

## ACCESS Division 33 Podcast: Special Episode on the Public Health Crisis, April 2020

### Full Contributions

#### PARENTING ISSUES:

*Laura Lee McIntyre (University of Oregon)*

Kids do best when they feel safe and secure. With a rapidly changing world with many restrictions on daily life, this sense of safety and security can feel threatened. Parents can help their children cope by creating a structure and routine at home and by talking with them using plain language about the steps their family is taking to stay healthy and what kids can do to take care of themselves. Although this is a very stressful time for families, parents can show their kids how much they love and care for them by making time each day to connect – through a preferred activity or through something more mundane, such as cooking or a bedtime routine. Parents who validate their child’s feelings (rather than trying to change their child’s feelings) create a sense of safety and security for their kids and open the door for meaningful communication. For our kids who cannot verbalize how they feel, it is even more important to create opportunities for comfort, safety, and security through routines, play, and loving interactions. It probably goes without saying that parents are experiencing heightened stress during this time. Stress management strategies such as seeking social support, taking time to exercise, pray or mediate can go a long way in relieving some of the stress. As a parent myself I sometimes feel incredible guilt about what I “should” be doing with my kids right now. My 6- and 8-year old kids are now at home being “home schooled” and spending entirely too much time in front of a screen. Expectation management is a strategy I use frequently to keep things in perspective. My motto right now is “good enough”. We do not need to be perfect for our kids, we need to be “good enough”. Sometimes “good enough” simply means showing up, spending time, and showing them how much we care in ways that they understand.

*Dr. Eric Butter (Nationwide Children’s Hospital):*

- What is really important is to build a schedule of structured routines. How do you do this?
  - Keep in mind that activities for most people, let alone children and especially younger children or those with attention or cognitive and learning differences, should not last much longer than 5 to 7 minutes. Frequent transitions between activities is important.
  - Vary the activities.
    - Do active things first. Anything that gets big motor movements going and coordinated activity is very good, and especially very good before you sit down to do any school or learning or quieter activities. Every hour, try to do a gross motor, coordinated activity (e.g. ball game with running, obstacle course, dancing, etc).

- Do things that tap multiple senses. Do things you listen to (story time, no matter your age, it is fun to be read to!; music; play sounds and pretend to be “there” e.g. maybe a beach, or in a rain storm). Do things you see. Do things that “feel” different to the touch (sand, water, goo, etc). Do things that smell (guess the scent!).
- Schedule fun stuff after less fun stuff, this way your child always has something to look forward to. It is so hard for any of us to stop doing something we like, to go do something we like less, unless we are reassured that fun stuff will happen again soon!
- Limit screen time as much as you can get away with. Video games, TV, Youtube, and other screen activities are generally not great bargains. An active and engaged child is going to be a more regulated and eventually tired child!
- Schedule your activities with a “visual” schedule. If your child can read, structure the visual schedule in words, just like your calendar or to-do list is structured. If your child needs picture supports rather than words, use pictures to build a visual schedule.
- Build in expected routines. Start the day, end the morning, start the afternoon, end the afternoon – really any part of the day – with a very predictable regular activity is fun and maybe a bit silly (e.g. “let’s bang on our drum/box/pot to start this part of our day” or “let’s do our happy dance here” or for an older child, “let’s find a joke to tell each other”).
- Share the burden. Keeping a busy schedule is exhausting. If you have another person at home to share the burden, schedule in time when each of you is “off” and really “off stage”. But, remember, just because you “need a break” doesn’t mean your child/children do. They will benefit from continued structure even when you need to “exit”.
- Don’t waste your breath shouting instructions and requests to your kids from some far away part of your house. If you need them to do something, go to them where ever they are. Get their attention, ask them to look at you. Then, tell them very clearly what is you want them to do. You may even be clear with them about what happens after your next task. For example, if is time for lunch, leave the kitchen and go to your child. “look at me, Alex”, you might say. “Good, now put your Legos down. You can come back and play after you eat. Now it is time for lunch, then you can come back and play with your Legos. First, let’s eat lunch, than you can have come back to play. Stand-up, let’s go”. Using “First/Then” or “When/Then” comments in your instructions and transitions between activities. Also, help guide your child with gentle nudges or gestures to “get up” or “come over” to you at exactly the same time you are giving the instruction.
- Schedule time, several times a day, when you are just on the floor playing with your child and letting them lead the play. Imitate what they do. Describe what you see them doing. Be enthusiastic, but don’t ask questions and don’t tell them what to do. Try to do this for at least 5 minutes, 5 times a day.

- If your child is irritable, grumpy, or defiant, work very hard at ignoring them. Fighting with children is never fun. Just walk away when they are like this. Re-approach them when they are quiet again. If still grumpy, stop and walk away again. If you do this enough, no matter the age of your child, they will eventually simmer down and engage you back appropriately. If instead you keep pushing through their grumpiness, you will just get more grumpiness out of them and you will get increasingly agitated too.
- Whenever you can, either in your schedule of activities or just by chance, teach your child something new. Even if it is a small step as part of something larger to learn. Maybe you can teach your child to help empty the dishwasher and the first step is just teaching them to put a fork in the fork slot in your utensil drawer. Today, forks; tomorrow, spoons; and so on!
- When we are all stuck at home, the good news is we get to practice this stuff over and over again. Keep trying. Parenting is always a “practice”. Under these extraordinary circumstances, it is even more important that we recognize that we will keep being given opportunities to improve. Every bored moment, irritable exchange, and exhausted evening brings us a new chance to try something different.

Structured routines with varied activities on a frequently changing schedule and with visual supports will help. Giving commands being close to your child and helping them to comply with you with gentle guidance will help. Ignoring the bad stuff as much as you can and paying attention and praising the good stuff will help. Spending special one-on-one time with your child where they lead and you cheer will help. Being sure you get a break is essential. Teaching them something new, even small things, will help.

Oh, and wash your hands and their hands, often!

## **PARENT STRESS AND WELL-BEING**

*Dr. V. Mark Durand (University of South Florida, St. Petersburg)*

During these trying times being a parent can be overwhelming. One strategy for dealing with difficulties during this unprecedented period is to give yourself permission not to be a “perfect” parent. Letting things slide a bit is okay and may help reduce stress. Also, each night write down three good things that happened that day. They can be minor (e.g., you had a good phone conversation with a friend) or major (e.g., your child didn’t tantrum at dinner time) but it helps you focus on the good events during the day. Feeling grateful for the good things in life can also reduce depression. Stay as social and as fit as you can and focus some of your time on you.

*Dr. Cameron Neece (Loma Linda University)*

First, know this is a very stressful time for most people around the world, and stress is likely heightened for parents of children with IDD and ASD as these families are probably experiencing significant changes in services and supports as well as unpredictable schedules. Know that right now it makes complete sense to feel overwhelmed, anxious, and emotionally "on edge" and at the same time we as parents have to move forward and care for our children the best we can. Here are a few pieces of advice based on my work and others on mindfulness and mindful self-compassion.

1. Try, as best as you can, to think about *this* moment and not the next moment or many moments from now. Much of our mental energy is spent rehearsing the future or rehashing the past and if we can stay focused on the present moment it is usually much more tolerable than thinking about the future or past. Personally, when I think how long this might go on, how long my kids will be off of school, and many other anxieties about the future I feel very overwhelmed, but when I focus on what is happening in the moment that I write this I realize I am sitting on my couch, sharing my reflections with a group of families and professionals I care about deeply, and listening to my kids play on a weekday afternoon which I never get to do.

2. Try to extend loving kindness to others and yourself. Loving-kindness, or 'Metta', is an unconditional, inclusive love, that has no conditions; it does not depend on whether one "deserves" it or not and it extends to include all living beings, without expecting anything in return. Loving-kindness can be built up in people through formal meditation practice of loving-kindness and other self-compassion meditations. Research indicates that through practicing loving-kindness and self-compassion people experience more positive emotions and increased connectedness as well as physical health benefits like decreased illness symptoms, all of which are probably helpful to everyone right now. I would encourage parents to be compassionate with themselves and to try to extend loving-kindness to their children, partners, service providers, world leaders, and, most importantly, themselves. For a great audio file of a formal loving-kindness meditation please visit <https://self-compassion.org/category/exercises/#guided-meditations>

## **SCHOOL ISSUES:**

*Dr. Geovanaa Rodriguez (University of Oregon)*

I think the biggest issue and challenge facing our families during this time is the issue of **equity** and **accessibility**. Parents are having to deal not only with the loss of educational supports afforded by children's IEPs, but also with the loss of an entire team of professionals that provided behavioral, medical, and mental health support. They may also not have the knowledge, technical, or financial sources to access telehealth services or navigate online learning resources and telepractice in their homes. There are many stressors our families are facing and I think parents have to care for themselves at this moment, so that they can be present for their children. Federally, schools are not required to provide IEP services/distance learning while schools remain closed. My advice during this time is to do what you can and

create some schedules in your home. Our children crave routines and structure and this disruption to their school routine may create more anxiety and behavioral challenges. There are several ways parents can help children adjust during this time. Create a schedule and designated work space for yourself and your child. Setting specific times to start and end the academic portion of the day (much like school) as well as a place to go that's associated with learning time. Keep these sessions short (30-45 min) and build in breaks throughout the day. While we may have expectations for our children, don't push your kids beyond their edge of comfort and mix up activities so they have variety. Use this time at home to focus on daily life skills and non-academic activities. Create goals like dressing themselves independently, using utensils when they eat, cooking, helping out around the house, play, exercise, and hangout! Schools don't focus too much on interpersonal or life skills, so now is that time to give your child or adolescent that extra attention on skills they will need for their life and relationships beyond school. While screen time is okay, try to limit this as well. If you are really concerned about skills they are losing, contact your local education agency or service district for additional supports and resources or see what options your current providers have available for remote service or instruction. Even though some schools remain closed, certain providers may still allow paraprofessionals to provide in home services and supports. These will obviously be evaluated on a case by case basis, but may provide some respite and support to our families with children with very severe needs. Above all else, be forgiving. This advice may seem counter to what my school psychologist braing might say in other circumstances, but we are asking parents to do the impossible right now. There will be mistakes, there will be tantrums on both ends, but remember to be kind to yourself. Our children are watching us more than ever now and how we respond in times of stress will influence their coping and behavior for when they eventually go back to school. Remain calm and take it day by day, this too shall pass!

*Dr. Jan Blacher (University of California, Riverside):*

To all those parents with no teaching credential who find themselves at the head of the classroom – LOWER the bar! I'm speaking primarily to parents of elementary of middle school children, enrolled in regular education and those in special education. If only half of the academic goals for 2020, or even six months into 2021, are met, it won't be the end of the world. Your children will finish high school where they should be. Even colleges will be making exceptions for this period.

That said, designate short periods of focused school work, followed by snack and if possible, some time outside or with a game. Repeat.

While lowering the academic bar, how about raising the joy-of-life bar?

Here are links to some ideas of places to give yourself a break:

- Lots of museums have gorgeous online tours: <https://www.travelandleisure.com/attractions/museums-galleries/museums-with-virtual-tours>
- Symphonies have streaming: <https://www.thrillist.com/news/nation/virtual-operas-symphonies-streaming>, and :  
  
<https://slippedisc.com/2020/03/believe-it-orchestra-plays-beethoven-9th-from-their-homes/>

- Try some cultural sites with activities for children:  
<https://culturela.org/programs-and-initiatives/arts-resources-during-covid-19/>

Finally, I'm a big fan of yoga; trust me, we all need to take a deep breathe during this period of sheltering at home. There are dozens of sites so find one that works for you and your kids.

## EARLY INTENSIVE BEHAVIORAL INTERVENTIONS

*Dr. Diane Hayward (UK Young Autism Project)*

we have some in total isolation but all working remotely some 100% directly with our staff and some with an adult in home pairing with us, each child a different bespoke arrangement but all working. Some still have direct contact as we are currently considered key workers and we send in reduced staff with rigorous infection control measures and the senior staff oversee it all remotely. Not ideal but we are super pleased with how well the children are learning given the circumstances. We are also finding that it is so far a positive experience for parents even if far from ideal.

*Dr. Tracy Guiou (Kadiant)*

We consider ourselves to be essential workers. Similar to Diane's approach, we've instituted reduced contact (i.e., 1 or 2 in some cases RBTs per client paired with Telehealth from BCBA given the higher carload they carry). Some children are more safely serviced in the clinic, with far reduced capacity, than at home so those are still open (may be seeing only 5 children, but....). We've got more rigorous and frequent sanitation protocols in place. My primary concern, other than caring for more emergent aggression and SIB clients, is that in addition to losing time to bridge that developmental gap...were going to see an even larger gap to bridge with longer term negative implications for parents, siblings and our communities. I hope that helps! One more thing - I personally don't think you can be medically necessary when it's convenient.

- How do you recommend modifying schedules? I.e. Keeping the same blocks of time designated for specific tasks/classes, or updating a new at home routine?

Kids need structure. We would recommend sticking to as close to your “old normal” schedule as possible, keeping in mind that for those families who were looking at a change in how the day was going to be scheduled in the fall (e.g., a move from middle to high school), a gradual shift to that schedule may be desirable. As much as it is possible for families to adopt a scheduled routine that provides for modified classes, even when the content of those classes is different, the better. For families working with a Behavior Analyst or ABA Program Supervisor, even via Telehealth, the chance to systematically build the skill of coping with changes to routine, with those changes initially being from less- to more-desired activities and later to those that are less-preferred.

I will add that trying to do this is a LOT of work so please take it easy on yourself. If you don't stick to your created schedule 100%, it is OK!

- Are there any communication tips you have for talking with kids about why the normal routine won't be happening for a while?

While here I'd advise families to consult with their Behavior Analyst or ABA Program Supervisor on specific tips, some general guidelines would include using consistent language paired with visual guides to support the message. If not on a shelter at home order, driving to/from familiar locations such as schools, ABA clinics and SLP/OT appointment locations and using consistent language to describe that disruption in routine could be helpful. Taking into account the language level of your child is important; for example, what language has been used in the past to describe something being “wrong” such as “broken,” “boo boo,” “uh oh,” as well as “not open,” or “closed.” We would recommend avoiding language such as, “not yet,” or “not today” to describe this type of disruption to a routine, because we simply don't know how long it might last and want to avoid inadvertently increasing frustration.

- Do you recommend creating visual support for what the new daily routine looks like? (most of the parents we work with have younger kids so this might be geared towards them, but I'll take any feedback on it).

Visual supports can be extremely helpful for all children so yes, we would recommend using them for children with ASD or other developmental disabilities. Incorporating choices can be helpful to increase feelings of control over various activities – working with your local Behavior Analyst or ABA Program Supervisor to schedule blocks of activities that vary by color and having a child choose an activity within that color block (i.e., it's time to pick a yellow activity, do you want to (x) or (y)?)

- Any fun activities you suggest adding into the routine?

Yes! Ensure “group” activities such as storytime, arts/crafts and physical activity take place – they're important and can be enhanced using online resources. At Kadiant, we are continuously posting [activity ideas for parents](#) including videos on [Youtube](#) and have a regular Virtual Storytime. We have found that this virtual interaction is positive for both the child and the parent and can take some of the weight off a parent's shoulders.

- Do you suggest adding in video conference time or phone calls with teachers/BIs/etc to maintain their inclusion in the routine?

We believe this can be very helpful and for those families receiving IEP services, we would encourage you to contact your school district about whether or not that would

be a possibility. If your child is receiving ABA services through health insurance, make sure to use your authorized hours, as we know that increased intensity of intervention enhances progress. Most health insurance companies have approved the use of Telehealth services, so ask your Behavior Analyst/ABA Program supervisor/SLP/OT and try to maintain services as much as possible using video conferences and phone calls.

- Any tips for self care for parents?

It is critically important that parents recognize the demands they face are more intense and last longer than those faced by parents of typically-developing children. Having a child diagnosed with a developmental disability such as ASD means more chronic stress (extending sleep loss and disruption from infancy to much later in development, increased duration of and need for coping with behavior challenges, communication difficulties, etc). Please utilize various strategies that are more easily available (e.g., Calm, Headspace and other mindfulness/meditation apps, online yoga) as well as communicate with your child's Behavior analyst or ABA Program Supervisor about what would make a difference in your family's stress level (e.g., toileting skills), participate in parent support groups and seek personal assistance from a therapist. We need parents to be in a place to benefit from working with us for sometimes a rather long time – we conceptualize our work together as a marathon rather than as a race and we need for our parents to take care of themselves. Sleep, eat well, exercise, be kind to yourself, call a friend / support system and give yourself a break! In these challenging times, just know what you are doing is enough.

## **MARITAL RELATIONSHIPS**

*Dr. Sigal Hartley (University of Wisconsin-Madison)*

The COVID-19 pandemic has drastically altered daily life for many families and created new challenges and anxieties. These challenges can impact the marital or couple relationship for parents. Spouses/partners may now be trying to share small spaces, navigating how to juggle added responsibilities like working, parenting, being a therapist and being a teacher, and not have alone time or breaks from these responsibilities. Partners may disagree about how to best engage in social distancing or manage new child-related challenges. Partners may also each be grappling with their own feelings of being overwhelmed, frustrated, and anxious, and these emotions can spillover into the couple relationship, creating tension. Yet, on the other hand, the marital/couple relationship can be a great source of support during difficult times. In this brief segment, I wanted to highlight some things we know about the marital/couple relationship in families of children with ASD and tips that may be useful during COVID-19.

### What do we know about the marital/couple relationship in the context of child ASD

Parents who have a child with ASD, similar to other parents, often share the ups and downs of parenting with their partner. Growing evidence suggests that in two-parent households, a healthy parent couple relationship can be a key self-care strategy for positive psychological well-being in parents of children with ASD. As a group, parents of children with ASD report



lower couple relationship satisfaction (e.g., Brobst et al., 2009), more frequent, intense, and severe couple conflicts (Hartley et al., 2017), and have an increased risk for separation/divorce (Baeza-Velasco et al., 2013; Hartley et al., 2010) relative to parents of children without disabilities. Yet, despite this group-level risk for poor couple relationship outcomes, there is a wide range of marital/couple relationship experiences among parents of children with ASD. Many parents are in longstanding and highly satisfying relationships (Hartley et al., 2017b; Hartley et al., 2010). Unfortunately, these positive outcomes are often overshadowed in media coverage of ASD, misleading parents of children with ASD to fear that their couple relationship is fated for failure (Doherty, 2008; Solomon & Thierry, 2006).

A growing body of research has begun to investigate the marital/couple behaviors that may be influenced by child ASD status and the factors that differentiate couples who are thriving from those who are not. In our own studies, we have used a daily diary method to examine the everyday couple relationship experiences of parents who had a child with ASD, relative to parents of children without disabilities, as they naturally and spontaneously occur in every day life. We found that parents who had a child with ASD reported spending an average of 21 minutes less per day with their partner than did the comparison parents who had children without disabilities (Hartley, DaWalt, & Schultz, 2017). Although this difference may not sound like much, those 21 minutes add up to mean that parents of children with ASD spend nearly 2.5 hours less per week with their partner than their peers who have typically developing children. This reduced couple time could account for why fathers of children with ASD reported experiencing less daily emotional closeness with their partner than did comparison group fathers. Moreover, reduced couple time could, in part, explain why both mothers and fathers of children with ASD reported engaging in fewer positive couple interactions such as sharing jokes, having a meaningful conversation, or being intimate than the comparison group. The reduced couple time of parents of children with ASD may be due to increased parenting demands (e.g., taking child to therapy sessions, meeting with special education team, and assisting child with daily life activities). With limited couple time, what appears to fall by the wayside is time for emotional closeness – sharing thoughts and feelings about one’s day - and time for fun and enjoyable couple activities.

We’ve also found that at an everyday level, stress from parenting experiences can spill into couple interactions and vice versa in parents of children with ASD (Hartley, Papp, & Bolt, 2016). In one direction, mothers of children with ASD were found to experience fewer positive couple interactions (e.g., joking with partner, fun activity with partner, etc.) following a day with high parenting stress. This finding suggests that highly stressful parenting drain mothers’ resources such that they have less energy to put toward positive interactions with their partner. In other words, following a day with high parenting stress, mothers of children with ASD may feel too tired to take the time to say something nice to their partner or make a joke. In the other direction, mothers of children with ASD experienced higher parenting stress following a day with more negative couple interactions (e.g., critical comments to partner, ignored partner, etc.). Thus, the negative tension that came from within the couple relationship carried into parenting experiences, resulting in more stressful parenting.

Overall, studies indicate that global couple relationship quality has strong ties to the psychological well-being of parents of children with ASD (e.g., Ekas et al., 2015; Harper et al., 2013). In other ways, if a parent is unhappy in their couple relationship they are often unhappy overall. There is also reason to believe that the couple relationship may be particularly critical to psychological well-being in a context of high stress.

### **Potential Tips during COVID-19**

In the era of COVID-19, finding ways to connect with one's partner may be difficult. But this could be an important way to manage feelings of anxiety and stress. During times of stress and when parents are busy juggling multiple demands, what appears to go by the wayside is time and effort to emotionally connect with one's partner and interact in fun and causal ways. Thus, during COVID-19, it may take concerted effort to carve out opportunities to connect you're your partner. However, this does not have to be big chunks of time. This could be 10 minutes before bed (when children are asleep) or 10 minutes in the morning (while children are engaged in a TV show) or texting your partner a joke (even if you are in the same house!).

It may be important for partners to help remind each other that this is an unprecedented and stressful time. It is OK to feel overwhelmed, isolated, anxious, stressed etc. Process these emotions together. Also, communicate about what you need to feel supported by your partner given your new reality. Be clear – what is supportive and what is not supportive from your partner? What does your partner find to be supportive and not supportive from you? Is a new division of labor needed? Remember, this is all new and it takes time to re-adjust the roles and expectations. Anticipate road bumps, miscommunication, and frustrations.

While it can be helpful to talk process news about COVID-19 together, many couples may also benefit from not talking about non-COVID-19. Instead talk about other things – funny stories from the day, recent movies, plans for the backyard, etc. Consider engaging in relaxing and enjoyable activities like going for a walk or playing a game together.

### **ADOLESCENTS AND YOUNG ADULTS**

*Dr. Julie Lounds Taylor (Vanderbilt University)*

1. Even in these trying times, trying to keep some sort of a routine will be helpful. Particularly if you notice that your son or daughter with ASD has extra free time, it could be a good time to work on independence and skills of daily living (e.g., doing household chores, self-care, etc.). More daily living skills are related to a greater likelihood of employment, so working on greater day-to-day independence may have longer term benefits.
2. Its particularly important, at this time of great change, to pay attention to the mental health of your son or daughter with autism (and your own mental health as a

parent!). Many people's schedules have changed on a dime. A loss of routine and familiar activities is hard for many people, but can be especially challenging for a person on the autism spectrum.

## **SOCIAL CONNECTION:**

Dr. Elizabeth Laugeson (UCLA)

Social distancing doesn't have to mean social disengagement. Humans are innately social creatures. Many of us crave social contact and thrive through social connectedness. Research suggests that having just one or two close friends leads to better adjustment in life, decreases the likelihood of mental health issues like anxiety or depression, and can even buffer the impact of stressful life events—like the ones we're facing now amid the growing concerns over COVID-19.

Although individuals with developmental disabilities like IDD or ASD often struggle with making and keeping friends and fostering social connections, their desire to be socially engaged is often no different than anyone else. That's the good news.

So how do individuals with IDD or ASD form social connections at a time of imposed social distancing? It's not so different than the rest of us...

- Consider joining online meet up groups around shared interests (some meet ups are even designed specifically for those with IDD or ASD)
- Go for a walk or a bike ride in the neighborhood with your family
- Smile and say hello to your neighbors as you walk the dog (those neighbors are craving social contact, too)
- Host a virtual get together with friends, coworkers, or classmates over google hangouts
- Play online video games (many include video chat options for the players)
- Download a movie and watch with friends using web based video conferencing platforms like Zoom
- Dust off those table top board games (they've made a comeback with young people)
- Instead of making a call or sending a text, considering doing a video chat (seeing someone's face increases the feeling of social connectedness)

Those are just a few of the ways that millions of people across the globe are maintaining social connections during this unprecedented time. Yet, even with these suggestions in mind, those

with IDD or ASD may still find social interactions inherently more challenging. In that case, now might be the right time to consider getting some help in developing those skills. If you would like more information about social skills training using online telehealth options, feel free to contact the UCLA PEERS Clinic at (310) 26-PEERS or [peersclinic@ucla.edu](mailto:peersclinic@ucla.edu).

Meanwhile, stay healthy, stay safe, and stay connected!