

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

Ally Jordan, Ph.D.

October 9, 2020

Skirboll Family Autism Conference

University of Rochester Medical Center

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



shutterstock.com • 1443249503

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



shutterstock.com • 1675442791

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)
Everyone	100.0 % (n=28)

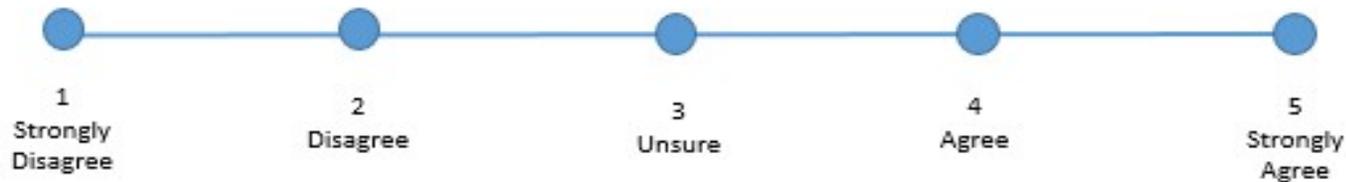
Survey Responses – Types of Services

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

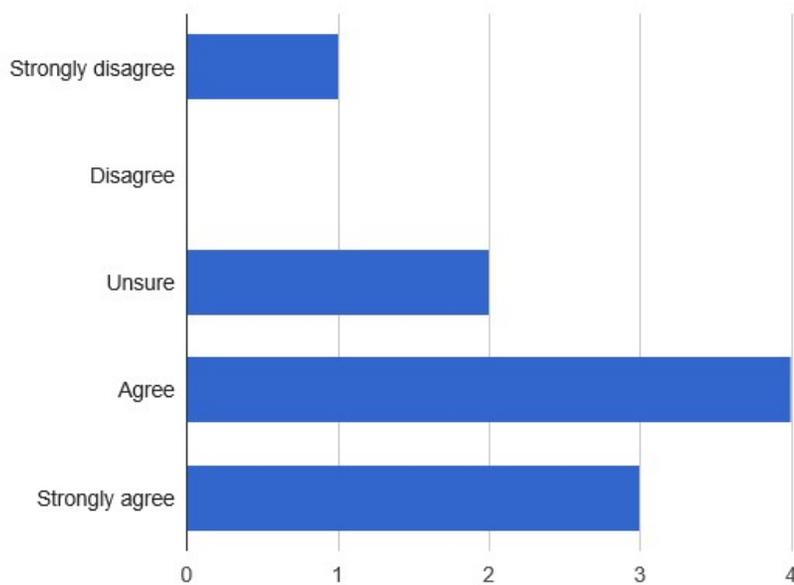
Please indicate how much you agree with the following statements:

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

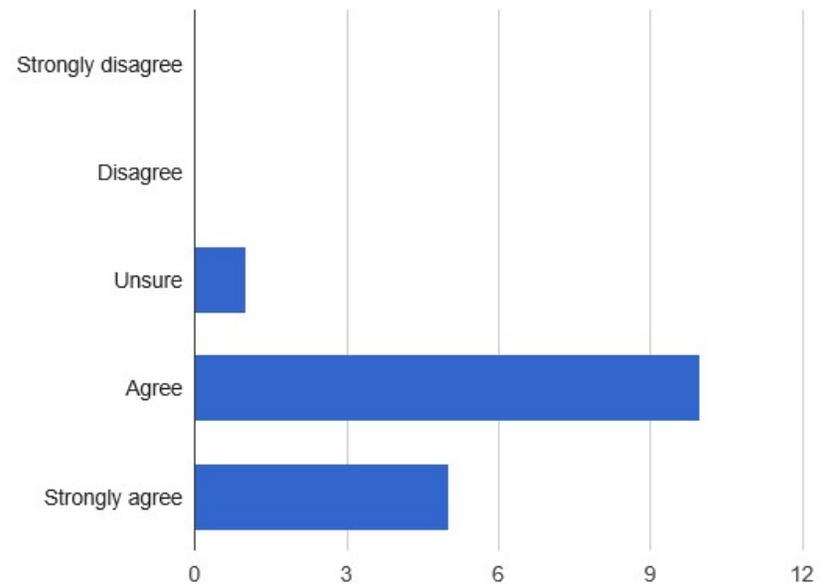


A telehealth visit makes getting services easier

Parents/Caregivers

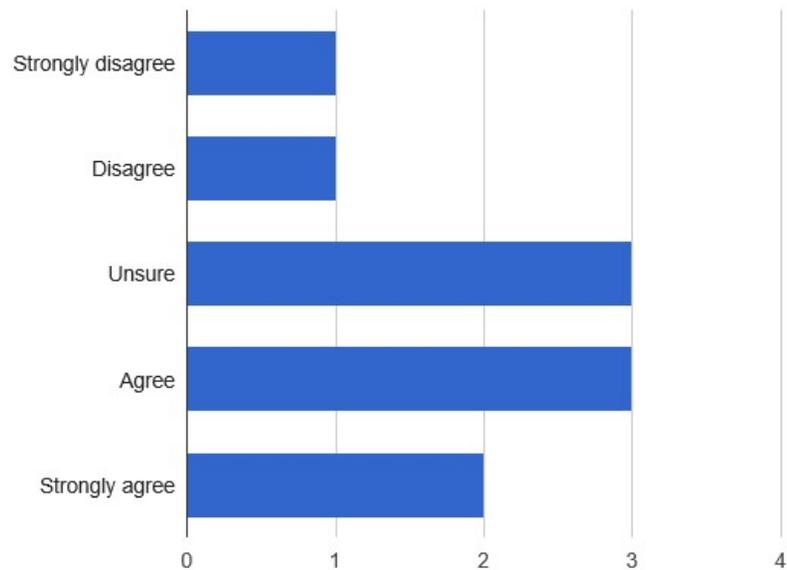


Providers

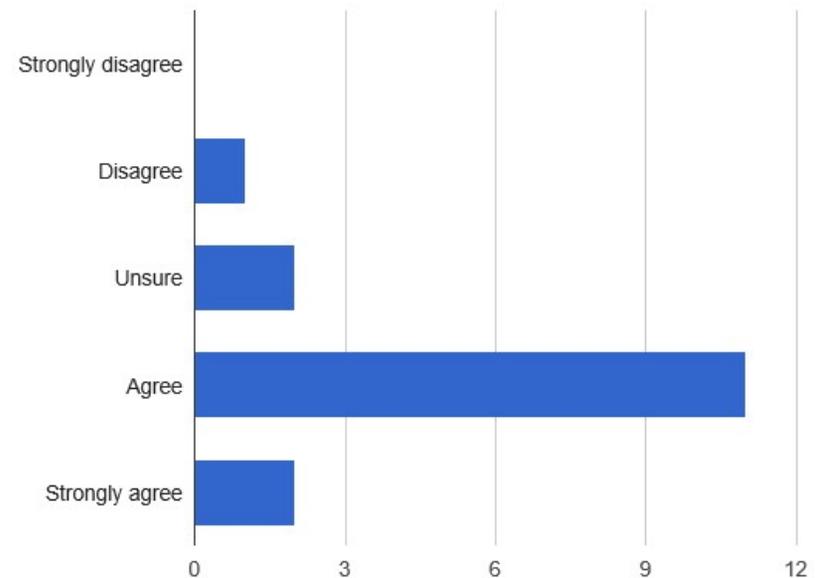


A telehealth visit is effective at helping me achieve my goals for a session.

Parents/Caregivers

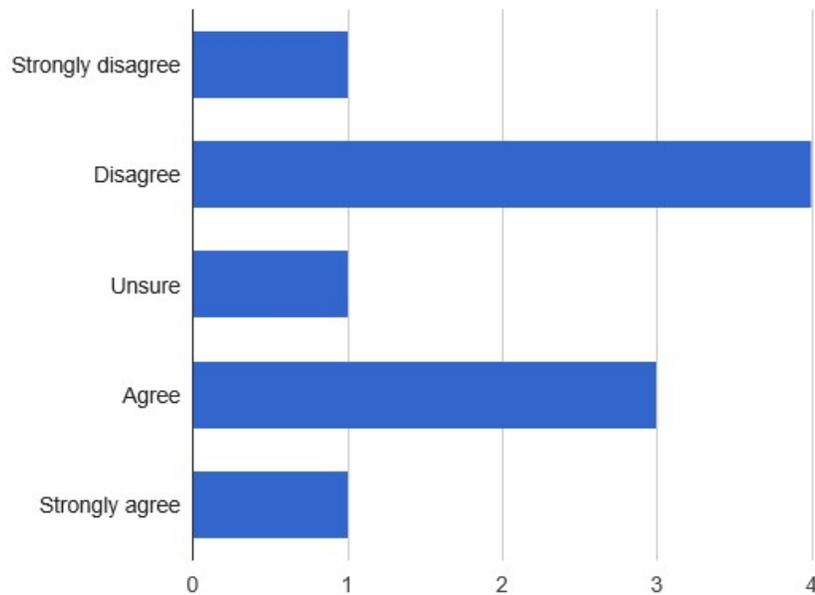


Providers

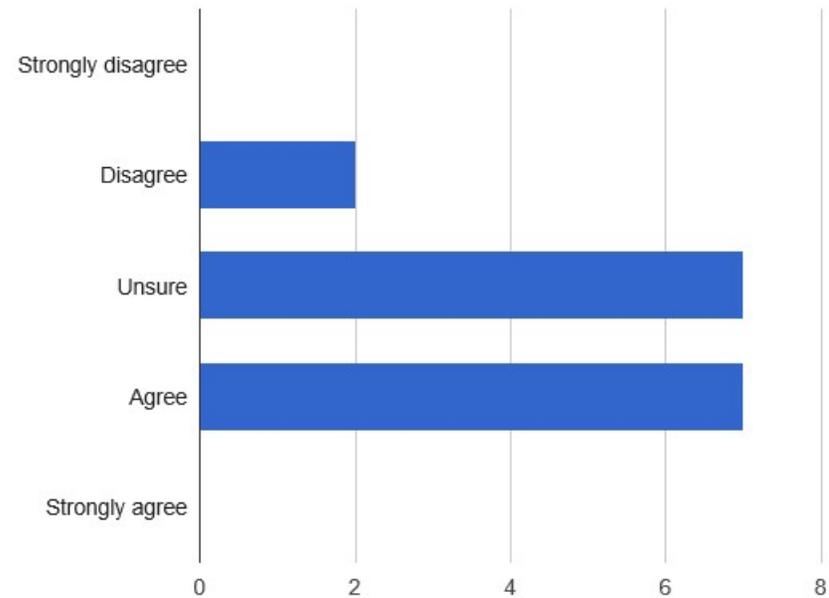


I think using telehealth is just as good as having an in-person visit.

Parents/Caregivers

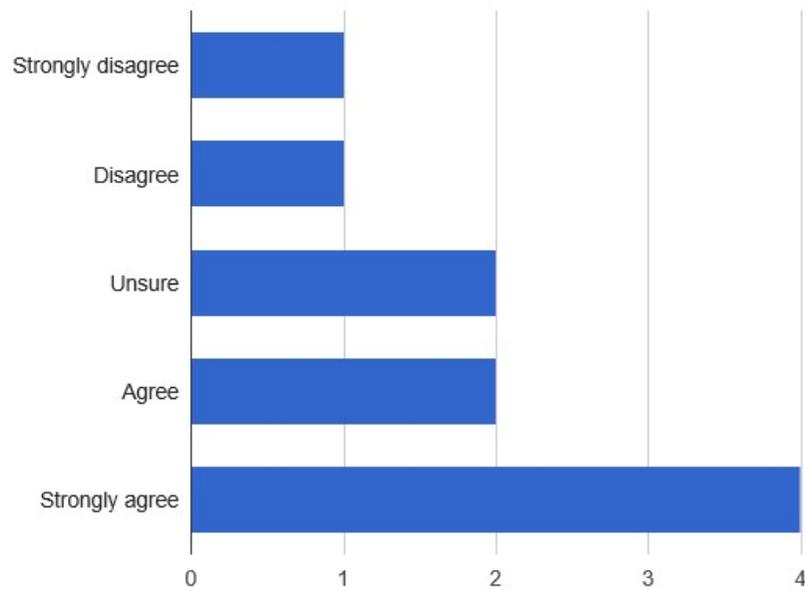


Providers

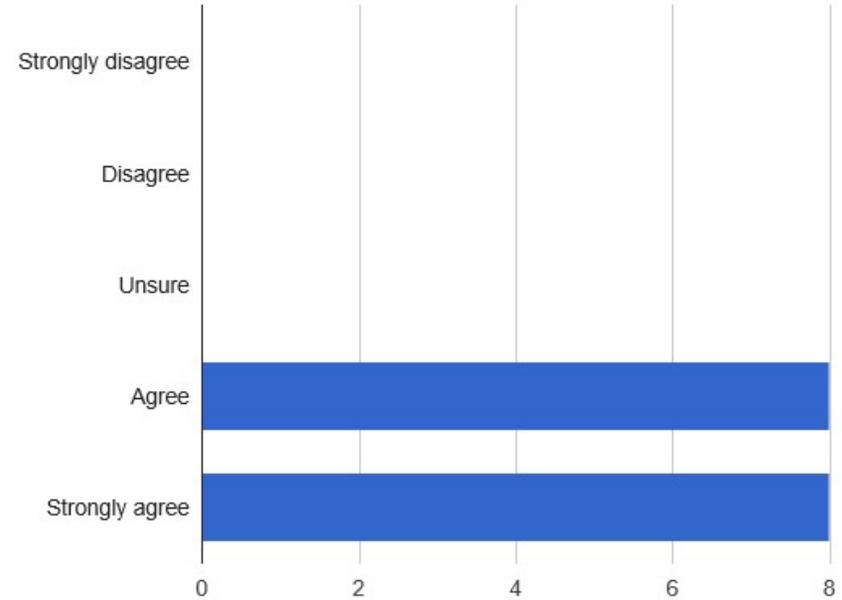


I would recommend telehealth to others.

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”

18

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...”

27

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!”

29

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:

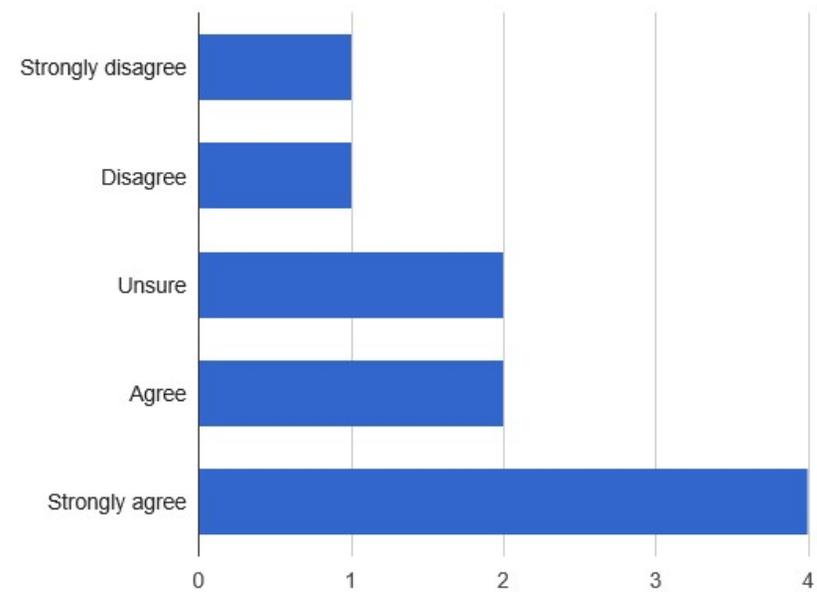
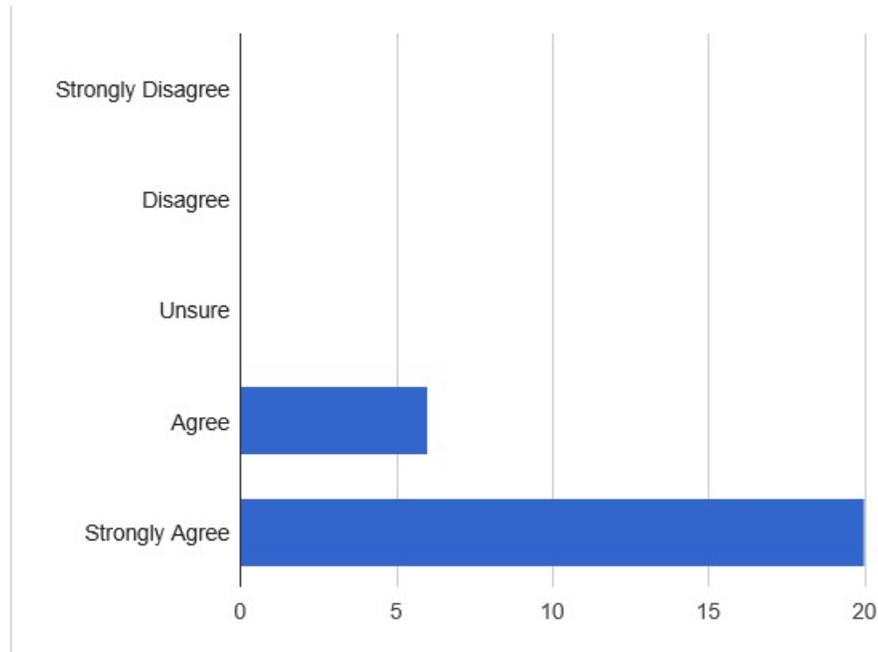
- “Volunteer for AHLN (Autism Health Learning Network) so [families’] input can be heard in an ongoing fashion to shape the care we provide”

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

37

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

38

Managing the Stress of New and Changing Caregiver Roles

Consider the structure of your day

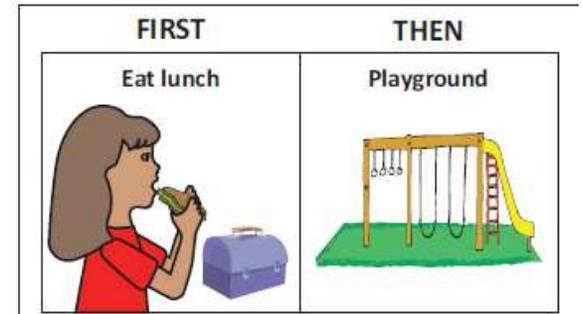
- When is school time (for children)?
- When is work time (for caregivers)?
- When are meal times?
- What other things need to get done each day and when?
- What will fill in the “gaps”? (e.g., outside time; quiet time – rest, reading; electronics time)

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

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
 - Calm app



Thank you!

Dr. Brenna Cavanaugh

DBP Psychology Team

Sam Hochheimer

DBP providers and families

Skirboll Family Autism Conference

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



MEDICINE *of* THE HIGHEST ORDER