

# How Telehealth has Changed Caregiver Roles and Responsibilities in Healthcare in the Time of COVID-19

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MEDICINE *of* THE HIGHEST ORDER



# Telehealth is a new way of life for most, if not all, of us

## Goals:

- Provide a forum to share experiences of telehealth
- Offer suggestions to maximize telehealth sessions
- Share ideas that may be helpful for reducing caregiver stress



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# Share Your Experiences in Real Time in the Q & A Box

# Overview

Context

“Experiences of Using Telehealth” Survey

- Perspectives on Telehealth
- Strengths and Challenges of Telehealth

Tips for Telehealth Visits

Adapting to Telehealth in the Clinic

Managing Caregiver and Family Stress

# Context

The COVID-19 global pandemic has impacted how we live our lives, including how we interact with school teams and healthcare providers

Virtual options have replaced in-person visits in many parts of life

- Social, work, education, therapy, healthcare

The shift to virtual options has meant that many of us are taking on new and additional roles, especially caregivers



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# Caregivers as Therapists

In the therapy setting, caregivers may be taking on more of an active role, especially when therapy is done virtually

Direct therapy vs. Caregiver-mediated therapy

This new role can have both benefits and challenges

# “Experiences of Using Telehealth” Survey

# Survey Questions

Role

Types of Services

Rated questions (from “Strongly Disagree” to “Strongly Agree”)

Open-ended questions

- Share experiences from telehealth (positives, challenges)
- Creative use of the telehealth model
- Perceived strengths and challenges of telehealth
- Any other helpful information you wish to share



# Survey Responses - Roles

Role	% (number of respondents)
Parent/Caregiver	35.7 % (n = 10)
Self-Advocate	0.0 % (n = 0)
Physician/Pediatrician	17.9 % (n = 5)
Nurse/Nurse Practitioner	10.7 % (n = 3)
Psychologist	21.4 % (n = 6)
Social Worker	3.6 % (n = 1)
Behavior Analyst	0.0 % (n = 0)
Fellow	3.6 % (n = 1)
Another Role (e.g., patient)	7.1 % (n = 2)
<b>Everyone</b>	<b>100.0 % (n=28)</b>

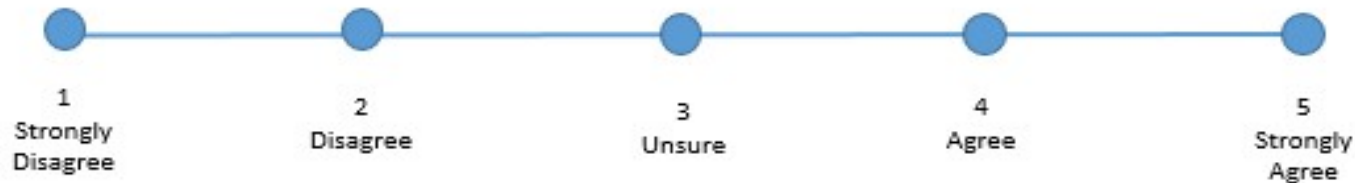
# Survey Responses – Types of Services

Type of Service	% respondents
Medical	71.4 %
Behavioral	50.0 %
Feeding	10.7 %
Another service (Diagnostics; OT, PT, speech therapy)	21.4 %

# Survey Responses – Rated Questions

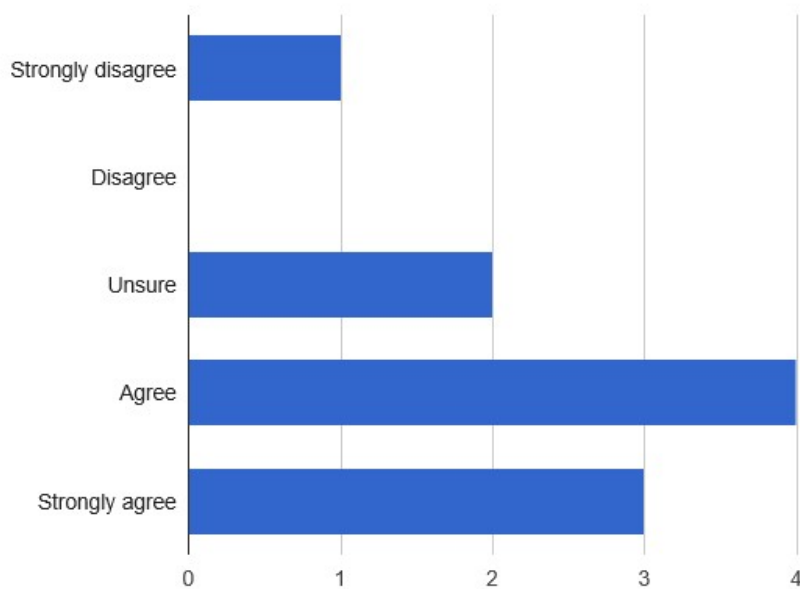
**Please indicate how much you agree with the following statements:**

A telehealth visit makes getting services easier.	4.2
A telehealth visit is effective at helping me achieve my goals for a session.	3.7
I think using telehealth is just as good as having an in-person visit.	3.2
I would recommend telehealth to others.	4.2

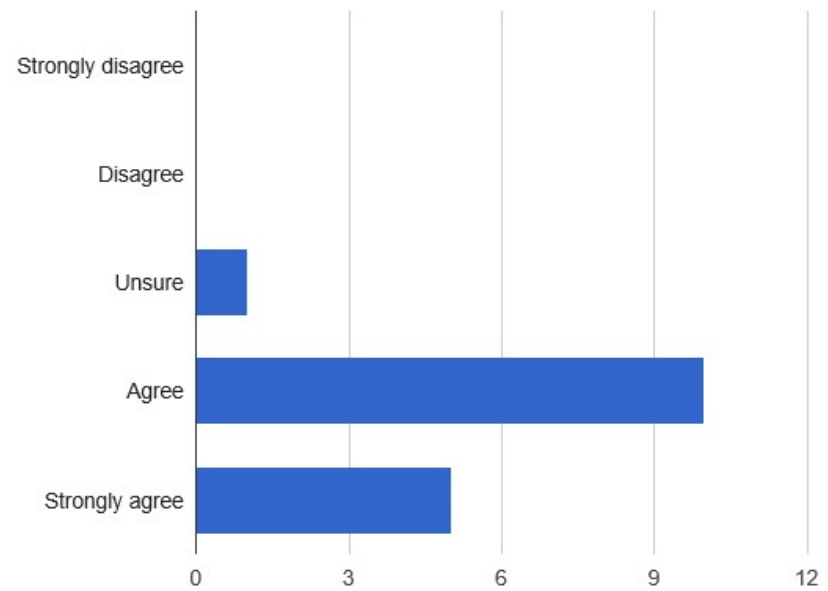


# A telehealth visit makes getting services easier

## Parents/Caregivers

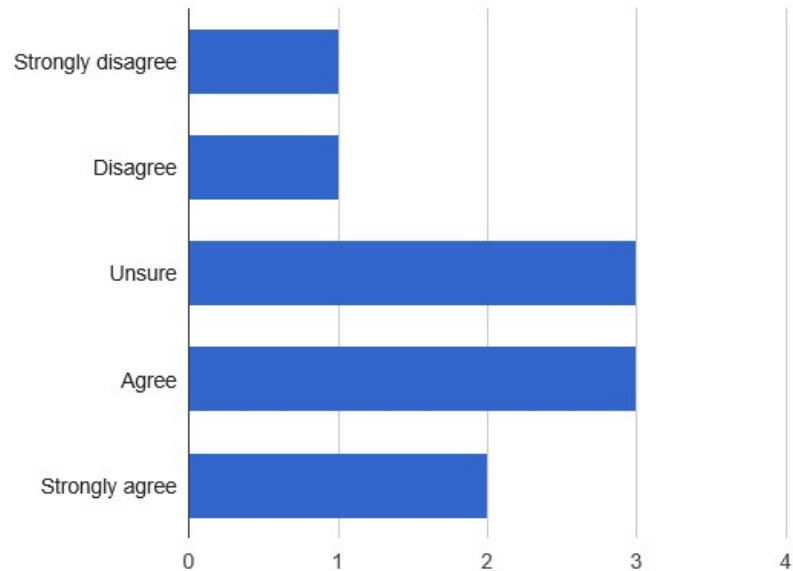


## Providers

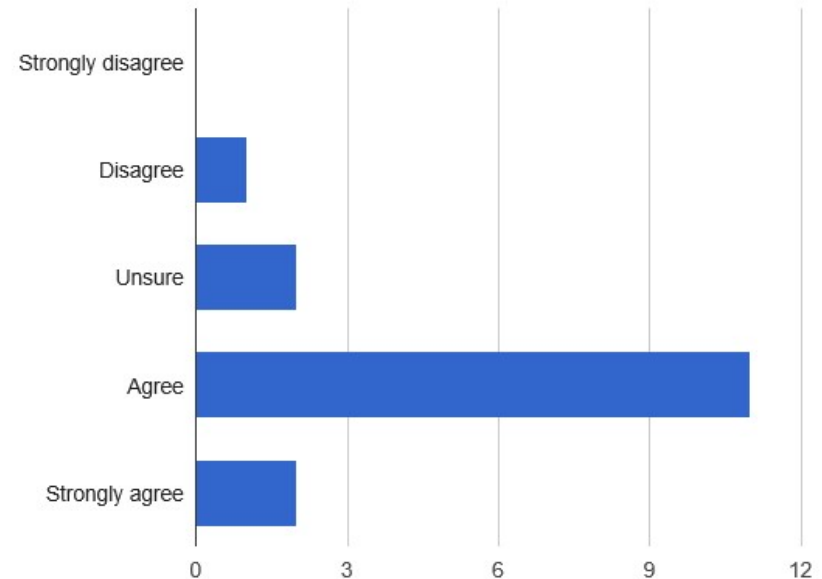


# A telehealth visit is effective at helping me achieve my goals for a session.

## Parents/Caregivers

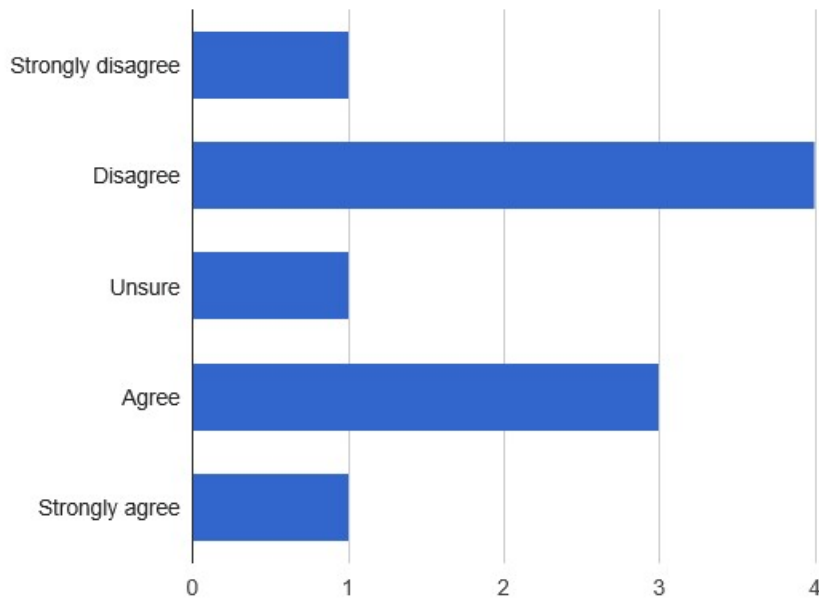


## Providers

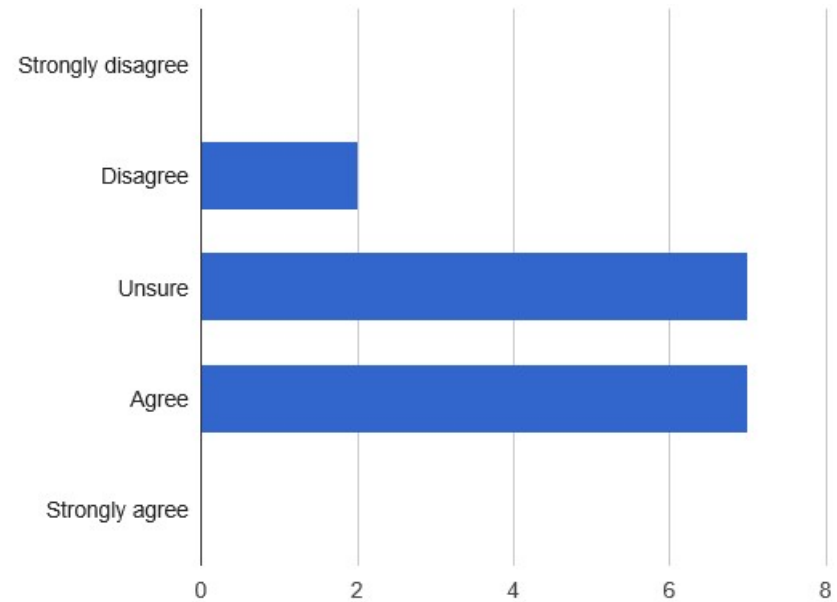


# I think using telehealth is just as good as having an in-person visit.

## Parents/Caregivers

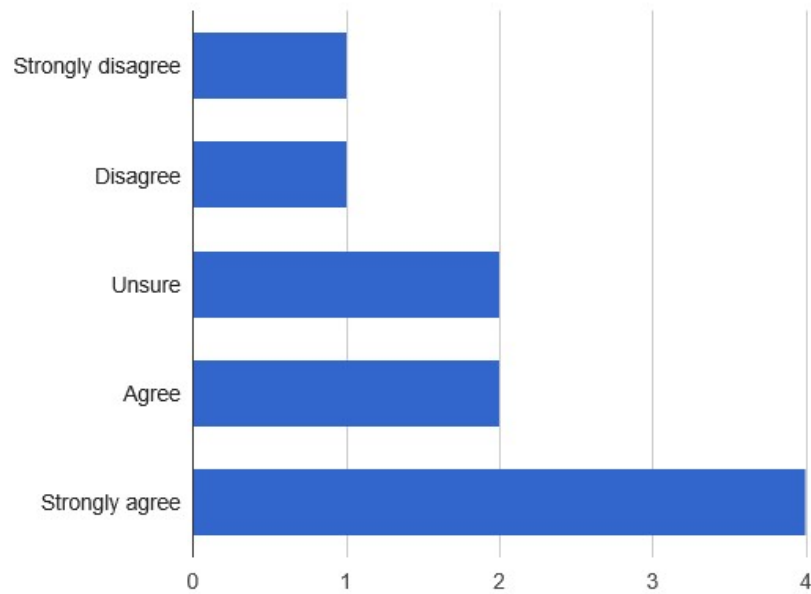


## Providers

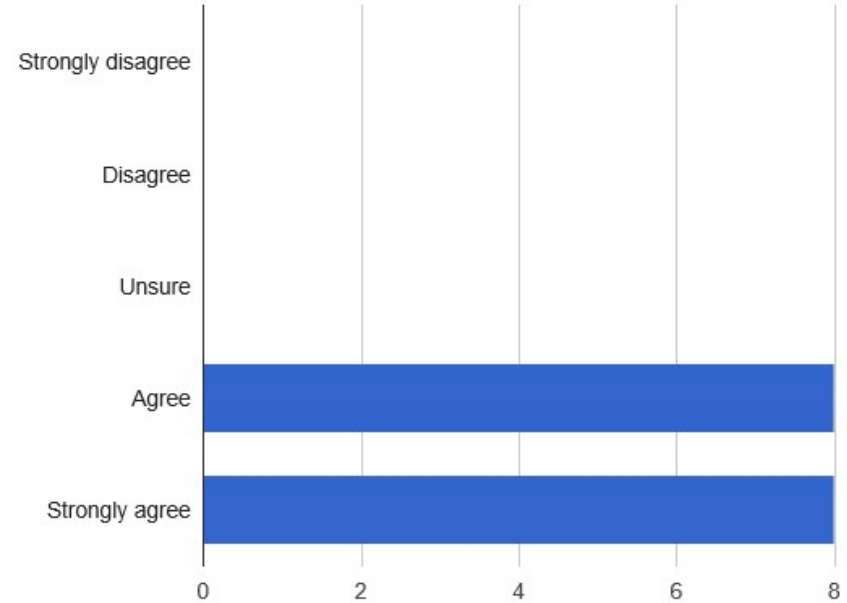


# I would recommend telehealth to others.

## Parents/Caregivers



## Providers



# Parents/Caregiver Perspectives



# Caregivers –Telehealth Working Well

Good for straightforward questions:

- “I had some pretty straightforward questions about one of my children and I found the telehealth format was perfect. I felt like I had the full attention of the provider.”
- “Able to send a picture, received quick assistance...”

Efficiency and convenience:

- “It helped me save gas money and travel time.”
- “We live 1.5 hours away and sometimes the weather isn’t suitable to drive, so it is a huge blessing!”

Minimizes gaps in services:

- “For emotional therapy and support, we were able to ensure no visits were missed.”

# Caregivers –Telehealth Challenges

## Communication difficulties:

- “It’s hard to get the provider a good visual if there is something that you want the provider to see.”

## Hard to engage:

- “My child is very disinterested in Zoom sessions and requests to see his providers in person.”
- “...My daughter who is 3 had a terrible time with all of this therapy [PT, OT, and speech therapy]. She responds better with in person interactions.”

## Technology:

- “Not able to log on with codes we were given.”
- “Technology is great when it works; it is frustrating when it doesn’t. I had to resort to a telephone call for part of a visit due to connection issues.”

## Life Happens:

- “Remembering to log on, on time”

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# Caregivers – Perceived Strengths of Telehealth

Efficiency and convenience:

- “Perfect for really direct questions that involve more talking than examining...”
- “...easier/quicker to get an appointment...”
- “Time saving... less time needed off work.”

Comfortable:

- “...nice when you’re waiting for the provider that you can do that in the comfort of your home...”
- “...still provides benefit of interaction...”

# Caregivers – Perceived Challenges of Telehealth

Difficulties with technology:

- “...not everyone has high speed internet. I have to pay per GB for my Internet...”
- “...disjointed connections and pictures [related to internet connectivity issues]...”

Limitations of what can be completed online:

- “...feels less thorough when there is something you would like the provider to see.”
- “Vitals can’t be taken.”

Difficulties with engagement:

- “...reluctance of some to interact with a screen...”

Managing family needs at home:

- “It can be challenging when you have other children to care for while you are trying to focus on a televisit...”

# Caregivers – Creativity in Telehealth

Flexible (and safe!) locations:

- “Locate to a small area that the child could not exit from”
- “We did a session in our car!”
- “I had to set-up a location for my child and I to participate comfortably. I think it needs to be a situation where you consider having space for both of you to be able to see the screen as well as be able to be seen.”

Take advantage of resources:

- “Using the phone flashlight so that the provider could see inside the mouth”

Supporting your child during the visit:

- “Have something that my child can do quietly but not too engaged that they can’t answer questions”

# Caregivers – Any Other Helpful Information

“...it’s not for everyone but for some it’s a great option...”

“Telehealth won’t replace an in person, traditional appointment; but... it can bridge a gap to ensure connection, continued interaction, and ongoing care...”

# Provider Perspectives

# Providers –Telehealth Working Well

Effective use of session time and resources:

- “One patient has been able to attend sessions more regularly during telehealth... this improved continuity, grew rapport...”
- “I have been able to save parent time away from work and child time away from school.”
- “I had a case that would have had to spend 3 hours of their day to access services with an experienced professional. By using telehealth, we were able to successfully start toilet training...”
- “I had a great experience with a child who was socially anxious... I was able to engage her in conversation about toys I saw in the background”
- “Permits families to attend visits without a need for child care for siblings...”



# Providers –Telehealth Working Well (continued)

Insight into home environment:

- “Excellent opportunity to see what families describe as concerns at home – at home!”
- “Got to see what life at home looked like...”
- “...Being able to see the toys available and the set up of the home allows unique insight...”
- “Telehealth has been great for some of my toilet training cases. I have been able to see the bathroom [at home]... and do active coaching... it is much more natural...”

# Providers –Telehealth Challenges

## Distractions during sessions:

- “Some patients are more distracted during teletherapy and are eager to get back to whatever fun activity they just left...”
- “...telehealth are REAL appointments and cannot be done at the supermarket...”
- “A parent was attempting to participate... via video while driving... felt unsafe – I ended the visit and rescheduled later.”

## Difficulties with engagement:

- “A child that would not stay in view of the screen due to lots of activity...”
- “One session included working with a young man with severe inattention... gaining attention and not being able to introduce physical materials made it really hard...”

## Technology issues:

- “...We have encountered barriers with using Zoom. Sometimes it freezes, or is very choppy.”

## Lack of privacy:

- “...the loss of privacy for visits has changed opportunities for effective work. A few cases parents did not want to use Zoom, apparently due to the sense that it would be intrusive.”

## Lack of in-the-moment team support:

- “During a visit when a patient was decompensating behaviorally and emotionally, I was alone as a provider, whereas in an office setting I would have had the support of behavioral specialists, nurses, etc.”

# Providers – Perceived Strengths of Telehealth

## Convenience and ease:

- “Convenience for families in not traveling to Rochester, or getting child care for siblings...”
- “Comfort for the patient, so a truer representation of behavior...”
- “Less stress transitioning for many patients”
- “In the context of feeding assessment/session, the family has access to all of their kitchen/food items needed... this helps make the session quicker and helps any progress generalize to home.”

## Effective use of services:

- “...it makes some of our services more available for individuals who live further away and/or do not have the time/resources to attend weekly clinic visits...”
- “Decreases no show rate”
- “...often more efficient and take less time to accomplish the same goals...”
- “...Improvement in MyChart utilization and reinforced use of portal for information and communication...”

## Safety:

- “Stay safe from infectious disease”

## Flexibility:

- “Many opportunities to flexibly include the patient, siblings, and/or multiple caregivers...”

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# Providers – Perceived Challenges of Telehealth

## Competing demands:

- “Distraction of being at home”
- “Privacy concerns, not being able to see the whole room/patient’s full body, who else is present...”
- “Many parents are OVER-ZOOMED... an added session on some days is just a burden...”

## Difficulties with completing visit tasks:

- “No vital signs for med follow up”
- “Lack of in-person physical exam”
- “...challenges in demonstrating behaviors needed for assessment...”

## Differences in engagement:

- “...it can be harder to keep kids engaged in therapy without control of the environment and motivators”
- “Loss of the in person eye contact and traditional ways to show connection and warmth...”

## Other barriers:

- “Not everyone sees the visits as formal”
- “Technology barriers”

# Providers – Creativity in Telehealth

Finding fun ways to engage:

- “Giving patients an opportunity to show me one thing about their house/room/family...”
- “Sing a song, like Baby Shark...”
- “Have child ‘beep’ my nose on screen to get engaged with me.”

Being flexible:

- “A child was distracted by the video of themselves in the Zoom meeting, so the parent placed a sticker on the computer screen over the image.”
- “...change the typical order in which we would conduct a visit in order to best fit the child’s tolerance for the telehealth visit.”
- “...For children with social anxiety, turning off our video (so the child does not see us) has helped make the child feel more comfortable...”

Presenting material in new ways:

- “...time and care was taken to find ways to give visual/digital feedback...”
- “Watching video clips on screen sharing to demonstrate concepts.”

Innovations in providing care:

- “Nationally, there has been a collaborative movement to embrace the Telehealth-ASD-Peds to help in telehealth diagnosis. It would have taken us years to get to this efficiency and convenience in diagnosis of young children if not for necessity!”

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# Providers – Any Other Helpful Information

Maximize session time and resources:

- “...These are REAL visits... need time and space carved out for them”
- Encourage families to use MyChart and complete questionnaires prior to visits to maximally use time”
- “Prepare... as you would prepare for an in-person appointment!”
- “I was pleasantly surprised by how much we can do over telemedicine. In most cases, a diagnosis can be made over telemedicine, in which I feel confident. In all cases, I am able to collect valuable information... and provide interim recommendations to families.”

Supporting sessions as a caregiver may look different:

- “...Parents may need to do more active supporting of their child during appointments or be a bigger part of therapy. Although this can be more burdensome, I think there is a lot of benefit to having the parent be an active participant in all types of therapy.”
- “Point the camera at your child, even if parent is talking. In clinic, I am often talking with parents directly, but observing the child out of the corner of my eye...”

# Providers – Any Other Helpful Information (continued)

We are in this together:

- “Everyone is adapting – parents, children, providers. All parties need to have realistic expectations for what anyone can do in this unprecedented time.”

Find ways to continue to collaborate:

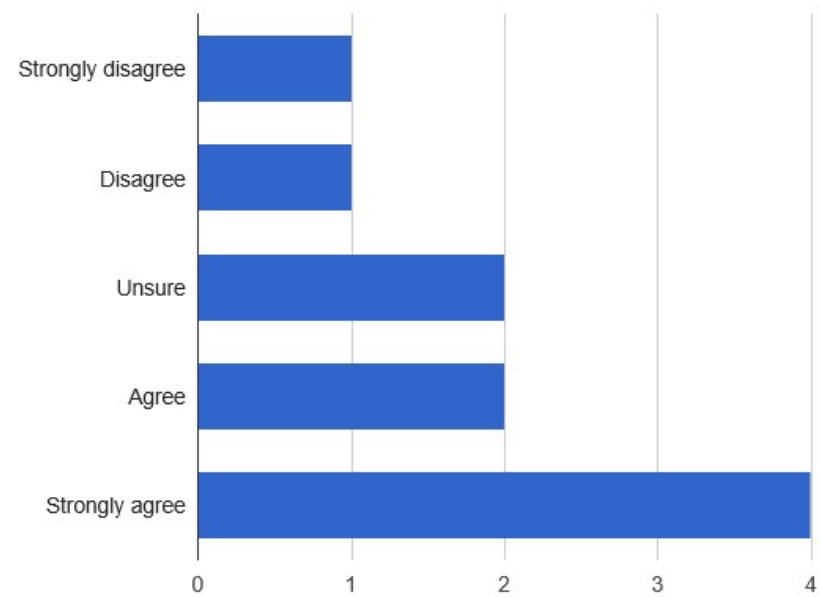
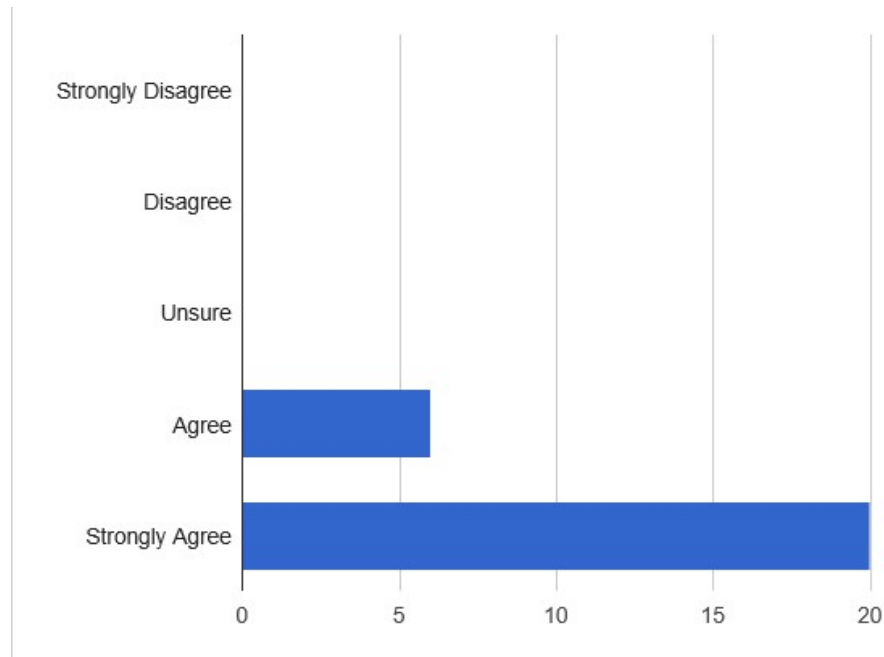
- “Volunteer for AHLN (Autism Health Learning Network) so [families’] input can be heard in an ongoing fashion to shape the care we provide”

# Comparing to pre-COVID-19 times (Caregivers)

I would recommend telemedicine/telehealth to others.

**Pre-COVID-19 (Corning Project)**

**During COVID-19 (Current Survey)**





## In summary

Telehealth has benefits and challenges.

In some cases, telehealth minimizes barriers

- Decreases transportation/travel needs
- Decreases need for time off
- May reduce need for childcare for some families
- May reduce gaps in services

For some children and families, engagement in telehealth is difficult due to:

- Child factors
- Technology
- Competing demands at home

Our perceptions of telehealth may vary depending on context.

There are ways we can work together to maximize telehealth sessions.

# Tips for Telehealth Appointments

Prepare as if you were still coming into the clinic

- Have paperwork completed and ready, if needed
- Have questions prepared, if needed
- Have the materials you need (e.g., documents, pen & paper)
- Make sure everyone who is needed is present (including making sure your child is awake and ready for the appointment)

Assess your environment

- Find a quiet spot to log on to your call
- Let family members know that the visit will be taking place
- Minimize distractions – turn off the TV or other electronics
- Find an appropriate environment where you can concentrate – Avoid being out at a store or driving in your car. Your provider may ask to reschedule if you are not at home or in a less-than-ideal environment.

# Tips for Telehealth Appointments

## Check your technology

- Connect Wi-Fi (if possible)
- Charge your device and have your charging device nearby
- Try out the Zoom app (or other app) before the visit – contact the clinic if you have questions

## Consider your child's needs and behavior

- Have toys or other activities (e.g., snacks) prepared for your child – this could be helpful to keep them occupied while you are talking OR your provider may ask if they can observe you/your child engaging with the toys, depending on the type of visit
- Take a video of your child before the visit if you think there are things your child does that might not be seen during the visit

# Tips for Telehealth Appointments

Be patient with one another

- Your provider will make every effort to be on time. If they are not on the video right away when scheduled, they may be wrapping up with another family.
- Likewise, your provider is mindful that things come up in your life, as well, and will try to be flexible with you

Consider your goals and expectations for the appointment

- Many things can be done well with a video visit
- There may be limitations to phone-only appointments
- Providers can often rule out certain conditions, and provide resources and helpful ideas via telehealth
- Feel confident that your provider will ensure you have an in-person appointment as soon as possible if they feel they cannot provide adequate answers via telehealth only

# How Our Clinic is Adapting

URMC's Developmental and Behavioral Pediatrics has shifted to more telehealth and caregiver-mediated models

- Diagnostics
  - Telehealth-ASD-Peds – a telehealth option for diagnosis that involves coaching and observing parent interactions
- COVID BIFF
  - A clinical service created in response to the COVID-19 pandemic
  - Includes:
    - Identifying priorities and goals for each family member
    - Providing structure and a schedule at home
    - Including caregiver self-care
  - Feeding and other behavior services continuing via telehealth

# Managing the Stress of New and Changing Caregiver Roles

Assess family goals and priorities

- Spending more time at home may shift the focus of family goals and priorities
- Roles and boundaries are blurred as caregivers may work from home and children may be doing school from home part- or full-time
- Structure and realistic goals for each day may help
  - Setting priorities for each family member (yourself included) may help everyone focus – not everything can get done, everyday!
- Being home may mean new or different goals for families, for example:
  - Daily Living Skills
  - Sibling cooperation
  - Getting in physical activity/recreation each day

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# Managing the Stress of New and Changing Caregiver Roles

Consider the structure of your day

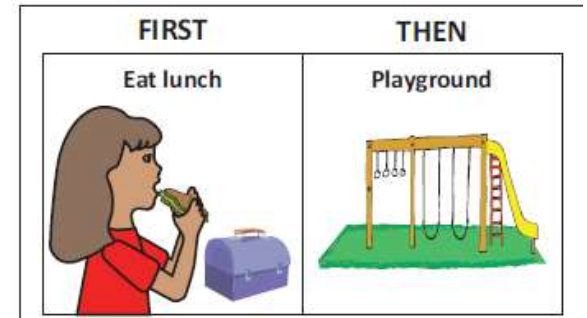
- When is school time (for children)?
- When is work time (for caregivers)?
- When are meal times?
- What other things need to get done each day and when?
- What will fill in the “gaps”? (e.g., outside time; quiet time – rest, reading; electronics time)

Write down the schedule and adjust as needed

# Managing the Stress of New and Changing Caregiver Roles

Use visuals to support daily structure

- Make your own visuals at home
  - Cut out pictures
  - Print pictures from online
  - Create a Word document or PowerPoint
  - Take pictures with your electronic device
  - Use sticky notes
  - Write it down on a piece of paper or on a white board
- Simple and homemade works – no printer or laminator needed!



*From Autism Speaks Treatment Network*

Additional Resource: ATN Toolkit – “Visual Supports and ASD” through [AutismSpeaks.org](http://AutismSpeaks.org)



# Managing the Stress of New and Changing Caregiver Roles

Consider your interactions with your child

- Stress and frustration are understandable and expected during this time
- Have there been more positive interactions, negative interactions, or a mix of both?

Increase praise and positive attention

- Balance reprimands with praise
- Tell your child what they can do
- Respond positively when you see your child doing something “good”
- This can look different for every child
  - Verbal praise
  - Nonverbal – thumbs up, high fives, smiles

# Managing the Stress of New and Changing Caregiver Roles

Don't forget about your own self-care

- Caregivers are balancing many different roles and personal stressors
- Take time for yourself – even 1-2 minutes can make a difference
- Consider your own coping strategies and what helps you manage your own stress
  - Exercise
  - Cup of tea or coffee
  - Quiet time
- Mindfulness resources
  - [www.stopbreathethink.org](http://www.stopbreathethink.org)
  - Calm app



# Thank you!

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DBP Psychology Team

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DBP providers and families

Skirboll Family Autism Conference

All those who took the time to give their feedback via our survey



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