I communicate using:

Emergency Information Form for Children With Autism Spectrum Disorders (from AAP)

- Baseline neurologic status
- Description of cognitive/developmental age for Receptive language Expressed language
- Description of cognitive skills
- Description of gross motor skills
- Description of fine motor skills
- Comfort items
- Does he/she wander off? If so, to where? Describe.


What protections are in place at a hospital to ensure a person with developmental disabilities receives the same level of care as anyone else?

Three federal laws that protect these rights:

1) **Americans with Disabilities Act (ADA)**
   - The ADA prohibits discrimination on the basis of disability in employment, State and local government, public accommodations, commercial facilities, transportation, and telecommunications.
   - ADA Title II: State and Local Government Activities
     - Title II covers all activities of State and local governments regardless of the government entity's size or receipt of Federal funding. Title II requires that State and local governments give people with disabilities an equal opportunity to benefit from all of their programs, services, and activities (e.g. public education, employment, transportation, recreation, **health care**).

2) **Section 504 of the Rehabilitation Act of 1973**

   Section 504 states that "no qualified individual with a disability in the United States shall be excluded from, denied the benefits of, or be subjected to discrimination under" any program or activity that either receives Federal financial assistance or is conducted by any Executive agency ...

3) **Section 1557 of the Patient Protection and Affordable Care Act**

   The law prohibits discrimination on the basis of race, color, national origin, sex, age, or disability in certain health programs or activities. ... Any health program or activity any part of which received funding from HHS.

U.S. Department of Justice  
Civil Rights Division  
Disability Rights Section  
A Guide to Disability Rights Laws  
https://www.ada.gov/cguide.htm
Is it true that people with developmental disabilities would not be given a ventilator if needed at the hospital?

NO!

Recent case in Pennsylvania regarding triage for COVID

Office for Civil Rights (OCR) at the U.S Department of Health and Human Services (HHS) enforces the federal anti-discrimination laws.

American Academy of Developmental Medicine and Dentistry

https://static1.squarespace.com/static/5cf7d27396d7760001307a44/t/5e94a57e52eaaf1bad4b70ac/1586800000891/Ventillator-PolicyStatement.pdf
Social Distancing
What can I do to help my child with sensory issues become comfortable with wearing a mask in public settings?

Recommendations by the American Academy of Pediatrics (AAP)

- children under the age of 2 should not wear masks due to suffocation and choking hazards
- children with severe cognitive or respiratory impairments should not wear masks, and if they do, respiration should be monitored.

Practice at home, for short periods and try different types

Make it fun:

- You can help your child decorate a mask using crayons, markers, stickers, etc.
- You can give your child a matching mask for his/her favorite doll/stuffed animal to wear.
- You can have the child help you make a mask of his own and let him/her choose fabric (superhero).

Allowing kids to decorate their own masks is great way to ease them into wearing it. It can provide them with some sense of control over the situation and more likely, for them to wear it without much fuss.
Can you discuss strategies for addressing sensory and movement needs for individuals with autism who have trouble distancing socially outside?

Explain reason why at a developmentally appropriate level

Give concrete examples of 6 feet

Make a game inside the house and practice

If not able to understand and cooperate may need
- Tether
- Stay home-stay safe
Can you share some resources or tips for creating virtual social interactions for children on the spectrum?

Here are some platforms that parents can consider for increasing children’s virtual interactions:

1. FaceTime
2. Zoom
3. Movie party (netflixparty.com)
4. Game night (jackboxgames.com)
6. Virtual Karaoke (https://www.karafun.com/karaoke/)
7. YouTube

Your child’s teacher or behavioral therapist may also be able to provide you with additional resources.
Is there any way to seek out new therapists now? What happens if you don't have a pre-existing therapist to lean on?

PerformCare is available to assist with CSOC services (including Mobile Response and Stabilization Services) 24 hours a day at 1-877-652-7624. At this time, Mobile Response services are also available remotely through telephone and videoconferencing.

Parents needing support can contact the Mom2Mom hotline at 877-914-6662 which provides peer support services to moms of children with special needs.

Important for families to stay connected with their child’s healthcare provider to address any concern they may have regarding their child’s overall health.

Reach out to :

- Early Intervention (0 to 3 years)
- School Child Study Team (case manager or school psychologist)
How can I mitigate a summer slide from my child’s social/emotional learning if he's away from friends for five months until September?

Distance socializing will never be a perfect substitute for real life.

Use those household members for practice -siblings.

Keep child in contact with “old” friends through Zoom, Facetime, etc

Reach out to “new friends”- child’s cousins, etc through Facetime, etc

Have child express emotions/keep in touch with their own feelings through:
  ◦ Drawings/art
  ◦ Journal

Emphasize the positive- children will hopefully come out of this experience more compassionate and caring, with a new appreciation for family and community.

“We’re all in this together”
NJ Early Intervention System

STATEWIDE REFERRAL LINE: 888-653-4463
What is Early Intervention?

Statewide system of supports and services for families and their children birth to age three with developmental delays or disabilities.

Individualized to the family’s concerns, priorities and resources related to their child’s development

Families & the EI System working together as partners.
Is EI continuing to provide services to infants and toddlers (birth to age 3) and their families in their homes or communities?

NJEIS is excited to offer **telehealth services** for evaluations, ongoing services, and family meetings.

• Due to the COVID-19 pandemic outbreak in New Jersey, Governor Murphy has directed all DOH non-essential personnel to work remotely and maintain social distancing, which includes the NJ Early Intervention System.

• In response, NJEIS has worked to re-think how early intervention evaluations and services can be done during this time.
What are telehealth services in Early Intervention?

- The use of video technology so that families and EI staff can see and talk to each other
  - Laptops, smart phones, tablets, other devices

- Currently being used across the country
  - Although telehealth in EI is new to NJ, many states have been using telehealth for a number of years
    - Increasingly popular
    - Research has demonstrated telehealth is effective
EI Steps for Families of Eligible Children

- Referral System Point of Entry
- Evaluation/Assessment
- Family Information Meeting/Family-directed Assessment (FIM/FDA)
- Develop Individualized Family Service Plan (IFSP)
- Implement IFSP
- Transition Beyond NJEIS
Your Partners in Early Intervention

- SPOE Referral Service Coordinator
- Evaluators Targeted Evaluation Team (TET)
- Ongoing Service Coordinator (OSC)
- EI Practitioners
How do I Make a Referral to Early Intervention?

Call the System Point of Entry (SPOE) Referral

Statewide Toll-free Number
888-653-4463

Families or primary referral sources (after discussion with family)
- Call toll-free number
- Caller leaves voice message & contact information

SPOE Service Coordinator
- Discusses with family their developmental concerns for child
- Provides information about the EI system, eligibility criteria, and answers additional questions for the family
- Arranges for a developmental evaluation/assessment for eligibility
What can I expect during my virtual Early Intervention Evaluation?

First: Pre-Planning Call
- Discuss what the evaluation will look like & schedule
- Find out what platform you are comfortable using (Zoom, Facetime, What’s App, etc.)
- Ask you to gather some household items for the day of the evaluation – items will vary by age, e.g.,
  - Cup, bowl, container
  - Empty water bottle
  - Small snack, such as Cheerios
  - Mirror
  - Small toy-car, block, ball
  - Children’s book, etc.
What can I expect during my virtual Early Intervention Evaluation?

**Conversation**
- Evaluators will be asking you questions about your child’s skills and development

**Play/ interaction/ Observation**
- Evaluators will guide you to present toys and objects and ask you to do something specific so they can see the child’s skills
- Evaluators will also observe your child interact with you, your family, & various objects

**Evaluation tool(s)**
- Developmental evaluation tool(s) to gather information about your child’s development
- All areas of development: gross motor, fine motor, communication, cognition, social emotional and adaptive
Will an EI evaluation via telehealth be able to provide a good picture of my child?

Yes. Evaluation will give you a “snapshot” of your child’s development

- Valuable information about your child’s strengths and challenges

Evaluators are qualified & trained

- Experienced providing EI evaluations
- Backgrounds: Child development, SLP, OT, PT, SW, Special Education, etc.

- Uses many of the same developmental tools & methods that are used during in-person evaluations
- You will get ideas & strategies on how to help your child develop and grow
A Family’s Perspective

“I know these times are stressful for all, but I want you to know that the telehealth OT services have been working really well for us. Of course there are limits (and I’m sure it’s hard to develop new relationships this way), but in some ways, I think it is even more helpful for the focus to be on OT coaching us through how to interact with our son. We as parents are building more skills than ever.”

-NJEIS Spotlight on Telehealth

(Vol. 1 Issue 5)

https://www.youtube.com/watch?v=RgQpTMSieTU
NJEIS: Two Paths to Eligibility

Measured Developmental Delay

1 area of development:
- 2 standard deviations below the mean

2 areas of development:
- 1.5 standard deviations below the mean

Identified Condition with a High Probability of Developmental Delay

May establish eligibility in absence of delay with written documentation of diagnosis and a statement of high probability

- Including (but not limited to) conditions such as autism spectrum disorders, Down syndrome, hearing or vision impairments, cerebral palsy, other chromosomal or genetic conditions
I heard EI is offering services via telehealth now. My child won't stay and attend in front of the screen for that long. What do you suggest?

Don’t worry!
• No one expects a child this age to stay in front of the screen for a long time. We will work this out together.
• Child can move around & do different things

EI staff will work with you on ways you can interact with your child
• Videocamera set-up – may move to see both child & family
• Take breaks as needed

Discussion time with family & evaluators
• Child may do other things (as long as safe)
• Observe child in their natural setting – doing what you and your family does
I heard EI is offering services via telehealth now. My child won't stay and attend in front of the screen for that long. What do you suggest?

If your child is eligible, together with your team, you would be developing a plan for future visits through the phone, tablet or computer. You can decide how this will best meet your child’s needs.

- EI services using telehealth would look very much like our in person evaluations or home visits. It may include coaching, routines-based intervention and learning opportunities.
Maximizing Learning Opportunities

By focusing efforts on families, one hour of intervention could identify 

**multiple opportunities to learn**...throughout everyday life of the child and family.
# Enhancing Learning Opportunities within the Natural Environment

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<th>Daily Routines</th>
<th>Learning Environments</th>
<th>Everyday Learning Opportunities</th>
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<tr>
<td>Everyday activities that occur regularly in the life of the child/family such as:</td>
<td>Places in the community where all children and families live, work, worship and play such as:</td>
<td>Activities to support &amp; encourage development</td>
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<tr>
<td>- Mealtime</td>
<td>- Libraries</td>
<td>- Listening to music</td>
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<td>- Story time</td>
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<td>- Car Rides</td>
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<td>- Shopping</td>
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<td>- Taking turns</td>
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<td>- Pool</td>
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How do you engage children with autism spectrum disorder in telehealth consults? How do you continue delivering care to kids who have difficulty interacting through verbal communication and require a different approach?

• Every child and family is unique – this means that we partner with you – the family to make sure strategies are individualized to your family and child based on how your child learns & to encourage active engagement

• NJEIS focuses on coaching the family, asking questions, suggesting strategies, noticing/commenting

• Follow the lead of the child in the context of family routines
  • Work on child’s favorite activity or incorporate what he/she likes
  • Brush teeth, wash hands, wash dishes, pile of laundry – use everyday moments

• There may be more talking, problem-solving, and planning between the practitioner & family than direct interaction with the child
  • Working with the family to make a picture schedule
Some research: Parent Perspectives of an Occupational Therapy Telehealth Intervention

Study: Examined how parents perceived the mechanism of service delivery (i.e., videoconferencing) and the content of the intervention

- OT delivered via telehealth can support families of young children with autism spectrum disorders (ASD) in everyday routines such as mealtime, bedtime, and play

Themes that emerged from the data included *Compatibility with Everyday Life*, *Collaborative Relationship*, and *Parent Empowerment*.

- Parents expressed how telehealth *fit within their daily lives*, how telehealth supported a *collaborative relationship* with the occupational therapist, and how the content of the intervention built a *sense of empowerment*.

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NJEIS Public Expense Services

- Child Find, Including Public Awareness & Referral
- Service Coordination
- Comprehensive, Multidisciplinary Evaluation/Assessment
- Individualized Family Service Plan (IFSP)
- Procedural Safeguards
Telehealth Early Intervention: Videos

https://ectacenter.org/topics/disaster/ti-service.asp
To see Telehealth EI in Action & Other EI Resources

www.thefamilymatterswebsite.org
Questions?

THANK YOU