



Coffee Talk 4 (A Podcast with NIP):

Inclusion at Home - Disability & Family During the Pandemic

A Podcast Discussion of the Ups and Downs of Family Life & Disability During the Pandemic

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TRANSCRIPT

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Amanda (National Inclusion Project): Hi Everybody, just want to welcome everyone to listening in today to a discussion that we're having about the family experience during the pandemic. We are going to chat with some parents as well as parent resource specialists working with families of children who have disabilities. And what the ups and downs of pandemic life has been for them this summer in terms of social experiences, camp experiences, as well as the transition, into school this year. And what it is that experience looks like for them and their home life as well as their daily life experiences.

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So, going to start off with a few introductions of our panelists today, and then we're just going to chat. First and foremost, I want to introduce a good friend and a parent DeAnna. DeAnna, take a minute to introduce yourself to our group today to tell us why you're here and who you are and what you can contribute to our conversation today because it's really powerful!

DeAnna (Parent): Thank you so much. My name is DeAnna and my husband and I have four kids three of which came to us through adoption both domestically and internationally and have orthopedic conditions that affect their day in day out lives. We also have some concurrent learning struggles and just differences in learning profiles. So just a lot of uniqueness in and around our family. And so I hope that some of the things that we've learned and some of the things that have worked really well for us over the pandemic might be helpful to others.

And I really just want people to know that we don't get it right all the time. It's messy. It's loud. And so much of this is just an un-lived experience for any of us adults or kids alike. And so for me and my family, we found a few things that work.

We hope they would help others, but we know that every day is kind of a new experience at this stage in life for all of us.

Amanda: I think that point is really important for parents or providers or caregivers to understand that there's no use in comparing to what "was" because every day of this is new. And that's something that we can take away from this for our experience as families of children with disabilities in general. Every day is new.

There's always something new to discover. There's always something new to figure out. There's always something new to celebrate. And I think that that can be a really powerful message going forward. And that if anybody tells you how to do this, they're lying. There's no, there's no rulebook. There's no right. There's no wrong. There just there just is.

Awesome! I'm very much looking forward to our discussion and we're going to introduce our other two discussants this morning. I would like to invite Carol to jump in and then we can lead into Nancy.

Carol (FSN): Hi, I'm Carol Cranford, and I'm with Family Support Network of Southern Piedmont, which is in the Southern Piedmont region of North Carolina.

Amanda: And what do you do at the Family Support Network here?

Carol: Okay what we do... There are twelve regional programs across the state. And what we do is we help families to find the resources that they need, help make connections, help them navigate the service system throughout.

But the main thing that we do that connects all the programs across the state is parent to parent matching because those parent to parent connections, that's where parents really get the most information. They get information about resources, but they also get that emotional support because when we have a child with any type of special need (our program works with families that have infants in the NICU all the way up) So when you have a child with these special needs it just turns your life upside down! And I do know that from experience.

While I am not caring for a child right now with special needs, my mom who is 85 years old has Parkinson's so I am her caregiver from a distance. I am her caregiver. The one that's taking care of her. And that too has been a struggle. So if anybody out there who has kids in their home or an elderly

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person, it could be really tough right now. Those are the main things that we do we help parents connect.

And we train parent mentors and then match them one to one with other parents or help parents get connected with support groups or start support groups when they come to us. So it's all about those family connections.

Amanda: Awesome! So powerful, important and necessary, right? It gives us as families that deep breath moment knowing that there are organizations out there like yours who are there for them from beginning then beyond! Excellent!

And then, Nancy would you introduce yourself and tell us who you're representing today?

Nancy (FSN): Yes. Thank you. My name is Nancy Mega and I'm with Family Support Network of Central Carolina and am very excited to be here today. I think the main mission we all have is to let families know that they're not alone in their journey. That alone in itself is just so empowering to families, especially now during a pandemic when there's so much isolation.

We know the power of positive social connections. So we want families to know that they're not alone, especially if they have a new diagnosis and it's like you said, it's just a new world and every day is a new day.

I'm also the parent of four grown children and our oldest son John is with us, he's 41. He has a chromosome anomaly called 18Q Deletion and he's just a great guy. (He's puppy sitting in the other room for me right now!) He has global delays and he also has a vascular condition. So we have made the hard choice to kind of pull him out of the wonderfully rich and full life he had pre-pandemic. So we've really had to kind of build a new normal for John and our family, and so I feel like we've learned a lot along the way.

Amanda: That's an important message for us to hold onto during this discussion and beyond. How much has changed for families based on the particular needs of healthcare for their children who may have fragile medical needs or the change that they've experienced in the social interactions for kids who have lived and breathed and grown through varied and rich social interactions. Then moved into a more isolated space of perhaps learning from home or spending most of their time in self-isolation. Or in small groups and what it is that means for their family experience as well as their growth and development.

So, we're going to touch on a variety of those topics today. Thank you all so much for that introduction! Just a reminder to folks who are listening in that you can access the web links and web page information for any of the organizations that are discussed in our call today, especially for the Family Support Network.

We are just going to start off with a quick question...

Since the National Inclusion Project is an organization that is based in North Carolina, but serves programs and schools and families throughout the country, Is there a national link to your organization that can benefit families beyond North Carolina as well? Carol or Nancy?

Carol: Ah, yes, there's actually Parent to Parent USA and you can find them online at parenttoparentusa.org. I believe that is it. And they have a little map for you click on your state and just about every state it's going to have something similar to ours. It might not be the same model as Family support Network of North Carolina, but there will be some ways in that state for you to connect with other families.

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Amanda: Awesome. Thank you so much.

Again, just a reminder and a comfort to the folks who are listening in that one of the goals that we have at NIP is to promote relationships and connection and collaboration especially during times like these.

We try to find like-minded people who are passionate about the same things.

Who are passionate about inclusion.

And advocacy.

And educating all kids.

And supporting all families.

So, I'm so happy to bring such a diverse group of professionals and parents together today to build those relationships and build those connections.

OK, we're going to dive into our first topic of discussion! We're going to start off with DeAnna because I know that you have some stories and advice and anecdotes to share and want to spend a few minutes talking about some of the successes and hurdles that you've experienced through your life at home with your kids since the pandemic has occurred and what has gone really well in sort of navigating this new world. And what are some things that may have been bumps in the road or things that haven't worked so well for you.

DeAnna: Okay, so obviously I mean like everybody else when all of this started was a little bit stressful for everybody in the house. My husband works in medicine. And so he of course is one of the many essential workers who was continuing to go out the door every day and to, you know, what in March was just a very unknown space for all of us.

So, coming out of school, (my kids are in a public school a public charter school) and coming out of school... coupled with their dad going out the door everyday to work...and not being allowed to see their friends and caused quite a bit of stress and anxiety for my boys.

They are all very very different personality wise, but the effects of that were just tremendous for all three of them and so in different ways, we just really had to learn and cope. I feel pretty confident in saying that within a couple of weeks, we kind of fell on our kind of level ground.

We just believe in open communication and talking about our feelings and talking about these frustrations and worries out loud and sharing those with one another giving space for our kids to feel those things. Even though we as adults may not feel those same anxieties that they were feeling. You know, sometimes you have to fight the urge to say as a mom like, "that really doesn't matter that you're worried about missing PE today. You can go outside in our yard and run!" (Laughs)

But to one of my sons going to PE every day was a place where he excelled. It was a place where he connected with friends who were in other classrooms. And so that for him was a major loss. So we've had to really very very quickly work through some of those ,just some of those initial losses coupled with anxiety of dad continuing to go out the door. Of course with it being kind of an unknown indefinite amount of time that causes a lot more anxiety for all of us.

My kids will tell you (if they wouldn't have told you this before pandemic life) they would certainly tell you now that one of my favorite things to say gently most of the time is, "One step at a time."

We're going to take this one step at a time.

We're going to take this one day at a time.

We're going to take this when it comes to schooling one assignment at a time.

And we're going to do our best with what we have.

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So that has just been a theme that has been what we hope and what we've gotten better at is very graciously woven throughout every day.

One thing at a time.

I know you're nervous.

I know you're worried.

And I know you're frustrated.

We're going to take it one thing at a time.

So I mean, everything in the beginning felt like a hurdle. I realized very quickly that my mindset as a mom really projected onto my kids whether I liked it or not. You know, it's that whole phrase about "If mama ain't happy ain't nobody happy!" (Laughs) So I had to really work through my own anxieties in private or with my husband at night and not in the presence of my children because they needed me to be as calm and collected and peaceful as I could be.

So that was definitely a challenge for me personally in the beginning. But again, you know, even my husband and I just really had to walk through some hard tough conversations in the beginning to work through some of that. So very quickly I had to work on my mindset.

I realized in about a week. (It didn't take me very long at all) to count the number of teachers that I was attempting to replace.

So we have three boys. We have a 13 year-old next week. We have an 11 year old and we have an eight-year-old and so we have a seventh-grader, a fifth grader and the third grader. So this spring they would have been, you know a grade behind... so middle school middle and late Elementary School and between the teaching staff, therapists that they worked within the school, guidance counselors, and regular everyday staff that my children were interacting with and had a relationship with. For three of them, it was 18 teachers! And that doesn't count Administration that they were familiar with seeing, and other people just woven throughout the school that they had relationships with.

So it became very obvious very quickly for me that I am but one person. And I cannot on my best day, with even the best systems in place and all of the right things, I cannot replace 18 people! And we have a toddler daughter who was literally on top of our bar one day hanging from the chandelier when my husband came home. So she is an active engaged Neurotypical young girl that's just a joy, but when you try to balance out the challenges that my children have, that my older boys have, and toddlerhood there are some unique challenges there!

So the best thing I think I did in the beginning when it came to school was to email back and try to be very gracious and gentle and saying I cannot replace 18 people. Two out of three of my boys have IEPs and have wonderful supports. But I cannot replace EC (exceptional children) professionals who are trained to support my children in the school.

I'm a very smart woman by the world's standards. I'm a pediatric nurse practitioner as a professional world. So I use a lot of those skills in my everyday life as a mama, but I am no teacher and I am no therapist, but I have worked very hard to try to figure out how to balance what works for us.

So, I don't know how much more you want me to go. Do you want me to keep going or do you want me to kind of...

Amanda: No, that's great. And that's a great start because I think a takeaway that that you had mentioned I think is particularly important for us to reflect on is the importance of communication within family and giving children that a safe space and place that they can communicate their new stressors and worries to those close to them about how different the the pandemic makes them feel or what it is that they experience but also, and I know we'll get to this in upcoming questions, the importance of seeking out additional support through through trauma counseling and guidance support

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as well as mental health support for for kids who need help in processing this. Many of them children who have disabilities who have social emotional needs that are experiencing a whole other layer of need right now.

And all children have experienced some level of change and trauma in their daily lives because of this. So seeking out that permission and that grace and that support for processing those feelings is particularly important. Also for parents and caregivers and family members to have that support and those resources as well are very important.

The other thing that you had mentioned was the strain and the struggle that schooling at home takes on parents and families and kids in general, especially when it's not planned for. But also the particular strain and stress that parents and families of kids who have IEPs, or receive specialized supports or instruction or, or who have 504 plans. And what it is that that means through a computer screen. Or in a daily home setting with other siblings and other needs to take care of or the professional life of the family members around them to balance out that.

We know in general that teachers do an extraordinary job trying to be all things to all kids throughout the school day, but now we're faced as families to be things to all kids in all ways throughout the morning, the school day, and the evening for our families. So setting boundaries on that and getting collaboration and support and really developing a much more unique and reciprocal relationship with the school is very important. With the understanding that we have to define things differently now because tomorrow is a new day and it's going to look very different from what it is that that we experienced yesterday.

That's an awesome start! Thank you so much! Carol or Nancy are there things that you've seen professionally that have been particular thumbs up moments for what it is that you've been able to provide as resources to families during this time or those moment that are sort of the bumpy road moments that you've seen families experience or what it is that you've experienced through FSN?

Nancy: Sure, I think of many of our FSN groups had regularly meeting parent groups. We have at our program, we have four different parent groups with a mom's group, a dads group, a after the NICU group, a rare disease group... and we were able to turn those all from in person to virtual like a lot of programs. And just kind of getting the word out about those to give families a chance to connect not only for that positive emotional/social support but to brainstorm on ideas, right? What's worked for you? What hasn't worked. How did you approach it with the school? Because families are struggling. It is so hard in one way for the parents who have children with special needs. They've been down this road before, right? Facing the unknown when they get a diagnosis. They don't know what the future will hold they have to make more decisions without a lot of concrete guidance for their families right from the beginning. So we've had some practice in this. But it is still very very challenging and stressful for families.

The other group that I always think about is, (many of us, I know Carol has too) we have a strong sibling Support Program. Because the brothers and sisters already faced so many unique challenges in growing up with a sibling who has special needs. They're so proud of them and they're so responsible and great with them and then when you when it comes down to a pandemic and everybody's just kind of too close for comfort, right? It gets a little stickier. It gets a little harder. So having some virtual opportunities and outlets for siblings to connect with each other and talk about the joys and challenges and how they are helping and again giving themselves the grace when a day hasn't gone that great just like DeAnna recommended for parents giving ourselves grace that we can't be 18 teachers. And that for siblings, it's not always going to go great and that it'll be okay.

"Tomorrow's a new day!" is what we always say at our house.

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Carol, did you have something to add?

Carol: And we too have a sibling program with our agency and those kids are often forgotten to begin with because the focus is always on the child with a special need and that is the child that always takes up the parents' time. So we've been doing virtual meetings with ourselves as well. And I think that's a great way for them to really release some of their frustrations and to get that out in a very safe place.

Amanda: One of the really positive things I think that we've seen come about through virtual meetings and virtual resources and even virtual instruction is that you're connecting and collaborating with and building relationships with many more people than you have been able to before. And I think that that's actually a very exciting time for disability support or advocacy or education to have specialized opportunities now for folks from all over the country and parents who are experiencing similar things and kids with similar needs as well as dissimilar needs connecting with each other and learning from each other and learning about each other. So I do think of that something that we can hang on to as a benefit or a positive opportunity that has grown out of all of this change. And I think that that's something that is exciting for us to see in that I think many of us will continue to use those virtual opportunities for connection beyond all of this. So even when this is all over which I think is great! And we're all learning better how to do so as well, right?

Next, we're going to move into recommendations or specific strategies that you have for supports or resources or respite care. And DeAnna before we go into those in general you had shared with me before this discussion about some particular strategies that have worked for you just in terms of setting up your space at home so that your kids can be more independent as well as more self-determined for taking some of the pressure off of you for a lot of the caregiving during the day. What are some of the things that you've done?

DeAnna: We became, I became, a pseudo occupational therapist as well during all of this. I think I mentioned earlier that my boys' primary needs are orthopedic in nature. Three, very very different presentations of Orthopedic differences.

So one of the things we always say is that it's a "DIFFability" because my oldest looked at me one day and said, "Mom you keep DISsing me!" And I thought, well if I were standing in his shoes, I would not want to hear DISability either because he's capable. They're all three capable of a tremendous amount. So they're very differently abled. So we say a DIFFability in our world and what that means is that for every different child all three of my boys have their own learning space in our home.

So our home is not that big, and we still managed to navigate three different learning spaces. So, one of my children can't lift his arms independently up to like shoulder level or up above his head.

And so what that means is all of his learning supplies needed to be down low and that was just a very simple easy fix now. We had to keep it out of a toddler's way, but we figured it out so he needed a couple adaptive pieces of equipment from the school that we were able to check out during the school year and then purchase over the summer so we could have them as school has started back in. But we, in those three different learning environments, went through with our boys and said "Ok. What do you need?" What did you like from school that you had and what can we, how can we make that work at home or what do we have here that's different? Perhaps Works a little better?

And so over the course of the spring semester we were able to tease through.

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Like...one of them uses a clipboard quite a bit. Never used a clipboard in school, but it works here because it helps hold his paper in place and then he doesn't have to. That's one less thing to worry about.

"Dictate-to-Scribe" has been tremendous.

We've used Read to Write from Google or Read and Write from Google- they're extension plugins. That has been tremendous! And it's just decreased the physical fatigue and therefore my two that struggle more with physical fatigue have produced so much more. And so in that sense, the virtual learning experience has been great because they're in these little separate pockets of the house. They can Dictate to Scribe. They can pull up the Read and Write and it will highlight as it reads aloud to them. So when you think about things like Dyslexia, and other learning disabilities, ADHD, those types of things it really helps maintain their focus.

One of the things that we used to use for limiting screen time was a "triple lock" on an iPad and then what that works for in an academic setting is I have one child that is just very impulsive and he may be doing his assignment but oh then wants to play the racing game instead. So he'll pop over to another app. And it still looks like he's sitting there working while I'm helping another child or two. (Laughs) So turning on that parent lock on the iPad allows him to focus. So I lock it when he's on an assignment, he completes the assignment, I unlock it and we move on. And that's something...even today, he just asked me, "Mom, I'm just going to lock my iPad and then you can you turn it off when I'm done?" So it's something where we try really hard to find a balance between adapting the environment to fit their needs because we never want our children to believe that they're "broken." Because they're not there just differently-abled.

So the environment has to be an environment where they can be independent as much as they can. And then as a mom I have to balance out not pushing them too far down the independence track and just remembering that you know, what? Opening a Ziploc really is hard for that kid. (laughs) So when it comes to snack time... "Get your snacks!" and I just opened their Ziplocs for two of mine.

So it's a balance!

Individual work spaces have worked tremendously. There are a couple of things that I'll send you Amanda that we use that one of them is an "iPad Crayon". It's incredible. It will record things and it will help my child who has difficulties with fine motor so that when he does all his assignments on his tablet. We got digital textbooks. That was a tremendous blessing because then he can adjust the size and complete the work right there on the iPad, then shrink it back down and when the teacher gets it it's the same as if he turned in a PDF or a regular file that another child might use!

So I'll send you a couple links of things like that that we've used that you can add into the notes & things. Some of them are free, some of them cost money. So it's things that you have to work with your school system to get. But what pandemic schooling has taught us is if we can make a case for it at home, that oh, it works then now coming back into this next school year that EC Director said, "how did you do that?" "What was that program?" "I have another kid. I think it might work for." "If we can find another kid or two. Then I think the school will buy it!"

And we can you know, just making it... because in this world, like you were mentioning earlier so much of us learn from each other. And so if we are using something that works, and the school finds out about it, and we can justify how and why it works for our kids. Then the odds are there is another child or 10 who may benefit from it as well!

Amanda: Excellent and to understand that there are other resources that we can explore and recommend through different organizations to help connect parents to information about how to get funding for or seek these things out or support their schools in getting. And just the awareness about

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what it is that the working well to meet an individual child's needs. Because as you said, if it worked for one child, it may be beneficial to more or could simply become part of what that Universal Design is to help all kids. Right?

And the goal is always to think about how can we design and create things well enough that they can benefit all kids in their learning and then have additional layer of something that specialized.

I can't wait for those resources! But also want to touch on what you had said about the way you've created adaptations and accommodations in your home and you're using assistive technology right?

DeAnna: Yes.

Amanda: Okay. But people forget that assistive technology doesn't always have to be high-tech. There are a lot of low tech and no tech versions of assistive technology that we put in place in our homes simply by preparing the environment for the child everything from place, space, and materials to also then leading into preparing the child for the environment where it is that we promote independence and promote self-determination and promote advocacy in the child themselves so that they can grow into meeting their own needs. And asking for support when they can't. And making sure that that learning experience is there for them to not only in having those conversations with their families and their parents, but then also with the adults around them, and in schools, and with their teachers, or camp counselors as well. That difference between do for me, or teach me how to, and do with me kind of learning. Awesome!

DeAnna: Yes. Can I add one more thing to that?

Amanda: Yes Ma'am.

DeAnna: If it's a task that I think that they can achieve whether it's academic or an ADL or anything. If I think that they can achieve it and I would have leaned on a therapist to help me figure it out. A lot of times, I will just give it to my boys under the right pretenses...Obviously, good mood, you know nice and calm atmosphere...

Give it to my boys and then I will say "I need you to try three times." And a lot of times, I'll just stand back and watch them and one of mine inevitably will figure it out on his own in the first maybe the second try. It looks nothing like what I would have done. But it helps him develop that problem-solving skill. One of mine, it often takes us 10 or 15 times to figure out how it's going to work for him. But I always do the, "Try it three times and then Mom will help you." But I watch and encourage them and I always try to say you're doing a great job you can do this! You can figure this out. And when you can't I'm here to help you. You know, there are adults that are there to help you as life goes on.

Amanda: I love that rule of three. I've always had that with typical children too where it is that I have the rule of "You try three, then with me." So you try three on own, let's see what it is that you can figure out, then I'll try with you. Won't do it for you. But I'll do it with you and we'll come up with a way that that works well.

Super super important advice! I love that! And again within parameters, within a safe space, where it is that they feel supported in that, right? Excellent.

But now, Carol & Nancy recommendations for supports? Resources? Things that you as an organization or you as individuals would love for families to know that that are available? Or things for them to think think about?

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Nancy: I would definitely say reach out to your local Family Support Network or Parent to Parent group. They are a fantastic resource to just have a phone conversation with without any specific need. And most of us are really good at reading what might be helpful for a family that they might not know exists in their community even during these trying times.

I would say that our local Parks and Recreation department has done a fabulous job with inclusion and virtual events for kids that are social, leisure, sports bases. So that's been really neat to see and helps develop those friendships.

Also, there's so many virtual workshops and Zoom meetings that do focus on self care. Whether it's for the parent recognizing when they need more self care, how to find it in just tiny little increments. It doesn't have to be this big long process. I don't have time for that. I have so much on my plate.

You can make all these tiny little things. And also the same thing for kids self care for kids understanding their own feelings and there's just great resources out there.

So lean on your resources, reach out to your friends, even when you feel like you don't have time to connect. And just know that this too shall pass. Eventually, it will pass. We don't know when. (Laughs) But we will get past it, and like you said Amanda, will bring with us the things that have really enhanced the way we function as families and community members and friends.

Amanda: Absolutely! And the things that we thought were very difficult about this at the beginning, then are not over time. Right? We, we figure it out. We learn more, we move forward. And we see that with kids and their learning curve as well. Right? I've seen kids adjust to social distancing, and a mask wearing, and health and safety protocols, beautifully!

I think if we trust how amazing and how resilient and how open to change children are! Especially many children with disabilities because that's just their life experience. They're really good at adapting.

They're very resilient. They've got grit, right? If we celebrate that, and trust that that's in them, then we can see really positive change in them that we may not have expected.

And I want folks to keep in mind... don't sabotage the success before we give the success a chance to happen. Right?

You had mentioned Nancy the great things that the Parks and Recreation programs and local recreation programs, sport programs, and community programs have been putting in place for to keep social experiences and physical experiences alive for kids this summer. And that's something, of course, at National Inclusion Project that we're particularly passionate about is creating those opportunities through recreation and through creativity and through discovery to bring kids with a wide variety of needs together to simply play, to simply experience, and simply interact.

And if you aren't aware of what's available in your community Google it. Log on and ask. Start making some phone calls. Because if you can connect with other families and ask them, "Well, what are your kids doing?" Right? If you can connect with organizations like yours or with ours, we can find those places and spaces that are doing these amazing things even at a distance, right?

And if we don't know we will help you find out because no one wants this to be something that is isolating and lonely and overwhelming. So everyone is carving out really innovative things to serve the kids in the families and their communities. Which I think is another powerful thing that will take with us. The collaboration and the camaraderie and the collegiality of individuals coming together to say "we're in this together" is really exciting.

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Nancy: There are so many silver linings and if we can really focus in on that and have that mindset of looking for all the positive ways that our families are more empowered and have richer lives and just even the slowing down has done so much for our family.

Amanda: Yeah absolutely.

Nancy: Many connections.

Amanda: Carole are any things that you want to add about resources or supports or way to connect families to what it is that they might want or need?

Carol: Again, I want to reiterate what Nancy said about connecting with your local Family Support or Parent to Parent program. Because they will know what's in the area to get connected to. And also I think, I think DeAnna really hit on something earlier when she was talking about, you know, if "Mama ain't happy, ain't nobody happy" and I think that it's very important for moms to take care of themselves so that they can be there for their children. And I know, one mom here I know just made a game out of wearing masks. You know, because she, she knew how important it was for her child and he did not want to wear it. So they pretended like they were ninjas then she took him out into the community like this.

So you got to do things like that to make it fun and I know it's one more thing that we're adding to your place that you could stress over.

But, one of the things that we did here, and this was early on during Covid, is we have a program called "Powerful Tools for Caregivers". And so we had eight parents (we limited it to only parents) we had eight parents who signed up ASAP. One of the things that we taught them is to every week have a goal is something that you want to do. That's just just for you, you know, and so parents were and they would have to tell us what it was. So it might be to take a walk through the neighborhood for 15 minutes and to do it every day and then we would check in with them at the the next week to see what were you able to do this and what kept you from doing it. Or it might have been somebody was learning to play a musical instrument, but they were not taking time to do it. So she was going to spend a certain amount of time each day. So it'll be different for every every person that's whatever makes you feel less stressed and you feel relaxed, but I think setting that goal will help you to do it.

Amanda: That goal and having that accountability partner. We're used to having those for what we consider the really hard things, you know, like working out, or setting a budget, et cetera, but it's important that we have them for self-care as well. Having that other parent to reach out to or that parent liaison to check in to say, "Did you take that half hour nap today that you needed?" is really important.

DeAnna, I saw you nodding during that discussion quite a bit. Is there anything that you want to share there?

DeAnna: Well, I just think you know, when we look at the self-care movement from a woman's perspective and a mom's perspective. What Covid did was it stripped us of a lot of the things that a lot of us have been reliant on. Runs to Target or getting your hair done or your nails or the pedicures. You know things that, that certainly make us feel better, but they don't nourish ourselves long-term. And when you're constantly in a position to serve your family and you're needed in that capacity, to me, the draining was just exponential. You know, my, my husband needed me and still does to support him and

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love him and all four children need to be in their own different ways. And so those semi typical self-care things were just completely stripped. And so I had to really do my own soul searching and my own processing of what does truly rejuvenate my soul and gives me the perspective of every day can be beautiful even in the middle of a global pandemic.

And so for us we looked at ways that we could as a family safely serve others, like dropping off cookies for the police people and sidewalk chalk drawings. Lots of people came up with lots of creative things and kids with these different abilities are still able to participate in those things. So we did the hearts in the window for healthcare workers and my boys just loved all of that stuff.

So those turn out to be some really bright points in our day for my kids self-care as well because then they got to contribute and be a part of things. For me,

I have semi selfishly loved slowing down because I am spending so much less time driving (which I used to love) and much more time grounded at home. So, time outside, flowers in the garden, I became a house plant person. (Laughs) We only killed like three so the majority of them did survive so that was kind of fun. I put on earrings and a little bit of makeup every day. Even when I'm in athletic wear. just because for me, even if my hair is not done, if I've got my big sassy earrings on then I'm ready to take on the day. My kids know that I overslept if I don't have my earrings on. (Laughs) So that's kind of funny! But I've so enjoyed quiet moments of reading and for me, it's been our scriptural studies together. And seeing my kids engage in some of that.

And so I think when those typical things that we would have leaned on for self-care are stripped away now, we do get to take some of these new normals into the future no matter what it looks like. For me that's been a really cherished time as to be able to develop even as a 37 year old woman. (I had a birthday during Covid.) Even as a thirty seven year old woman, I learned how to mow grass. My boys loved that because I got on one of those big lawn mowers and it's like driving around in circles for 20 minutes in the boys laughed hysterically, but it what it showed them was we can all learn new things and that has become a therapeutic thing for me. To have that time on the lawn mower with my music playing alone. I would have never considered mowing the yard "self-care" prior to a global pandemic but it's a nice little reprieve.

So I think it's important to be very creative to look at our husbands' self-care or partners' and our spouses' to look at our children's self-care knowing that they're probably honestly going to be dependent on Mom to help facilitate some of that.

So anyway, I've learned some wonderful self care skills that are just very different than what I had before any of this.

Amanda: But how cool is it that your kids who are used to themselves having to constantly adapt. Right? And change the things and the ways that they do things because, let's face it. The world is not built for individuals who have disabilities. It's not. We have to, we have to navigate places, spaces, people, and experiences differently. And so for them, to see the the adults around them, and their family, and their mom, and their dad have to suddenly adapt to the way that they've always done things. I think that's a really powerful and empowering learning experience for everyone. Right?

I think it helps us appreciate their unique life and the way they live and experience the world from a different lens and for them to do the same for others. Which I think is really cool.

DeAnna: On the days that we handle it well, right? (Laughs)

Amanda: (Laughs) Even on the days that we don't! Where it is that I think that that's also important. I will never forget as a child growing up with cerebral palsy seeing my mom break down and cry because

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she was just physically and emotionally exhausted not only because of having to lift and carry me but to have the having to shoulder all of the struggles and strife that I was experiencing. And just watching her go through that and then talking with her about what it is that she was feeling and experiencing and then of course getting the professional supports and help that she needed to. I think it's a really unique experience that our families have. And a gift that we experience that many others don't get to have. Which is very cool.

DeAnna: Amanda?

Amanda: Yes? Go ahead.

DeAnna: I'm sorry. I was just gonna say I think it's helped my kids to see me have "not great moments". And to say, "This is stressful for Mom." Like I tried to hold it together for everybody. But sometimes we just "feel" it and that's okay. We're not allowed to hurt each other when we're hurting or angry or frustrated, you know with our words or certainly not with our bodies, but it's okay for us to share in that this is just really hard for everybody.

Amanda: Absolutely and saying that out loud and being able to express that is really important also. So I want to close with any words of advice that you have as kids transition into other types of summer activities, or moving into school year activities. Many programs who were typically serving kids as before care or aftercare programs or summer programs are now supporting kids virtually all year long with the shift to virtual instruction. Or kids are transitioning back into hybrid school experiences where they're spending some time in person and some time at home. What tips do you have moving forward that you would use as sort of your cardboard sign? (You know that you see on the internet...) That you would hold up with words of advice for folks as they move into September (can you believe it?!)

Nancy: I know it happened so quickly. I think the one thing that we haven't mentioned yet is giving ourselves permission to feel one way about something and then change our mind. "It's OK to Change Your Mind." Whether it's that we're going to send our child to school virtually, or we're going to or in person, or we're going to remain virtual. There's a lot of very personal decisions and we might change our mind and that's okay. And we have to be okay to support each other in respecting everyone's decisions. And that's a really hard thing sometimes for families and moms especially I think, to make their decision and feel confident in that it's the right one and it might not be the same one as their peer or their next door neighbor. And, and that's okay. And I guess the other cardboard sign I would have is "Don't Forget Laughter." If things are really really bad, we just turn that radio on our favorite song. We have a dance party in the kitchen and it just makes the world of difference that we use humor and laughter to kind of break things up a bit.

Amanda: I love that! I need to remind myself of that daily, especially when you're in those hold your breath moments, right? And I think we're all having those as educators and as healthcare professionals and as parents and advocates right now as we find ourselves holding our breath so much. So just letting it out and letting yourself smile about what's going right. Or even better...what's going wrong.. and going from there.

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I love what you said about that it's okay to change your mind. I think if we remember that the decisions that we make, especially in working with and being a families of kids with disabilities, is that that decision is right at that time and making a change simply shows that you're making an informed decision about what you have at another time, right?

It's, it's based on your learning. It's based on your experience. And it may be completely different from what the other one was. And it probably should be. Right? if we're not making different decisions progressively. That means that we're not growing. That means that we're not learning. So I love to see family experiences, and parent decisions, and school decisions change over time. Because it simply shows that growth which is really awesome!

Carol, any advice that you have and going forward as we move into September and new school and new social experiences?

Carol: My cardboard sign would be "Cut Yourself Some Slack". Because having a child with any type of special need is difficult anyway, and it's especially difficult during Covid. And even with myself, I don't have a child at home. But when Covid first started, I found myself sleeping a little bit later. And then I thought I cannot do this. So I went back to I've got to get up by this certain time every day. And then I thought, after I did that for a while, I really don't you know. It's okay some days for me to get up early and there are other days it is okay for me to sleep a little bit later. And that's okay.

If your child doesn't get his work all done in the day that he's supposed to get done. That's okay. And I think going in too knowing that kids probably are going to regress a little bit in their learning just because this is new to all of us. It's new to families, it's new to teachers.

And, and that's okay too. You know, they are going to learn and they're going to get where they need to be. It might take a little longer than we planned but we're going to get there so, "Cut Yourself Some Slack".

Amanda: I love that! And we also need to remember...regress compared to what? Right? Okay. This? This is baseline. This is now step one for everyone. No one has experienced anything like this ever before or started a school year in this kind of environment ever before. So I think we need to keep a really open mind about what it is that are those priority skills and what it is that priority path or scope or speed is that our expectation for those skills are because it's going to be a whole new ballgame. And again with the understanding that there's a level of social and emotional support as well as trauma support that kids are going to need that are going to impact an interface with their school based skills in ways that we've never known before. And so our priorities and our benchmarks and those yardsticks that we have will change. Because they have to. So take a deep breath, and cut yourself, and them, "some slack".

Right? I love it!

DeAnna, we're going to end with you. What would your cardboard sign be? What are your words of advice?

DeAnna: So I'm going to be with Nancy and hold two of them. My first would be I mean, we've said it in our friendships, my husband and I say it all the time. I say to my parents every day, "Grace Upon Grace". It feeds right off of what Carol is saying. Just "Grace Upon Grace". Because for my husband and I, we've just decided that what matters in all of this is our boys' mental health and their character as men because that's what, and my daughter as a young woman, because that's what they're going to be as they grow out of this. So "Grace Upon Grace".

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And then when we talk about the school environment, "Communicating As Much As You Can As Kindly As You Can." With the school, advocating can kind of feel a little bit gruff and harsh sometimes even under the best of circumstances. But even I would argue that every child has experienced a major trauma. And that any child with a different disability has already lived in a world of trauma before now. So we're compounding that. So advocating for that can often feel very harsh and sometimes communication is strained or things go unsaid and when it comes to the school environment and looking into that just communicating clearly. "This is what we're capable of doing." "We're a family I can't replace the teachers." "Thank you for all you're doing we will do our very very best." Recognizing that the schools are doing their best. None of them went to school for this. They weren't trained as professionals in pandemic schooling. So we're all doing our best. It's just that sometimes those things kind of bump into each other and the IEP world anyway, and then when you add a global pandemic, sometimes I think it can just feel harsh. So communicating as clearly and kindly as we can with our school professionals so that our kids are supported as they can be to learn on whatever path on whatever trajectory that looks like for the individual kid is important. So, I'm going to be like Nancy we're going to double fist our cardboard stands on the corner. (Laughs)

Amanda: I think across the four of us we'd all be able to hold up, you know, each other's signs and get our words out there to just remind everyone that inclusion especially is not relegated to a particular space or a time. Inclusion is about building relationships and building connections and community and understanding that we now as a community of professionals and families of kids with disabilities are here to take care of each other more than ever.

And that's really powerful to know that even an isolation, we're not alone. And if you don't have the words to speak your needs, or advocate for your child, or you don't know the resources, or you don't have the tools, someone does!

And we as parents, we as professional organizations, we as NIP, we as Family Support Network we can make those connections and have those conversations to remind each other that we really are in this together and that if I think is more important than ever as we move into this next phase of what it is that this looks like.

So, I want to thank everyone for their discussion and their support today! For everyone who is listening I'm giving a silent round of applause to all of our discussions and thanking you for your experience and your expertise for your time and your support.

I am going to remind everyone as well that in addition to the transcribed version of this discussion, we'll have a resource list for you with the recommendations and highlights that have been mentioned here and then others for you to access in general. And seek us out. Connect with NIP go to our website at www.inclusionproject.org and I'll make sure that you get in touch with everyone that's on our call today and folks beyond so that we can tackle this tough time together.

Thank you so much! Appreciate your time. Take care and be safe everyone!
(Everyone waves & claps.)

Nancy: Thank you Amanda. That was a great hour!

PLEASE NOTE: Responses listed here represent information provided by NIP partners and participants contributing to the Coffee Talk series—lists are not exhaustive or exclusive.

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For more information, please visit inclusionproject.org/covid19