An Open Forum: Drawing on Our Strengths to Respond to COVID19
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Expert Facilitators

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The goal of this discussion is to provide a space for transparent, honest discussion about navigating through life during this pandemic

Everyone has their own unique experience and that is ok. We are helping each other move towards actionable steps so we can create meaningful change

Q: What has this experience been like for you?

E: Relative continuation of life, with some tweaks. My brother has ID/D and is immunocompromised so now we must be extra strict with sanitary protocols (cleaning groceries before bringing them into the house, extra precautions leaving the house). He doesn’t understand why he can’t leave the house. Why don’t we go to McDonald’s when he brings us the car keys?

D: My wife passed away 7 months ago. My son and I are in this together, just the two of us. I’ve been focusing on loving my son and learning who he is. Human decency is a great thing; my neighbors left butter pecan ice cream on my porch after I mentioned I hadn’t had it in a long time. People are focusing on what we CAN do to make this as decent as possible.

J: I have three sons in high school, middle, and elementary school. I’m feeling a little overwhelmed by all the communications from the different schools (email, twitter, facebook, ahh!). My son struggles with seeing kids playing outside but I don’t let him, and I’m struggling with that balance. I’m feeling stretched and more busy than usual. Everyone is having their own struggle.

Q: What’s been helpful to you? What has been challenging for you?

E: Continued access to mental health treatment with waived copays has been so essential. I worry about my brother right now; I work from home now but I’m also his DSP and it’s hard balancing. How are we building his independence? How are we enriching his day? I’m worried that I’m not doing enough and it will negatively impact him.
D: I speak with my therapist 2x a week via telehealth. It’s been extremely vital; my son is nonverbal so I rarely talk to any adults. The feeling of isolation is real. His team of therapists have been the most helpful – OT, ST, PT, ABA (4x week). My BCBA drove to my house to drop off visuals, and she lives on the other side of DC. That meant a lot to me.

J: My children are creative and adaptive. We are relying on our love of art, music, and movies. Spending dedicated time outdoors has been helpful. My strong partner was struggling a couple of weeks ago – it surprised me. I was so immersed in helping everyone else, I didn’t realize how much he was internalizing. We started taking evening walks together and creating plans to alleviate those feelings of anxiety.

Q: Any strategies or resources that have been helpful? What do you wish you had?

E: Access to MH services and removing the financial barriers. I would love to have a guide for how to enrich my brother’s day, when he can’t leave. A guide for people who are nonverbal and have ID would be good. Having special health care needs myself, I wish there were a streamlined communication process for my providers to share information and problem solve (i.e. what happens if my meds run out?)

D: My son’s therapists have been exceptional. For me, I’d love to change distance learning for special education. It hasn’t been meeting my expectations. I’d like to see more substance and engagement. How can we make online learning more meaningful?

J: I’m trying to resist the urge to stay in a reactive state and shift to a more innovative state. This has worked for me both professionally and personally. In times of change, I try to shift my focus to experimentation – how can I throw a birthday party? How can I continue providing services? We must create new solutions and new ways of doing things.

Q: How can we foster more meaningful relationships across families, caregivers, providers, systems, etc.

The strength and resilience of communities when faced with tough situations shows us the untapped power of our communities.

We need to reshape our systems to meet the diverse needs of our communities, and to be reflective of the real-life experiences of the families we serve. How can we close the gaps that have been exposed from this pandemic?

In times of disruptions, we feel disoriented. We need to stay mindful of ourselves and our mental health. Focus on the things we can control.

Small acts of kindness are so treasured and important right now because they show appreciation.