

Dr. Raquel Halfond: Hello, good afternoon – my name is Raquel Halfond; I work in the American Psychological Association Practice Directorate. Welcome to today's webinar on “Caring for Children and Adolescents with Autism during COVID-19”. This webinar is for parents and caregivers and will offer psychologically sound advice and address questions you have about caring for children and adolescents during the COVID-19 pandemic.

Okay, today our panelists, Ms. Arianna Esposito, Dr. Sigan Hartley, and Dr. Russ Shilling, will be responding to your questions. I'm going to introduce each of them.

Ms Arianna Esposito is Director, lifespan services and support at Autism Speaks. She has over 10 years of experience working with individuals across the spectrum and holds a master's degree in educational leadership and an executive MBA from Saint Joseph University, where she is also an adjunct instructor of autism behavioral studies.

Dr. Sigan Hartley is associate professor of human development and family studies at University of Wisconsin-Madison. Her research studies the resources and context underlying positive well-being and individuals with developmental disabilities and their family members, and addresses many relationship aspects, such as marital quality, parent/child interactions, healthy aging, mental health conditions, and stress and coping.

Dr. Russ Shilling is Chief Science Officer at the American Psychological Association. He's an experimental psychologist with wide-ranging scientific policy and administrative experience, including positions within education, the federal government, and private industry. He's a retired military officer. Russ is also the parent of two children with autism, ages 18 and 20, both home with him now.

And they [the panelists] will be responding to questions submitted in advance as well as questions posted during this webinar. We've received quite a few questions already; we'll try to get through as many as we can.

Now we're going to do a little bit of housekeeping before we get started. So, you can feel free to ask questions during today's presentation using the questions box on your dashboard. We already have quite a lot of questions submitted as I noted prior to the webinar; we'll try and get through as many as we can. Following the webinar, a copy of the recording will be sent to all registrants, along with a survey, and we would really appreciate if you could please take a few moments and fill it out.

Okay, and now we're going to switch over to the panelists and let me turn to the first question.

Okay. So the first question: in terms of COVID-19, how is the challenge different for parents of children with autism as they stay home together?

Arianna Esposito: So, in terms of COVID-19, this challenge looks a little bit different for parents of children with autism because not only are they adapting as... as a family and parents to having their children home being responsible for homeschooling, but in addition managing the needs of a child with autism, including specialized... those specialized services that they're kind of used to getting during the school day in addition to challenging behaviors that may arise during this disrupted routine and I'll pass it to Sigan next.

Dr. Sigan Hartley: Yeah, I think this is a great question. And I think, you know, in many ways, these are families who are dealing with, you know, the same challenges that a lot of us are dealing with, but I think when you think about some of these added stressors - just like Arianna said - you know, you think about these are often kiddos who are used to getting daily, if not weekly, therapies and services through the schools and through clinics. Often those services now may be completely stopped. They're reduced

or now they're looking a lot different, and so that's a big thing to sort of navigate and to make some major life adjustments around. I think also from caregivers: you know, caregivers often receive respite care and respite care services may be completely on hold as well, as we think about social distancing and how we're all sort of trying to navigate that. And then just, you know, living under a single shared household can be a lot; you know, often if you think about caregivers, one of the built-in ways that you may get a break and be able to focus on some of your own care needs is when that your child maybe is involved in school or involved in therapies outside of the home or if there's a provider who comes into that home. That provider may be sort of the one who's supervising and sort of responsible for that child and the caregiver gets a break. So, all of those built-in breaks that are often key parts of a routine are often no longer there for parents. I think that's a big way that these families are altered. That can apply to other families as well, but it's sort of a particular pressure point.

You know, the other thing, I think, is a lot of these kids may be - because of comorbid medical conditions - may also be in a high-risk group for COVID-19 and that can be a big source of stress for families that we hear from because now not only are, you know, sort of... are you dealing with all the changes in the anxiety, but if you have a particular family member who you... who had... who is at high risk, you know, the whole sort of ball game around social distancing just comes that much higher and it can create new anxieties. You know, the other sort of thing that I think we've been hearing a lot about in our clinics in Wisconsin is just the impact of these sort of disrupted daily routines. And, you know, I don't know if for many of those of you like myself, daily routines are a way that I thrive. And I think that's really good for a lot of us. You think about... if you think about a child with autism or another type of neurodevelopmental condition, often daily routines are really the cornerstone of their lives. These are very important parts; a lot of work went into creating these daily routines. It can be really hard to... to try to explain and build in flexibility about this, but this is a key way also that we make a world predictable for kids who... who are on the spectrum or kids who have other developmental conditions. And so suddenly, we're taking away all that predictability from these individuals and, you know, these daily routines are also a big way that we help communicate what we want out of them for behavior. And so suddenly, we're taking away all these cues about how they should be behaving, what's the appropriate ways to behave, and so, you know, I think in some ways these are... these are issues that a lot of us deal with, but they're kind of amplified for these individuals because there's such a key part of everyday life. Russ, do you want to add in other stuff?

Dr. Russ Schilling: Yeah, so again let me... I'll certainly second the... the structure and I think it goes beyond that for a lot of our kids. So, you know, as we mentioned at the beginning, I have two kids: 18 and 20. My 20-year-old is doing some college work, so he is now home full-time rather than getting out of the house, but still doing some of his college work. My 17-year-old has Intellectual... or... yeah, intellectual disability as well as autism, and it's really impacting him in a big way. So it's not just the day-to-day structure - and we've been lucky enough to have an ABA therapist who still coming to the house occasionally - it's really the things that he considers pretty predictable that ground him on a day-to-day basis. So, I think a lot of us can identify with obsessions over Disney and Apple products and you name it. And if you see the news, you're going to run into the fact that these things are all being delayed or there are issues happening or things that actually really tweak anxiety through the roof. And so trying to work through them and doing the social stories and trying to get them to relax and exercise: to get them out of the house has just been a huge thing in our household.

Dr. Sigán Hartley: And, Russ, I think that's a good point too when you think about sort of some of these daily routines and things, you know, a lot of that is great; they're calming mechanisms and coping opportunities. And so, you know, often with social distancing and no longer access to schools or colleges and services, a lot of these like coping resources that were key parts of their day, we no longer have

access to. And so, that can be really hard for families now to try to figure out what... “How am I going to deal with this if my child or my teenager or my young adult doesn't have access to these devices and these tools and these activities that used to be so crucial for us just to manage and get through the day?”

Dr. Russ Schilling: Yes. In fact, right now I can tell you, I can hear kvetching upstairs, so just... just to let you know.

Dr. Raquel Halfond: Thank you all. Right, we have a next question up: are there strategies that you would suggest for managing increased aggressiveness, especially self-injurious behaviors during this time?

Arianna Esposito: Great question and during times of uncertainty and disrupted routines, it's very common and expected to see an increase in challenging behaviors, specifically ones that are more high risk, like self-injury or aggression. While I can't give specific strategies about how to handle those behaviors, what I would recommend is staying very closely connected to whoever is providing your behavioral health services or behavior therapy services, whether it's a BCDA or a licensed behavior specialist in your... within your school district or provider network and ask what, you know, the... My tips are one: stay in constant communication throughout this period of uncertainty with whoever your... whoever is providing the services for your child, not just behaviorally, but if they're receiving speech OT or PT – like we said earlier, one: that will help kind of maintain some normalcy, but also there are grounding and calming techniques that might be utilized when your child's receiving those type of services throughout the school day.

The second one is consistency across, you know, when in this disrupted routine the way that these behaviors would be managed at school are very concretely managed where the team hopefully is on the same page and responding consistently, that consistency can go a really long way during a time of uncertainty like what we're experiencing right now. So, I would recommend connecting with your behavior specialist and ask... explain the behaviors that are happening. Ask for strategies, resources, and tips and make sure everyone in your entire household is aware: so not just the parents – the caregivers, the siblings – having everybody on board with when the behaviors do occur. How to respond appropriately, that consistency will also really bolster efforts in maintaining safety for your whole family.

Dr. Sigan Hartley: Those are great tips. I guess the only thing I would... you could also consider is doing a little bit of... a sort of informal functional analysis. I mean... so what I mean by that is, you know, again sort of, you... everything we used to sort of expect: that whole setting and that whole daily routine is done, so maybe taking a few minutes just to sort of think about what may be contributing to this. You know, do you feel like it is sort of... is the child stressed? Is the child tired? You know, have you altered sleep routines that used to be there? is it that the child used to be outside and get more fresh air and exercise that no longer you're getting – could that be contributing to it? And so, just thinking about all the things that... that can contribute to self-injurious behavior or aggression and emotional dysregulation and sort of doing a little bit of a check to see what might be contributing to it in the situation.

And I think we're reaching out with special education providers, therapists, and... and sort of seeing what they... what they... what they think as well. Sometimes, you know, monitoring that behavior at home; so, you know, keeping track of when it's occurring. Is occurring mostly in the mornings? Is it occurring at certain times of the day? Maybe there are ways to alter the new schedule you're trying to create within the household to sort of deal with the times that might trigger the individual can also be effective ways in understanding what elements could be contributing to it if you're seeing increases. But

yeah, you know, I think, you know, in some ways, I think caregivers should anticipate that this might be a time that you are going to see a lot more behavioral challenges and anticipating that and... and trying to stay calm in that and trying to figure out ways... things that might be contributing to it and working with therapists about.. about strategies for addressing it. That may be a nice first step.

Dr. Russ Shilling: Yeah. The only thing I would add to that is really kind of self-care as well. So, you know, don't discount how much the kids are picking up on your own stress being home and worries about the virus and things like that. So, you know, try to be as calm through all of this yourself as you can be and some of that will transfer over to the kids, but we're certainly seeing that in my household. And I guess the only other thing I would say is don't be too hard on yourself when things aren't going well because I think, over the long haul, we're going to have some good days with our kids and some... some... some really bad ones and we just have to kind of bear with that some, but safety first for everybody.

Dr. Sigán Hartley: And I like that that message, Russ, about that this is such an important time for self-compassion or self-kindness, right? That we're all under so much stress... stress or so much anxiety and to make sure that we are engaged in self-compassion and setting... reducing expectations during this time and anticipating frustration and things are going to go wrong and we're going to have to learn by trial and error, but definitely a time to... to be compassionate towards yourself.

Dr. Russ Shilling: Exactly.

Dr. Raquel Halfond: Great advice. So, our next question is: can you share some resources or tips for creating virtual social interactions for children on the spectrum?

Arianna Esposito: Great question, and we're seeing a lot of these types of questions floating in as well at Autism Speaks. And what we recommend is whatever, you know, virtual channels you're using to connect with your community and your friends and family whether that's Facetime or Zoom or phone calls, setting up virtual play dates are a really great idea. If you have, you know, the phone numbers or contact information for your student... the students in your child's class or, you know, friends from the neighborhood, close family, friends – things like that. I know, too: try reaching out to your teacher and ask is there a, you know, time where they can utilize like the Zoom platform or have one: have time for the students to connect, but with what... building off of, you know, what Russ and Sigán were talking about earlier: sometimes connecting with the parents within your school group can also be a really nice way of one: engaging in some self-care but two: taking some time to just connect outside of your day-to-day disrupted routine.

Dr. Sigán Hartley: You know, and I think if you're feeling like if... this is a great time to reach out to teachers, too, if you feel like you don't have information for classmates and that's something that you're interested in, so lean on them and get them to help set something up. A lot of the or... local organizations like Autism Speaks and other sort of state-specific organizations are also really trying to get some parent support groups, but also some teens support groups, in some online formats. So that might also be another resource. If you want to try to connect your child with other people to make sure that they feel that social connection. And I think family members is also a great... a great way to do it right and make sure that they are feeling connected. we can all feel isolated during this time. And so I think it's... it's so important that you think about those ways that you are able to build that into your schedule, that... that's appropriate and helpful.

Dr. Russ Shilling: Yeah, and not much to add to this, you know, we had a great experience this week where some of my son's caregivers - my younger son - basically came in on Zoom and talked to him for a while and it really lifted his spirits; it was a great experience. I think the parent-to-parent care groups are

also important, so a lot you can really gain from just setting up some of these informal discussions online, I think, because it is wonderful.

One other thing: since we're talking about virtual connections, military Tricare has just approved for military families the ability to have one-to-one education and training with the parents and they will cover the costs, if you have the ABA services approved. So, it's not child-to-therapist, but it is parent-to-therapist, which could be useful for a lot of you as well.

Dr. Sigan Hartley: The other thing I also imagine is I think, you know, often with COVID-19, we get... we get really focused on sort of Zoom and connecting out – which I think is absolutely vital for a lot of people – but I also think about, you know, taking the time I feel like, you know, to connect with family members who may be in your same home in ways that are more casual and positive and in like how you connected prior to COVID-19. So, I think, you know, some of our research has looked at the parent-couple relationship for families who have a child with autism and one of the big differences we're finding in a daily diary where they would report... where we ask families to report what they were doing every day and we had a comparison group of couples who had typically developing children, and one of the differences where it was not in the negative interactions, but was actually that couples who had a child with autism were... were spending less time together and were spending less time in positive coupling reactions. And so they were... they were interacting but it was often to problem-solve or to navigate specific challenges in the schedule. Who's going to drive who to therapy? Who's going to do what? who's going to make dinner? And so what seemed to be going by the wayside was this time that couples may spend just to sort of joke, tell each other about their day, talk about a movie: not engage in the problem-solving sort of task-oriented things. And I think, you know, in times of stress, I think that's something we can all fall into is that we get really fixated on sort of problem solving and in part, it's... we need to, right? These are new things we have to solve; we have to figure out the day, but I think, you know, making sure to spend some time to try to maybe not talk about the news together. Just talk about a backyard project or talk about a movie together that you guys had seen is also a really powerful way to make us feel some of that sense of sort of normalcy and some of that social connection that I think in times of stress we tend to ignore. And so, I think that's also a really positive thing. It doesn't have to be a lot of time. I always say, you know, could be 5 or 10 minutes in the morning when you share a coffee. So, just try to joke and not sort of, you know, problem-solve, but just enjoy each other and I think that's not just for parent-to-parent couple relationship, but also with your kids as well. What are some normal things? There are typical non... non-COVID-19 things you might have done together in other ways. you can try to... to sort of set aside the news and sort of stress and other things and just enjoy some of that and really small birds of... bursts of time.

Dr. Raquel Halfond: Thank you. Next question: 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?

Arianna Esposito: Great question. What I... what I would recommend is whatever you were doing for self-care before COVID-19 happened, try and find ways to incorporate that into your... into your daily schedule. One of the strategies for helping your child adjust to a new routine is creating a new schedule and a new routine for them. And that's step one of the process; step two is now create a schedule and a routine for... for your entire family. And that's going to take time and it's not going to be perfect and it might be one small thing every single day, but working with the, you know, your partner, your other caregivers who are in the house to say, "These are five minutes. These are going to be my five minutes where I'm going to focus on me, whether it's I'm gonna go take a walk, I'm gonna listen to a podcast" -- whatever your sort of ways of self-care. "I'm gonna do a quick yoga class and can you just hold down the fort while I just go take these five minutes?" and then reciprocate as well. Self-care is something that

every person in your house should be focused on and developing some type of system where you don't have to worry if you step away for five minutes that everything is going to fall apart, that someone in your household is going to be able to tag in and support you while you take the time that you need.

And the other thing I'll add is if it's a particularly stressful day or you feel like you're about to lose it or, you know, it's a stressful day at work and things aren't going right in the home, that's a... that's a sign to take a break. And so having that conversation proactively with the people in your home to say, "There's gonna be a time where I'm going to need to tap out and this is... I'm at my breaking point. This is the word I'm going to use or I'm going to ask you and then can you just come in and sort of take care of this while I go, you know, pull myself together?" Because having a family member down who's really stressed and isn't in a good headspace isn't good for your whole family either.

Dr. Sigán Hartley: I think that's... that's wonderful comments. The only thing, you know, thing to add is I think that, you know, study... in times of stress, you know, I think the other thing that research suggests is that the ability to pay attention is... and memory and sort of cognitive skills can... can really be impacted and so I would say in part that just as a good reminder to set realistic set of expectations. Again, engage in this... that self-compassion about knowing that, you know, the goal is not to necessarily replicate a 7-hour school day with your child at home and to break it up and to say what's manageable right now. What do we absolutely care about? What are things that we don't need to care about? And to focus on the things that that you feel, like, may be going right and to give yourself a break on the other stuff. And for me, in terms of the, you know, the inattention, I found that, you know, I try to limit how often that I read the news and try to just do it twice a day so you don't get overwhelmed. And I think that is a really important self-care strategy, too, in sort of the era that we live in right now where you can be bombarded with messages and bombarded with news and, you know, you read stories and it brings up new anxieties and overwhelmed you and it's distracting and so little ways to... to focus in on things that don't make you feel anxious is another good self-care strategy.

Dr. Russ Shilling: Yeah, I really don't have anything to add. These are all excellent suggestions. Meditation - also a good way to spend five minutes, if you can break it out or even for shorter amounts of time during the day. You know, caregiver fatigue is a real phenomenon and a lot of us have gone through that before COVID-19, and we're certainly all going through it now. So, it's normal and we just have to try to carve out at least five minutes and hopefully more that we can just, you know, have some down time.

Dr. Raquel Halfond: Thank you. So this next question I'm going to ask, then answer. It's a quick one. So the question is: are there line black and white drawings of the virus that parents can let their children color? And yes, so if you look on your... on your... on your screen on the right side in the grey, there are some boxes. One of them on the title, it says handout; if you look down there, there is a resources handout and on there, there is one of those drawings in there. And these resources will also be made available to you, along with a recording, after the webinar

Dr. Russ Shilling: And I'll drop in another good set of resources I've been looking at. Sesame Workshop has some really good general resources for small kids discussing... for the parents how to discuss the virus. So I'd recommend going to that site as well, and that's in the handouts.

Dr. Raquel Halfond: And that actually leads into our next question: how can parents talk about COVID-19 with their child with autism?

Arianna Esposito: Great. So, when discussing, you know, COVID-19 with your child, you want to meet them on the level that they're at and give them enough info... you want to explain to them so they have enough information of what's going on, but not too much that's going to cause panic and that will vary

from child to child and from family to family. Some tips: Autism Speaks and a bunch of additional organizations have written social stories and teaching stories that can help facilitate that conversation. If those are useful strategies that are effective for your child, then, by all means, use them. I would refrain from utilizing news clips unless that's something that's like a preferred item or something that they enjoy to do because, you know, like Sigan said earlier, it can become very overwhelming very fast with the amount of news that we're bombarded with and explaining this is an important part: I think all of us are still... still trying to wrap our heads around is that it is such an uncertain situation. So, there are things that we really know about the virus but then things that we really don't know about the virus and that's okay. That... that uncertainty and not knowing is normal and we're all kind of going through this together.

Dr. Sigan Hartley: Yeah, I would just echo I think those are great points. I think social narratives or these social stories that really draw on, you know, pictures and text to sort of help explain some of the changes in life and introduce some of the new social distancing policies can be a nice way that... that a lot of parents will find helpful and there are a number of research... resources out there now that are being developed. So, Autism Speaks, APA... the CDC has come out with a couple and so, I believe that Kirk is going to send some resources following this webinar that are great places to sort of start with. I think this is a difficult thing; there's no one right answer, you know. I think you know your child the best; you sort of know what may be helpful, what may not be helpful. I think for some questions... some kids and adolescents and adults going, you know, back and forth dialogue and answering questions about what's going on is very useful. I think, for other kids, maybe you just want to cover basics and maybe going into details would not be useful at this time. So, I think, you know, you're definitely the expert, but your therapist or your special education teacher's also a great resource... resource to reach out and get their take on what may be the best strategy to go forward with your child. They may have some good insights as well.

Dr. Russ Shilling: And I guess my input for this one would be to try to frame the discussion around something that is also comforting to the child as well. So, rather than just, you know, the straight facts to say, "You know, but when this is over we're going to..." you know, and give them some kind of a positive goal out there beyond what we're going through right now. And again, I think the other issue is it really does depend on the child. So, I know one of my sons likes to have the facts. The other one wants to have specifics and doesn't deal well with the ambiguity portions. And so, we have to really message around both of those for both kids.

Dr. Raquel Halfond: Oh – no, I was just going to add that you also think about what the child can control and not control. So, with my oldest, I've talked about what we can control. So, we can control certain things like washing your hands, covering her mouth, covering her sneezes, but then there's some things we can't control and it can also help to give children a nice sense of what they, you know, control. Go ahead, Sigan.

Dr. Sigan Hartley: Oh, I was just going to say, you know, they say the... the best resource is often other parents, right? And so going to some of these support groups or some of these listservs around these professional organizations can also be a great... that'd be... it's a great question to pose to other parents and hear strategies of how they've explained it and what's worked, what's not would often also be a wonderful resource if you're sort of struggling with how to do this. And sort of... as Russ mentioned also how to combine this with... with messages also of comfort. So, you're not sort of just focusing on the negative and sort of as Raquel said also focusing on things that you can control, so you give them that sense that there are things they can do and these are the things we're doing and then, you know, focus on those positives and those things you can control quickly.

Dr. Raquel Halfond: Our next question is: 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?

Arianna Esposito: Another great question. So, for engaging with telehealth, you know, find something that's motivating to your child if you need them to sit and attend to the screen. If screens aren't reinforcing or, you know, the joint attention of watching something on the screen and... and repeating and modeling is something that's difficult for them, whether it's saying we're going to do this for 10 minutes and once this is over we can go do a fun activity or preferred item. For continuing to deliver care who have difficulty through verbal communication and may require a more tailored approach, utilize your support network. I know at a time like this where you're not able to see, you know, and be in the same room... as your special education teacher or your behavior support team and your other service providers. They are there for you, whether it's through telehealth or on the phone. Creating visuals: so, the one thing I would recommend is, you know, whatever tools your child is using at school, see if you can get a copy of those at home, whether it's their visual schedule, if they're using pictures to communicate, if they have any... if the teachers can share any specific tips about how there... they found to be able to communicate positive strategies at school and try and transfer those at home. If those aren't working, be proactive and reach out to your support network and say, "Hey, I tried this; it's not working. Maybe it's an additional session, so the therapist/service provider can kind of walk you through how to deliver or maybe it's an adjustment to strategies that have worked at school or in the community, but aren't working at home during this time.

Dr. Sigant Hartley: Guess a thing I'd add to that is that when we think about telehealth, you know, this this can look so differently and so for, I think, some kids, it may make sense that they're the ones in front of a computer and you are doing a live video conferencing and they're working with their therapist or the teacher on things. I think for a lot of other kiddos, oh, that model isn't going to work and it's maybe the telehealth port... part is maybe more of the therapist or that provider connecting with the parents and walking through ABA strategies or other strategies and then the parents sort of off-camera, off with outside of media is then sort of implementing. and so, I think that there isn't going to be a one... one fits all sort of model but I think in thinking about telehealth, think about this really widely – that this is going to look really, really different and it may be that some kiddos are able to be more self-directed and... and are able to interact on different software programs and do their learning that way. It may be that a parent's right there doing sort of every step along the way with them or it may be that the parent is consulting with a therapist and they're offline train... trying to do some strategies that make sense and that are manageable to do in home.

And again, you know, I think it's just so important with sort of telehealth and these strategies that these expectations need to be realistic. Parents need to be supported, you know, they are now sort of the ones off implementing this therapy, but they don't have those... that background training, right? and so I think, you know, again, you know, I think a part of that piece for that model is going to be really that we're supporting parents instead of identifying some really small manageable tasks and things that they... that make sense to work on at home with... with the child. And then I think also, you know, for in some cases there are still therapists who are going into the home or there may be some clinic sessions happening that, you know, in some places in Wisconsin, they are using Plexiglas, so their visit's there in a room, but they are separated, but they're able to sort of like see each other real time. So, I think it's going to look very different depending on where you live, depending on that child's learning preferences, but I think the idea of making sure that you are your own self-advocate reaching out to providers. Let them know what's working; let them know what's not working. You know, what's just not manageable that you know, they may be saying you should be doing two hours of X and they give you a

link to a website. But as a parent you're saying, "Wait a minute, this is not working. I can't manage this. I don't know what I'm doing. My kid's not paying attention." Give them that feedback and they hopefully can then adjust whatever that the therapy or whatever that education that they're trying to provide.

Dr. Russ Shilling: Yeah, I think those are two excellent answers. So, I'll just put my researcher hat on. I think we're going to learn a lot about telehealth with this... these populations through COVID-19. And I think what's going to evolve out of it are probably new techniques for telehealth and hybrid solutions that have interactive types of activities and other things that go along with a traditional telehealth experience. So, I think, you know, as we get input from the parents and the therapists, I think there are... there's a lot of hope for future activities in here. So, you know, just let us know what's working and what's not.

Dr. Raquel Halfond: Next question is: we have noticed Improvement in behavioral issues and aggression during this lockdown period. Any explanation or opinion?

Arianna Esposito: So, all behavior is communication, and so what we talked about earlier is, you know, during times of disrupted routines, we can see a real increase in anxious behaviors, challenging behaviors like aggression and self-injury, but at this... but on the flip side, for some this could be really, really nice - a nice time where they're not exposed to things that are either are unpreferred or difficult for them or aversive in some cases. So, maybe the ride to school in the morning, being on the school bus - those are things that are really difficult for them and set them up for a very challenging rest of the day. Now, they're not on the school bus and they're at home and their day looks and feels a whole lot better being in the comfort of their own home as well. You know, maybe not having to sit and attend in a classroom for the amount of time or their schedule. Maybe there are, you know, thinking about the patterns within their school day and where do those behaviors start to tick up. Is it happening before lunch? Is it happening after lunch? Is it a combination of, you know, going from a class they do like and then to an activity that they don't like. There are a lot of factors that - and a lot of different variables that happen throughout the course of the school day - that can affect someone's behavior and could be causing, you know, behavioral issues at school that those things just don't translate to the home anymore.

Dr. Sigant Hartley: Yeah, I would say that... that's a great thing to happen. So that's, you know, that's... that's wonderful, exact... you know, take it right? You know, that's... that's great and probably says a lot about the parents and their ability to sort of create this comforting and calming environment for this child during this time. So, first that's... that's great; kudos to you.

And yeah, I mean, I think there's all these reasons you can think that we have drastically shifted sort of, you know, daily activities and environment in some good ways and ways maybe really reduce stress for that child. I also think, you know, I know my own kids, you know; initially were very excited about this and thought, "Oh, this is great and I don't have to go to school. I get to, you know... I'm sleeping in; I'm doing all this stuff" and I've seen their own sort of mood over time kind of come down from, I think, that a little bit of that high. So, I also think, you know, see what happens. Hopefully, this... this lasts and... and, you know, you've sort of have reduced stressors or reduce other things that were triggering this at school. You know, it could be something that you're going to see that... an increased sort of creep back up. But... but yeah, I think that's it's a good thing to see.

Dr. Russ Shilling: Well, I'll start by saying first, I'll send my kids right over. But yeah, I think, you know, in some ways - I mean right now - I mean it's a big transition for a lot of kids, but we are also having a... creating very predictable environments for our kids right now. So, you know, they're... they're... they're

at home all the time. I think what Arianna had to say sums it up. It's a lot of good structure in here along with the chaos, so I think different kids will handle it differently.

Dr. Raquel Halfond: So, our next question is: please discuss strategies for addressing sensory and movement needs for individuals with autism who have trouble distancing socially outside.

Arianna Esposito: Great question, and this is something that I think we're going to continue to see on a larger scale, the longer social distancing is enforced and the more widespread it becomes across the country. You know, as times may... and this, you know, you're going to have to balance that... with this tip, you have to balance sort of the disruption routine versus like the cost-benefit analysis here, but going either early in the morning or times whether you have a playground or an open space in your neighborhood that you can go to that is not crowded. It's deserted; there isn't anyone really around and allowing, you know, for movement breaks and sensory needs at that time. If you have a backyard, that's even better. If you don't, you know, front lawn or even just explaining to going up to the people staying obviously six feet at least a part saying, you know, explaining your child's needs and ask if they can give an additional space or if your child starts to approach and break that sort of six feet barrier that they know to kind of be responsive and move around. Setting rules and expectations is another really great way, too, to have that conversation with your child on, you know, meet them on their level. So whether it's checklist, it's rules tying it to like a token chart. That's a great way to connect if you do have a behavior therapist or your special ed teacher about strategies that work in the classroom for expectations.

And that's a general tip I would give to families, whether you have a child with autism or not, is this is a great time to set school rules from the time, the normal school hours, whether that's, you know, 7:30 to 3:30 or 7:00 to 2:00, 8:00 to 2:00 and that can be part of it that... during those hours, if you go outside, you have to stay, you know, two legs' length away or however you want to measure it, but creating some type of predictability and setting expectations to can be helpful.

Dr. Sigán Hartley: Yeah, that was great. I think that... that sort of does a nice summary of things and I don't know if I have much to add, other than I think a token, you know, with the rules, balance that with the token system - lots of positive reinforcement. You know, this is a time that we are... to develop new rules, you know, balance that with should have lots of reward and... and I also like the... the strategy to of, you know, it's okay to talk with neighbors about some of these struggles and let them know that you're going to try to use the backyard. "We're really careful about social distancing but, you know, just so you know, my child is going to be out here and my child might wander over. We're trying to work on rules with reinforcements", but it's okay to let others know what's going on or try to go outside during times that a lot of other people may not be, if that's manageable – it's another way to do it. But... but yeah, I think it's okay to start having this conversation, start to set some... some rules, some... create some predictability around that and do lots of positive reinforcement to help learn these new rules.

Dr. Russ Shilling: Yeah, I have nothing to add other than I know in our resource materials that we put up online, there are also some good strategies in there discussed, in several of the links. So, I'd refer you to those as well.

Dr. Raquel Halfond: Thank you. So, our next question is: are you finding any public school districts IEP staying connections? I don't know if they meant "connected"? It says, "I have not in California", but the follow-up question of "How can school districts and government help parents in this time?"

Arianna Esposito: I'll start with the second question first and then answer the first one after, so for school districts and governments right now, you know, in this time of great uncertainty, it's providing resources and support to families and trying to maintain some semblance of normalcy, knowing that

normal.... the normal routines were all changed but having regularly scheduled meetings, checking in, doing your... if you can do, you know, school meetings over Zoom - if that's allowed - to do those types of things. If there are resources that the school district has to be able to connect with families, or do, you know, virtual coffee hours, just to maintain some type of social connection. But then also, you know, having teachers be... teachers and service providers being available and creating as much access as possible because one of the things during this time is that access to services are sort of more uneven than ever before, given things like internet and computers. So the more you can create access and opening channels, I think is really helpful at this time. And for staying connected on the school IEP, I would say that's probably on a school-by-school basis. If you do have questions related to your IEP, reaching out to your... your case manager, your special education teacher, the head of sort of your IEP team would be a great place to start.

Dr. Sigan Hartley: Yeah, I think that's great advice. I know here locally where I am, you know, they are trying to do some of the IEP stuff over the phone but I think, you know, school districts are absolutely faced with these same questions. I think that parents are - and I think everyone is - sort of at that phase right now of navigating how to do this. And so not only how would you get that IEP team sort of like formed, how would you guys all communicate? But you know to what extent you need to go back over that IEP... IEP plan now and actually modify it because, you know, a lot of the goals that may have been set or things are now going to sort of have to be altered and how you gonna track that? So, I mean, I guess I think, you know, the silver lining is that this process will hopefully lead to some better virtual tools that can be available to IEP teams going forward of how you would sustain this communication. How can we alter some of these goals in a way that everyone can access, everyone can give feedback to, and we can alter in sort of like a real-time unfolding process to meet the needs of kids? So, I do think that this is something that, you know, the Department of Education is, you know... they're coming out with some of their broad recommendations and guidance for how to handle special education. But a lot of those specific details are really lacking at this point. And so I think you're going to see more and more come out about that and I guess you over... only silver lining from the government standpoint is this could be a nice push to get some more. virtual platforms for our... to support IEPs that would lead to better services ultimately.

Dr. Russ Shilling: We should all be pushing for that, really. Yeah, the only thing I'll add and this is not directly to the IEP question, but at least at APA, we are looking at some of the discussions that are going on in the government about what types of resources needed to be... need to be provided in the classroom or in the non-classroom world we're living in to special needs children, and we're really advocating to make sure that they're getting what they need at home as well, so...

Dr. Raquel Halfond: Thank you. So, our next item is actually a comment. I'll do the comment and I'll move to the next question. It is a helpful comment from the audience; it says, "I recommend checking the local chapters of the National Autism Association for support groups. I'm on the board of the New York Metro chapter and run free parent group... 3 parent support groups for the New York metro area. I transitioned to a video platform and will now be offering them twice monthly." So, that's just a suggestion and if any panelists want to add anything to that.

Arianna Esposito: It's great. It's a great resource.

Dr. Raquel Halfond: So, next question is: how do you design programs to help children in the first three years with autism during this period?

Arianna Esposito: So, if you were... if you already have... if a child already has their diagnosis, chances are that they've been connected to some kind of early intervention service. Early intervention services

given the... the disruption because of social distancing and with the shutdown... with shutdowns, most of the services that happen around this age are usually done in the home setting, which complicates things. I would recommend first reaching out and having a conversation with whoever your service provider is at a local level. And then additionally, Autism Speaks has a great resource: the Autism Response Team. It's our in-house call center. I'll make sure that the contact information is in the resources. But if you need additional support or connecting to... if you don't have therapist yet, you have a diagnosis, but you haven't been connected to Services yet, or just need help navigating through this time. We have a ton of resources including a hundred day kit if you're recently diagnosed and things like that to be able to help navigate during this time.

Dr. Sigán Hartley: Yeah, I'll just say I do, you know, a lot during those really early years. You know a lot is sort of centered on these Denver start models and models really sort of involving applied behavioral analysis with pretty... often pretty intensive hours within the home. Sometimes it could be clinic-based. And so, I think in terms of what that would look like now, some families may still have providers who come to the home to provide this. Others, you know, at that age, it would be more sort of that therapist working with that parent to talk about how to engage in these strategies on an ongoing basis where you are encouraging language, encouraging social interactions, and encouraging sort of that child to help learn how to regulate their own emotions through sort of just interactions between the caregiver and that young child. And so, you know, really working with that therapist to develop tips for what's going right, what's going wrong, and, you know, why certain things might not be working, to problem-solve. Often, for young children, the therapist will have you videotape an interaction, so they'll say, "We know, we want you to read a book or play with your child for half an hour; videotape it." And then through that process, the therapist can provide some tips to the parent about things that may help elicit more communication or may help better gauge the attention of that child and direct the child's attention. So, those are some strategies that I think you could still navigate in a COVID-19 world through really good communication with therapists. And Autism Speaks has wonderful tools that can address not only sort of the ins and outs of some of these really early intervention strategies for young children, but also sort of making sure you're navigating other... the healthcare system, other things you might need - whether that's financial resources for families, whether that's making sure you're checking for other comorbid conditions that children may often experience to navigating the IEP process to just supporting the general family... the family in this process, and to attending other siblings in the home who may be impacted by these... by having a brother or sister in the spectrum or service providers in and out of the house and other issues.

Dr. Russ Shilling: Those are both an excellent answers, so I really have nothing to add but yes, very good answers.

Dr. Raquel Halfond: Okay. Next question is: do you have any recommendations about telehealth assessments for families who have been on long wait lists for an evaluation?

Arianna Esposito: I do not have any recommendations for telehealth assessments. We kind of touched on it earlier that this is part of telehealth. It's a little bit of uncharted territory, and we... I'm not as familiar with the amount of resources that we have regarding getting an evaluation via telehealth.

Dr. Sigán Hartley: Yeah, I think this is an excellent question. I think this is completely uncharted territory. If you think about autism diagnosis, you know, really the gold standard right now is an ADOS, which just stands for the Autism Diagnostic Observation Schedule, which typically happens in a clinic setting and between a clinician and that young child and is really the way that we observe behaviors that would inform whether a diagnosis of autism may be appropriate or not. In addition to other... other assessments, you do like assessing for overall cognitive functioning, other emotional/behavioral

regulation problems, communication level. So, I think about, you know, during this time and my heart goes out. I mean, I know that wait lists can be really long; unfortunately, in a lot of places for an autism diagnosis right now, you know, in terms of how clinics are going to handle this. I think you're... to get different... different places are going to handle this differently to the extent to which they're still seeing anybody or this is completely on hold. Whether you could go forward with a full diagnostic evaluation via telehealth - right now, I don't really know if there's any guidance on how you would sort of fully do this via... via telehealth system. As you get to adolescents and young adults, I think strategies for how we would administer the ADOS become a little bit more sort of modifiable for it... to a telehealth environment for you, but for young kiddos, it would be more difficult.

So, I think, you know, and as you're waiting for the diagnosis, I think it doesn't mean that families can't go forward and read about recommendations for what are these parent-child interactions that they're recommending for kids who have autism and going ahead and doing those services. You know, I always say that the types of behaviors that are recommended or beneficial for everyone. I mean any child, you know, benefit from these. So, I think there's no reason that you couldn't just say, "Hey, let me read some websites. Let me get a couple of tools and let me see if I can go forward and do some things that are going to support my family and support my child and help me manage my child's behaviors and help my child feels supported during this time" while you wait for an official diagnosis.

Dr. Raquel Halfond: Russ, you might be on mute.

Dr. Russ Shilling: Sorry. Sorry, yeah, it's so the only thing I have to add is I know this is not just an issue for the autism community. It really goes across a lot of psychological health. So, I think this is one of those areas where it's really showing us where we need to do a lot more work in the future.

Dr. Raquel Halfond: Thank you. So we have... we're getting close to our time. We have about three minutes left and we still have quite a few questions, so I may be able to get one more and I apologize that we're not able to get through all of them. But let's go to the next one: Is there a... is there any way to seek out new therapists now? What happens if you don't have a pre-existing therapist to lean on?

Arianna Esposito: I mentioned our resource earlier: our Autism Response Team. We have associates all across the country that focus on their... they know their local network providers, where you are by ZIP code, and I'll make sure that that resource is included so that you can reach out to them. They'll be able to help get you connected to a therapist in your area.

Dr. Sigán Hartley: Nothing to add - yeah, that'd be... that's a great resource.

Dr. Raquel Halfond: Do you want to add anything, Russ?

Okay. Another quicker question is: are these resources listed in other languages like Spanish and unfortunately the ones in this resource, this thing... unfortunately, not yet. But many online resources, especially the government ones, include an option to translate to Spanish and our team is going to work to make a Spanish version of the resource list available when the webinar recording is published next week. And then, let's see we've got about two minutes; let me see if I can squeeze one more in: 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?

Arianna Esposito: I would recommend trying to set up some virtual play dates with friends or classmates during this time, depending on how accessible that is. But even you could do - depending on how old your child is - setting up some type of like virtual study session or virtual homework time or, you know, part of the learning that happens really early on, it's not more academic; it's just real cooperation and that social/emotional stuff. finding a way, connecting with some parents within your child's class to do

an activity together, whether it's an art project and they're doing the art project independently, but they're talking their way through it or another game like tic tac toe or checkers or go fish. One of the bright spots throughout all of this is that we're a very technologically advanced society, so we have a lot of tools at our disposal and this is a time to really get creative and use... use those. there are plenty of games on phones and tablets that you can connect socially with somebody else. So that's another really great channel and I did read about a week ago that there's a way that you on Google Chrome can watch TV shows together with someone and chat the whole way through and comment. I think that's another really great tool to explore.

Dr. Sigán Hartley: Yeah, I think that's great. And I think that, you know, the nice thing is if you can think about what COVID-19 would look like, you know, a decade ago at sort of on a, you know, so different from today when we do have all these platforms and I think - we think about young kids, you know, young kids can still utilize these... these... these social platforms and it may look different and it may be a little clunky and maybe they just want to see someone's face and, you know, really they're kind of just not having a fully back and forth conversation, but even just facetimeing with a friend and letting them see that friend's face, you know, may be enough of that nice social connection to keep some of this sort of going. You know, the other thing is, you know, of course ideally this social-emotional exchanges will be synchronous, meaning you're doing it live and you're seeing each other's behaviors, but you can also think about asynchronous stuff. So passing... having your child write a letter to our friends having them pass the notebook, you know, my child will write it something in a notebook and go and she walks to a friend's house and put some the friend's mailbox. And then that friend would write a little note in that notebook and pass it to the next friend. So, I think, you know, this is the time to definitely, you know, seek out what other people are doing, seek out what works for you, and... and know that even if, you know, these interactions are short, even if your child may not be fully communicating or is not this really rich back and forth conversation, for them that still important. They are still seeing their faith... their friends. They may still feel involved in that game and... and they can very beneficial.

Dr. Russ Shilling: Yeah, have nothing to add, especially since I know I'm looking at the time and we're running out as for the other question that we didn't get to we will look at some of the questions about Spanish language for putting some of these materials out. So I'll discuss it with the staff afterwards.

Dr. Raquel Halfond: Thank you. And this is all the time that we have for today, but I'd like to give a really big thank you to our panelists for the very valuable contributions you made: wonderful group. And then, I'd also like to just remind everybody about the resources that are posted in a handout section. If you look at that gray bar on the right, the resources also does include a social story about COVID-19. So, do take a look at that; they will also be available to you afterwards, along with the recording, probably next week. So, thank you again, everybody; take care and stay safe.