

REALTIME FILE

AUCD
FAMILY LEADERS: WHAT THEY ARE SAYING,
AND HOW UCEDDS AND LENDS CAN HELP

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>> ANNA COSTALAS: Hello and welcome to “family leaders, what they are saying and how UCEDDs and LENDs can help.” I'm the resource manager here at AUCD. I thank you all for joining us today. Before we join, I'd like to address a few logistical details. Because of the number of participants, your audio lines are muted throughout the call. However, you can submit questions at any point during the presentation via the chat box on your webinar console to the whole audience or to the presenters only. This entire webinar is being recorded and will be available in the library following this event. There will be a short evaluation survey. We invite you to provide feedback for future topics. Please join me in welcoming Dr. Mary Beth Bruder to say a few words.

>> MARY BETH BRUDER: Thank you. Thank you to the panel who will have their formal introductions in a few minutes. I thank you all for being with us. This is such an important topic, especially now. I am going to take you through a very fast ten minutes to summarize what we have covered in the COVID-specific webinars we have done under the early childhoods for the past five weeks. They position us for today. I apologize, Darla's name isn't there. I will introduce her. We have a panel of family members that will help us understand how we help families access and participate in special education and early intervention for their children. Today's panel is special, but first I'm going to bring you up to date on what we've learned and mainly focus on archives. You'll see the summaries of the wonderful people who have talked to us. Next slide. The first person we have was Maureen, Greer. Next slide. She summarized the issues happening under COVID and in particular for infants and toddlers. Referrals are down, eligibility is a challenge, service delivery in terms of the depth and intensity of services is down, transitions is a question mark, though there's lots of wonderful ideas out there and states doing great things. Finance is a big concern. Next slide. This is the example of referrals. If you look in terms of how much referrals have fallen off, quite a bit. Next slide. And if you look what does this mean, it

means there's going to be financial impact, including loss of state revenues, but importantly, loss of providers. Next slide. Her closing comments to us was specifically how you sense UCEDD and LEND could step up to we don't lose it. A number of very specific roles. We had Joan who spoke to us in regard to the special education director's perceptions and how UCEDDs and LENDs could help them. He is the Executive Director. Some of the issues he pointed out that his surveys have is that we have a number of issues in making sure -- is being provided. Next slide. I will not read all of these. These are reference. I think more importantly, if you look at the first one right there, 43% of participants said that parents had asked for special Ed during the pandemic. Next slide. His very specific messages to us, we could help special education, local and state, with issues around the students. Best practices in virtual delivery of related services. Next slide. Parent and family engagement, which is what brought us to where we are, and assistance and professional development for research and future issues. Next slide. Last, we talked about family voices from the families and the colleagues at the Miami center presented a survey they had done looking at risk and resilience. They had a very rich sample, and a sample of families telling them exactly what they needed. Next slide please. This basically focused on a variety of needs that families identified, including the urgencies, their feelings of confidence, their causes of stress, and the types of issues. Next slide. We then presented survey they had done up here in Connecticut at our UCEDD, which is a broader base. Next slide. We had a population that was primarily middle aged. Next slide. And the children were primarily students of later elementary and middle school. Next slide. Here is the issues that they identified, and this is the group, about 505 to 509 who answered these. Concerns about the well being of family members and physical health and changes to education, online effecting services in special ed and delays in education. A lot of very specific issues. Big two needs of your family right now, these were open-ended and ranked to special ed and money and finances. In regard to a smaller group, Molly Cole, the associate director here at the Connecticut UCEDD and Darla Gundler, have been working with a group of families, and we call it the Family Cohort from the division of early childhood. You can go to the next slide. This is the states they represent. They have been working with them consistently for over a couple of years. Next. Next slide. That was a double slide. The five concerns, overwhelmed, stressed, and exhausted, protecting the health and safety, accurate and realtime information and guidance, step back and see childhood family strengths, and allowing the family to be the family, and that's what those families wanted. Next slide. They left us with ten things we could do because it's not business as usual. We need to understand that and start acting in order to the responses families want us to do. Next slide. I'm not going to go through all of these ten. Except for UCEDD, we have to take the 101st seriously, embed disaster objectives into our core grant. Next slide. Most importantly and what led us to have this second webinar for families was this quote they left us with. We have to rise and do better. I can think of no other opportunity than today to talk about that, very bluntly and very honestly. We have gone through two weeks. This was planned well before the crisis we find ourselves in because of racial relations and all of the other things we're watching on TV every night, and we're feeling this. I am a mom of four daughters who were adopted from China. For the first time, they're scared. More importantly, I wanted

to have -- I'm sorry. Molly Cole, who has taught me so much about what life is about for people of color. I wanted to turn it over to her so she could introduce everybody.

>> MOLLY COLE: Thank you, Mary Beth. You're right. This is a very timely opportunity for us to have a good conversation about what we can do as UCEDD and LENDs in early childhood, particularly seeing the impact of the last two weeks and the conversations around race -- have led us to. As Mary Beth said, for me, this is very personal. I married a man from West Africa. I have -- I had three wonderful children. One passed away. Two wonderful children of color and two grandchildren of color. We've gone through the experiences as everyone on this panel, I'm sure has as well. Indiscriminate -- police, hate mail. Interracial couples in the 70s were not welcome. Lots of worries about my children when they went off to school and how they'd be treated and where we'd live. All the way to having my son inform me after his year and a half in Ghana that the reason he left the country is he could then indiscriminately be stopped by police seven times over the course of one summer, once at gun point, never issued a ticket or warning. Finally decided what he needed to do was to get away from the country just to survive, so he left for a year and a half and lived in Ghana with friends and went to college there for a year and a half and came back. I raise that all with you just because as we think about what LEND and UCEDDs should be doing, how we do a better job of committing to people of color in leadership roles and determining our research and determining our training and impacting our communities. You're going to hear from powerful families in just a minute, and I really want you to take them to heart and think seriously about what we need to do to make the world better for our young children and families as they grow up.

With that, I'll turn it over to Darla to introduce the panel.

>> DARLA GUNDLER: Thank you, Molly. It is my honor to introduce this panel of family members that we have today. First, it's the passion that drives us all, but the passion that these three women shared also is just -- it's unbelievable. I'm looking forward to the conversation with everybody today. First off, we have Chioma Oruh. Chioma lives in Washington, D.C. and she's the mother of two brilliant young sons with autism who currently attend non-public schools. They have attended the DC public schools and public charter schools. If you know DC schools, you understand what that means because they have a public school system. Dr. Oruh is an experienced education advocate working over two years under the supervision of skilled attorneys to build cases that protect the educational rights of students with disabilities and versed in federal guidelines articulated section 504 in ADA. Then we have Karen Lewis, joining us from Georgia where she lives with her husband and son Cyrus who is a -- who has -- he is non-verbal and has a neuro developmental disability. She currently serves as the chair as well as the secretary for the local ICC. Georgia's Babies Can't Wait program. Going down the coast, we have Doris Tellado. Her youngest son has Larsen syndrome, effects the development of bone throughout the body. Also has autism and hearing loss. Doris works as a specialist at the University of Florida North Central Early Steps which is heart of the early intervention program for the State of Florida, and she's one of the specialists there. It's my honor to introduce Rud and Ann Turnbull. Distinguished professors at the special education of the University of Kansas. Between them, they've authored over 40 books, over 500 articles and chapters. In 1999, selected by the National Preservation Trust and developmental disabilities of 2 of 36 individuals who

changed the course of individuals with intellectual and disabilities in the 20th century. Wow. Their greatest learning come from their son Jay, who experienced multiple disabilities and whom they've always called their best professor. It is my honor to be here with these amazing presenters. I now hand it over to Rud Turnbull who wants to start us off.

>> RUD TURNBULL: Good afternoon, everybody. It's not easy times.

I wanted to talk with you about -- talk briefly about the concept of dignity. I'll try to put it into the theme of the last week.

As we think about early childhood services and we had a wonderful overview from Mary Beth, it's a question that came to my mind.

What does this thing have to do with the child and family's dignity? As we have looked at television and read newspapers over the last couple of weeks, what I puzzle about is not a criticism of the movement, but what I am puzzled about is this.

Where are people with disabilities included exclusively within that movement?

I think as we pursue specific social justice, we also must pursue, and we must be the people to do it because we are the leaders. We must also pursue justice for people with disabilities.

With that, let me turn our attention please to the notion of dignity.

Darla, I don't know -- or Molly, I don't know whether something not put on the slide. I think not. But there is a document that I prepared. It's two pages long. It would be in your archives.

Dignity refers to feeling worthy, honored, or esteemed. This is the opposite of stigma, dismissal, evaluation, and everything else. My special concerns, as I was trained as a lawyer, is how dignity fits within American law.

It begins on the international level with United Nations. It comes down to our federal government.

There is a strand of anti-discrimination -- and statutes that do not use the word dignity, but that themselves reflect that concept of dignity. Let me say again what I said just a moment ago. It is up to us, as we read the statutes, as we read the procedure and practice manuals, as we train people, to put dignity on the front burner.

Dignity must be an indispensable law of early childhood services and those who support the children and the families.

Why do I say that? There are three quick reasons. One, because a child with a disability, no matter who that child is, no matter whether the child has a significant disability or not, that child at the moment of birth has inherent dignity.

What we have to assert is the inherent dignity of all people, particularly those with disabilities. That all then becomes inclusive of the justice movements we have now. Second, we pay attention to dignity because dignity leads to trust between people. Those we treat with dignity learn they are to trust us. Finally, dignity is a measure of how well our laws and policies are performing. It's a measure of accountability and compliance with the law.

I have a little challenge for you. As you listen to these three brilliant passionate parents, I want you to write down occasionally what they say that resonates to your understanding of dignity.

It's inside of everything each of them will say, but just think about how we understand them from a construct of dignity.

We will begin then to understand how our business, our pursuit of justice, must be based on our claims to dignity.

That's all I have to say at this time. Thank you for listening. Thank you for the work that you do.

>> KAREN LEWIS: An a, do you want me to start?

>> ANNA COSTALAS: Yes please.

>> KAREN LEWIS: Okay. Slide up -- just to let you know.

Hi everyone, first of all. Thank you so much for having parent voices be heard.

That is so important. It's so important for what you do, and it's important for the families, and it is the center of everything you should focus on.

I want to take time and go back to the slide Mary Beth had. The first couple things, we talked about in the past webinars being overwhelmed, facing your family, need for accurate information. I will talk about the silver lining I saw, and allowing family to families. The framework. We all know how everything felt in the beginning. When COVID hit, there was little to no time to prepare for anyone. This is just a reference from what I saw. Of course, I do hop aa lot of chats just to keep up on what parents are saying. First of all, I noticed -- glaring. Even though there were issues with typical and atypical children, the bigger issues were with atypical children. That concerns me, and you may hear thunder because Georgia is going to have a storm in my area.

That concerned me. It's a lost opportunity. When COVID hit with no warning, I came home with a stack of papers, probably 2 inches of material that was run off. The material was light because when my teacher got a chance to get to the copy machine in school, it was light. Imagine this. I'm coming home with this stack of paperwork to try to figure out how to adapt to a non-verbal legally blind in the left eye, no depth perception, near-sided son, to use a computer, which is something that is not in his normal scope. That was very eye-opening, and I would have to say in listening to a lot of what everybody was saying, I heard these comments. Parents overwhelmed. Parents are exhausted. I wanted to take that comment, first of all, and the part I want to stress, these are the same parents in the school system or in early intervention that you interacted with at all times. Those words were not being said at that time. So, what overwhelmed them? What stressed them out?

We have to look at the delivery method. Yes, that goes to the point of accurate -- I think it was accurate realtime guidance.

I will say, and then for the safety of the family, we couldn't get out -- I will say just to back it up, the beauty and the silver lining was the teacher I dealt with was phenomenal because she took the IEP and she realized in working with me as a parent and working with other parents, the dynamic changed. It was not her working with her student. It was her working with different parents from different backgrounds, and she had to work with them to adapt what needed to be given to the children.

The silver lining with me was that I was able to see that little young man of mine, that he's brilliant. I say that that his IEP did not reflect it. That is because -- we can get into IEPs, but just to say on a high-level, it talked about the deficiencies. I got a chance to see in working with him what he is able to do.

Going back into the school system, whenever we open again, that's something I'll definitely revisit with his IEP. I think in the past webinar I wanted to point out I think we said something about due process, taking a lot of that from parents.

I would caution you to wait until school starts. When we talk about everything that's going to, you haven't gotten to the crux of how the parent is going to interact until school starts back.

I'm looking at notes to make sure I don't pass anything. The next part I wanted to talk about was the messes. The mess, to me -- or what stood out to me was the word "partnership." When I talk about partnership, when school was in, there was a parent/teacher relationship. That's different from partnership. The parent/teacher relationship was more of a relationship where the teacher shared with the parent or touched on things with the parent, but when the schools closed -- and this goes for typical and atypical children. What we saw was a fail. The system we had set up, the school systems we had set up, did not address our children with special needs. Did not address it adequately, I would say, meaning that when we had a step back and our child was at home, that teacher then had to turn and work as a partnership. It had to be equal because you have to work as a partnership to move forward. Whereas -- and another thing that struck me was the amount of work -- and this is typical and atypical. Think about it. The amount of things that came home to a parent, that definitely didn't come home to a parent. Conversations that were had. Typically, weren't had. There's that kind of overarching -- (Audio cutting in and out).

What do we see -- (Audio cutting in and out). Internet is unstable. Hopefully you don't lose me.

We were missing that partnership. To me, my focus is in early intervention, so I do work with parents. Partnership gives a voice to the people unheard -- to be better, to work for a system to be better.

Partnership brings unity. I used to use partnership the same way you'd probably use dignity.

When you have that partnership and dignity and equal opportunity to work, I think you will see that a lot of the things that we said we -- Lynn's program. That would help.

The other addresses issues, and I will definitely not take up all the time. Realtime guidance. I'll go back to that on the overwhelming. Another thing that I can speak to is when it happened, we had websites and -- granted, it was to be helpful, but we had websites thrown at us as parents. You didn't know what website to go to. There was not a centralized place or direction or words. Everybody was throwing things at us. Hey, here for this, here for this. A lot of parents shut down because there was too many directions you wanted them to go. I only have one job. Assume a parent had two jobs, or one parent in my class had two children with different abilities and two different classes needing special education.

How does that world look to her? If you take away anything from what I'm saying, partnership.

I think we can move the needle when we look at the partnership that we have and it's an equal partnership. How can you start a partnership if that person -- (Audio cutting in and out). It's a simple conversation.

Coming back to school and we noticed that things exactly didn't -- how should I put it? It's a conversation to learn from. Can we ask you what is the best way? What is a good way for us to do X, Y, and Z? That is probably the take-away I would say. I want to read something. This was written in 2014, and I'll end it here. This was written to a lady

that worked with me on being a person that I am. If you would allow me to take a few seconds, I want to read things to you, and I will close it at that.

I wanted to say, this is -- she gave they permission. Thank you for taking chance on a mom whose only claim to knowledge and early intervention was a class in child development in college. Any life experience class, 101. Little did I know at his birth that he would be my best teacher. I have learned to become an open book -- may learn, and in that process, I have touched deep within myself to analyze -- so I could understand other family's hopes, dreams, sorrows, disappointments, celebrations, to become a better resource to them. I talk about using the slides to help people understand. But I will always remember most the one simple gesture that -- from my son. It was after my husband and I spoke in one of your classes. I took fascination with her hair. She has white hair and -- if you can visualize this. A little chubby boy she was holding. This is a professor holding a little child in class. It is not a traditional professor giving information. He took his little chubby fingers and starting running them through your hair. I told him no, but he stopped and said let him explore. You did not mind in the least, but instead encouraged him. This has stayed with me for two reasons. One, we have a preconceived -- I need you to be approachable, but you showed not by words, but by actions of your understanding and compassion of children for special needs. This is refreshing to see someone instinctually react to a child's curiosity. It is not something that can be taught in the classroom with a book. A chance to make this child happy. The second take-away was more important. He showed me a great lesson by trying to stop a harmless interaction, by a child that has special needs. I was interrupting a natural learning experience from happening. Simple interaction allowed him to explore and become more aware and learn in the process. I could have shown him hair on a doll, and not gotten where you did in a few seconds. I now think before stopping and correcting him if it does not hurt him or offend anyone else, he is simply trying to learn. Please know that what you saw -- September the 30. This is not a job, but something I think -- I would like to think I would help him make a difference, however small it may be. In some form or fashion, I will continue to pay it forward.

Developmental delay and disabilities in children will not decrease as years come, but will likely increase as more knowledge becomes available. How we address these issues will effect how we shape the future of not only these children, but society as a whole. Your struggle for inclusion will lay the -- services for our children and better equipped teachers for our teachers, therapists and other professionals. I want to end it there and the reason I read that letter is two things. A, it talks about the partnership, and it also gave me that voice to be where I am today. Also, the inclusion and having the parent voice -- helps society thank you for giving me that time.

>> All right. Hi.

>> Hello?

>> DR. CHIOMA ORUH: Can you hear me? All right. Good afternoon everybody. Thank you all for taking the time to even be here and listen to what we have to say. I'm very grateful for the framing of dignity and partnership. These are things I'm constantly grappling with in myself and in my work. Next slide please.

My mothering journey. The pictures you'll see throughout this are pictures I took pregnant with my second son, Jedi. I have found function for them now. Part of my journey started as an advocate and as a parent advocate, specifically, I had my first son

August 2010. August 17, 2010. I started my PhD program August 20 whatever, that same year. My PhD journey was literally coinciding with my mothering journey. I ended up doing my dissertation on the crisis in the democratic republic of Congo and framing it on this concept of mothers being attacked because in Congo, if you don't know, it has the greatest agricultural resources in the entire world. They can feed countries for years and still have enough for themselves, but they also have mineral wells, cobalt, uranium, oil, a lot of great natural resources. The people historically have been women, like women have control of the land, have control of how their resources are distributed. The rape crisis, I was trying to understand why it was happening inside and outside of combat. They were working that land. They were the value of that land. The systems of culture, the indigenous systems were centered around that land. It really sent me down thinking about mothering, as I was mothering, having my first son right before I started my program, and now having my second son closer to the end when I was ending my PhD journey.

The background noise are my sons in the background.

Mothering is something that is very important to me and critical to me.

I want to frame this in how I carry out and why I'm so passionate about family being part of this process, indigenously, and what I've understood -- I'm also Nigerien, first generation America. Came to the U.S. when I was 9. Even indigenously, I'm just going to try and ignore because my mom is around. This is real life. (background noise). Actually, hold on one second.

(Standing by)

>> DR. CHIOMA ORUH: Interesting timing. Sorry about that. Again, this is real life. This is what my life is, and my boy is literally having a melt down over an iPad. My mom is there with them.

Mothering, again, my mom is mothering. I'm mothering, she's mothering, all at the same time. Next slide please.

For me, mothering is not just about mothers. At least what I understood as the political outfit of mothering. The grounding of why mothering is essential and important. One of the theories I ground in my dissertation was on African matriarchy. He essentially says that it's a concept that when mothers are prioritized in society, it's never meant -- at least in the African context -- a domination of women controlling society. It literally has always meant a condition in which women have been prioritized because they're so in close proximity to the next generation for the children.

These are pictures of my father who recently passed away from coronavirus, who literally mothered me, years my mother was not present working on different projects. My father was there to do a lot of the early nurturing for me and my brothers. (background noise).

In that respect, I want to honor him in this moment. Next slide please.

One more second please.

>> DR. CHIOMA ORUH: Okay. One of the central lessons I learned was that the family is a political institution, right? Families are constantly -- in any condition -- coronavirus, lock downs, no lock downs, poverty, homelessness, any kind of crisis that a family faces is extremely critical. You can leave it at this slide. It's extremely critical we center what we're doing on families. These are pictures of the women that mothered me. My grandmother and my mother. These are pictures of my son. The one circled

here is the one having a major melt down as we speak. (Laughter). He's 9 years old now.

We recognize that with any American context, as we center it back here and back home, neither men nor black women and people of color in general have really any control or stake in saying what happens with themselves, their bodies, first of all. Body is really important in the disability space because that's where we understand a lot of things that happen around ableism and discrimination. Beyond the body, that's the structure the bodies are most intimate, and that's within the family. Being an immigrant African, I've had to do serious learning what it means to be black in America and navigating the system as a black mother in the American context. There's been a lot of new introductions, new experiences, new things that are shaping my own reality through a black lens.

When people see me, they may or may not know off the bat, and whether -- I believe fundamentally in global black identity, but within the context of America, there are things I cannot assume that people would think when they see a black mother, or black single mother, black single mother of two boys with autism. I've encountered biased, discrimination based on a lot of assumptions around who I am and what I am and where I am. It's always throughout my life, to go throughout life in that recognition.

When I center around the black family and African American family, I'm talking about the tradition African American family in which me as a first-generation black American has to fit within that historical context and assume some of that historical trauma, which now my new trauma in navigating the system of care. Next slide please.

One of the things that I've picked up along the way is this really great book. You guys should pick it up. It speaks about intersectionality particularly from the black woman's experience and centers her thought in this particular thought around black mothers, black mothering, and the power of that. Within that, it was not the first time, but I think within the analysis, I also recognized part of the baggage when one is walking into any environment, into a school environment, into a doctor's appointment, into an SSI evaluation, whatever it is that you are facing that you'll need support, this is this baggage of reality of America and black identity in America, and disabilities fits into that. That is the one hand report, classic concept of where in the report, which is actually titled the negro family case for classical action. When families are seeking power within early intervention, for example, I got my certificate in early intervention from Georgetown, center for child and human development. One of the things that struck me in the literature we were reading and the opportunity to unpack was the concept of the unbalance of power between the provider and the receiver. All families are not equal. All families are not equally powered. When you send in a therapist or any kind of intervention in the home, which is great, we want to promote all of that, we have to recognize there's an imbalance of power and historic trauma. The provider is a mandatory reporter. Whatever their triggers are about what should qualify as reportable, really becomes something that can shape and determine the course of a family's entire life. Same thing with the schools. Bar families from schools because they're trying to advocate for their kids and not showing up the way the school wants them to show up. The more I think, I think about in 1965, this report was speaking about the so-called breakdown of the black family. I called it so-called because, again, I did my dissertation on patriarchy, in which the mother is literally the head of the

household. The bantu, in terms of language groups and etiology, not far from the people in eastern Congo. We share a lot of practices in which I've observed in eastern Congo. The mother is the head of the household. It's unquestioned in a lot of African societies. Even today, with colonialism, the mother runs the house while the father leads the family.

In context, sometimes fathers have multiple families, so running a house is a very important thing, and it's an honor and value mothers have. Mothers, being in the space where if a mother is coming as a single mother -- and I am a single mother now. I started my journey coupled. I go to a meeting by myself. There's an automatic assumption that can be made, and I have felt, and I know I've supported other families as an advocate that have been met with the same discrimination. The child is acting out because maybe there's no father in the home, or you're here saying you want X, Y, Z, why is your support system? Oh, you poor thing. Right. There some box you'll fit in that won't be telling the truth of the story. Next slide please.

I'll try and breeze through because I know I had interruptions. I should ask for a check here, when you want me to stop. I'm not tracking time. I don't know when I need to keep going, but I'll keep going until I'm told to stop.

In navigating the system of care, I've learned -- a picture of my boys. Again, the one kissing my oldest son. It means fearless. My younger son. His name means integrity.

Between the two of them, I know that part of my fundamental lesson, the lessons of my mothering, has been really -- it's not about just transforming our children so they can prepare for the world, which is what interventions mean, right? We want to intervene so the child can be healthy, safe, have access to different things. We're measuring the child's success, the child's growth.

But truly, the real work is in the system and how we measure the system.

To that end, the world must work for our children, bottom line. Right? Not just we fighting so our children can be included into what -- literally, fitting a round hole into a square peg. The work is broad.

Next slide. I'll breeze through these few slides now.

This is important. I think it's considering the times we're in. I want to note when we're talking about equity and access, some of the things I just touched on, I ground it in -- particularly mothering. The elephant in the room is yes, we want fathers to be involved, and yes, we want to be accommodating the language talking about fathers, but this is mother work and mother reality. In one of the first slides, mothering is something that women of color have. We're not afforded motherhood, per se, at least as some feminist scholars would say. Mothering is literally the action of constantly mothering our kids to keep them safe, to keep them alive, to keep them well, to keep them having access, to have in inherits they can receive from us and the world. My son has autism. Intellectual disabilities. 48% of people with autism have intellectual disabilities. We know intellectual disabilities is broad and fits a wide spectrum of people that are autism and not. I'm centering this around autism because that's my reality, and it's a reality of a budgeting number of people, and I believe that spectrum fits a lot more people than we allow.

In my native environment here in Washington, D.C., for some reason, the concept of autism is very limited. I want to say that having one minute that at the bottom line of equity and access, we as parents -- those who are mothering, are constantly fearing for

the safety of our kids, right? When I started my autism journey as a new mother, my oldest son was in preschool, or in daycare. He received services and transitioned quickly into preschool where he was actually in a school environment. He was constantly being sent home. That's actually what led me to take action, because it became a burden on my capacity to function in the world when I'm constantly getting calls to come pick up my kid or X, Y, Z. The reality is interventions receives now, his access, my level of knowledge of what to advocate for, my ability and other family's ability is really a measure and marker of his survival. Not just his educational outcomes. Not just his healthcare outcomes, but it's lifespan. In fact, people with autism and intellectual disabilities and mental health conditions are more likely to encounter the police, right? Than your typical person.

Oftentimes, that encounter between a person with an intellectual disability or autism specifically, can end in physical harm to that person is possibly death. We can breeze to the last one. I want to save this time.

My time is up. We can come back. Hopefully we'll have another opportunity.

>> DARLA GUNDLER: Doris?

>> DORIS TELLADO: Thank you so much, Chioma and Darla. I'm going to try to speed up to you can wrap up. I know you had something really wonderful to share with us. My name is Doris Tellado. Here is my family. My husband Jose, my parents, Maria. My oldest son who was graduating last year from high school. My youngest one who has a genetic syndrome that really put his life in a lot of stress. We try every day to make his life a happy life and a good life and for him to have a life of dignity.

I have to say, Dr. Ann and Rud are always in my mind when making decisions for my son. The first time I heard them talking about dignity, it really made an impact on me, and I follow that. I try in my work to do the same.

Today I'm going to share a Latina perspective, and we can move forward, Anna. On COVID. I'm going to give you a little bit of information on how -- in our community. The Latin X community, I prefer to call, to be more inclusive.

We are a multi ethnic, racial, lineal, generational. We come from different countries in Latin America. We have any races -- white, black, native, we have African Arab descent. It is very broad.

We are multi-lingual. Spanish is not the only language. There's 2.5 million people speaking -- and others that we are hoping to -- because they tell a story that cannot be told any other way. When I say generational, you will laugh and say every culture s but there's an important aspect that Chioma mentioned before. When you're first generation in the United States, it makes a lives on how you perceive things, how you react to things, and how the world perceives you. We are approximately 60 million Latino people who identify as Latinos or Latin X. 7.6 million are undocumented immigrants. This is very important. If we can move to our next slide.

I think it's important to know that there are many challenges. I don't want to spend too much time on the challenges, but I think it's important to know the challenges that we face before COVID in order to understand how we can impact our families during a similar crisis or what we expect will be a prolonged COVID crisis. Some of the characteristics we face -- and it's common for all minorities in this country. Limited financial resources. COVID is something we experience every day, close to us. I want to say before I say this, because we are so diverse, you will find groups that probably

are not -- have less or more of this. At some point, either by our connections or directly, we have been effected by these factors, and we are protecting the same challenges. Low-income jobs were the jobs hit first in this pandemic. Jobs with a high rate of Latino Latinx people working. We are talking about construction, agriculture. We all heard the stories of the processing plants where many of them were Latino workers who -- afraid of being deported, arrested right there in the plant. Now we're afraid also of COVID because there was not enough good conditions for them. Crowded places, no soap or access to water in many of the farms.

This reflects on the factor, our families are urban. The dynamics are different, but they all have many things in common, especially limited access to things like healthcare. They were talking before about the expectations when we talk with a doctor or teacher, especially going to a healthcare. I experience this myself. This is how I learned English.

I went to see my doctor, my son's doctor when he was little. The interpreter said something that was not what I was wanting to say. That was it. I was not wanting to have an interpreter. I want fought really hard to say -- and I remember what I was wanting to say. One doctor was pushing me to have the interpreter say no, doctor, you mean we are going to talk. The appointment was taking double the time, but I said no, he needs to hear my voice. I'm not going to let another person say what I have to say. There was a presumption I was not understanding, talking louder because I was not understanding.

Imagine when you are in the middle of a crisis where -- and (Audio cutting in and out). The internet.

Access to many of these things, especially in our rural areas -- and I'm sorry if my connection is unstable. Hopefully we'll get back. Yes.

Transportation is a huge issue in our rural areas, moving from point A to point B when you have 20-30 miles in between, it's difficult. Safety net, especially after the limitations that were put on safety net and I'm referring to services like Medicaid, food stamps. Many of our community is afraid of applying because even if you are a permanent resident, like my husband's case, from the Dominican Republic. When COVID hit us, we decided not to apply for food stamps, even when his income went to zero. We were looking for him to become a citizen, and we are concerned about how that will impact his application because there's a movement to prevent many people to naturalize if they have history to applying to any of these services.

Information. There's always literal information in Spanish. There's a language barrier at all levels. Very little information also on the official sides. Information, it doesn't tolerate vacuum. When you don't have reliable information, someone will come up with some idea of something you can drink to prevent COVID -- that's what happens when we don't have the reliable information. Our families will look for information, but many of them are not necessarily in areas that have access to even a pamphlet in Spanish.

I always say Florida is interesting because we have Miami and the South Florida where there's a lot of Spanish going on, and you need to know Spanish to move around. I live in the north part, and this is very different.

There's a huge barrier for families to get access to information.

In technology, we saw many families trying to access some intervention, didn't happen because -- like you're seeing with my internet, and I live in a more urban area, it

is not reliable, and it is really difficult for families to feel comfortable, and it was never offered before. Fear is the other factor. I think it effects everything I mentioned before. Many of our families, especially those migrants, undocumented, they are afraid of at every step. Not only do they not have access, but there's fear if I get sick, my job doesn't have any benefits, I won't get any healthcare because I'm afraid I will be reported as someone and deported right from the hospital. There's many families who cannot drive a car because they don't have a driver's license and they're afraid of being arrested. Fear, even if you're an American citizen and look like me -- my aunt who looks like me was stopped in Jacksonville. Didn't speak English. She was an American citizen, but she couldn't say. A difficult situation.

I won't compare to the stress of the African American and black brothers and sister experience, but we have our fair share of bias and discrimination. It's something we live every day with.

So, for my next slide, I want to talk then on the strengths. Yes, we all know the hard situations that many of our families face, but what I find -- and we have been hosting a group for families here in Florida. Also, in collaboration with the parent training center and the Florida virgin island for deaf and blind collaborative. This program has been wonderful because it allowed us to meet with families directly where they are.

We have phone calls, and we meet weekly. I found wonderful things.

Our families show enormous resilience. At the core of that resilience is more than X or X program.

The core of the resilience are the informal supports that have been developing throughout the years.

Families in all varieties, not only I have -- I have a more tradition family. We have families that are grandparent center, we have single parents, mom or dads, we have aunties. There's a variety of family composition, but they have strong sense of belonging and being part of that unity. Also, the responsibility to the community. Community is real. It's another person. It's not something ideal. When I asked my parents to provide some feedback on what helped them to go through this crisis, the response was fantastic. They said I feel that the plan that we placed at home, that we work with our children, helps us not only to -- to help the entire family system, but also to help our community. They feel that's their responsibility. That's something that caught my attention again and again. They were saying it's my responsibility to take care of my family and take care of the others. There's a sense of hope that I want to talk more about in our next slide, and we are close to finish.

What is you -- can do for our families? I will say at the center of everything is recognizing the dignity of the family unit and the organizations they represent. I will say, for me, I would like for UCEDDs to each out to locals to meet our organizations doing the work. For example, from that same column, we have parents who met in person, but helping each other because they met on that call and able to take food to another parent on that call who had COVID. That happened as a product of their initiative, so I think it's important to promote family leadership. I'm saying family leadership because creating tools and curriculum that will address the family. Support them in their efforts, their initiatives, building on their strengths and treat them as equals. I'm going to finish with a story I was going to tell before.

When I went to their home, their home was in a difficult situation. I was looking at all of this and thinking oh my god, they really need help.

I sat and talked with this parent, and she taught me something that will stay with me forever.

She said I'm grateful. I was having a difficult situation in my country. Now I can feed my family and my children are happy. It taught me to find hope and happiness in the most difficult situations. They are thriving because they have that in them. They believe. Those are my 2 cents. I will hopefully have more opportunities like this later to talk. Thank you.

>> DARLA GUNDLER: Thank you so much Doris. Thank you for cohort members. Ann and Rud.

>> DARLA GUNDLER: You're on mute, Ann.

>> ANN TURNBULL: I am. Rud, do you want to go ahead and then I'll chime --

>> RUD TURNBULL: No, no, no. She called on you first, darling.

>> ANN TURNBULL: (Laughter). I think right now I feel so much white privilege that makes me wonder why have I ever expressed concerns and how -- you know, as a parent, had not needed to live with fear of the police and of finances and of lack of documentation.

Of so many things that have been mentioned. I pay major tribute to these three amazing parents who have shared with us and honored their journey, and so much -- now more than ever before in our country, how much we need to lean into the voices of families of color and be led by their dignifying ways on bringing hope to all of us.

So, we are all at home in front of our computers, but join me in giving them a huge round of applause. Take your mute off, unmute, and join me in giving these families a huge round of applause for their presentation.

(Applause)

>> ANN TURNBULL: So, I want to emphasize Karen's call to us to trust partnerships and to realize the difference between relationships and trusting partnerships. Chioma, you demonstrated mothering so beautifully during this presentation. You take care of your children, and you walk the walk of mothering for us. As you were talking about mothering.

Your emphasis on this being mother's work and on -- it's not just about education, but it's about survival.

That's something that I will always remember, and certainly, the demonstrations -- the protest of these last two weeks and the loss of life of Mr. Floyd and so many, many others, reiterates that point of survival.

And Doris, this wonderful emphasis that you brought to us on strengths and resilience, overcoming fear, on hope, and on gratitude.

I just will long remember what has been shared.

Let's open it up and see what questions or comments that any of you have for our panelists.

I'm saying open it up. I see Peggy on. Peggy, so glad.

Peggy, can you show us our face? Maybe you didn't dress for the camera today.

Yes, welcome Peggy. Peggy is the one that Karen was talking about -- her son and letting her son run through her hair, Peggy. Thank you for the -- what you have done to Karen. Now she is doing it to us.

>> RUD TURNBULL: Let me just say --

>> ANN TURNBULL: Okay.

>> RUD TURNBULL: I've got five points of each of the three speakers. The point I had most from Karen is that whole business of your hair. Allow the child to touch you and for you to hold that child and to have that almost intimate touch.

It's really confirming dignity upon the child, that the child is conferring dignity upon you at the same time.

>> ANN TURNBULL: And Rud, before we open it up, you go ahead with your other points, okay?

>> RUD TURNBULL: Oh, very briefly. All right.

Chioma, when we have to fear for the safety of our children, that means that they themselves -- not having dignity -- (Audio cutting in and out). I have had the needs of fear for our own children's safety, not nearly as much as other people. But the notion that safety and dignity are related on a rather, rather closely. I think it's important.

Doris, for you, to say -- to give a person hope is, for me, to say we will also give them dignity.

They have it inherently, but we have to reinforce. Those were my take-aways. Back to you.

Actually, back to Dr. Peggy.

>> ANN TURNBULL: Peggy, anything you want to say in terms of your experience with Karen or anything else?

>> Well, I would just say with Karen, she always was a wonderful speaker and a wonderful -- she was always so open, wanting to learn.

It was so easy to work with her. It was a joy getting to know her son.

>> ANN TURNBULL: Yes. That's great. Well, you are very important in their life. That's wonderful.

Okay. Let's open it up. I see another person I want to call on. (Laughter). How is this for -- and Carmen Sanchez, you're on this call. You play an important role in the U.S. Department of Education for parent centers and the support of all parents.

Any comments you would like to make, Carmen?

>> What's coming across that we need to continue to emphasize is the strength that's inherent in the parents. The strength that is there. Not necessarily to look at the efficiencies I hear very much from the speakers, that's the way they approach their work and who they are as people.

And also, I liked -- and I'm going to butcher your name. Chioma's comment, you're in it for the long run. You're in it for the entire lifespan. Sometimes in early childhood, the vision stops at the child leaving early childhood, but it's the parents who will be there throughout the entire life of that child and taking care and encouraging that child to be all that he or she could be.

I think we need to do more of that. I'm actually in another conference during this week of the national family engagement, which is more general education. One of the things that's really coming across clearly is the extent to which many parents of kids who themselves are diverse parents, either they're African American or Latin X or -- they are really concerned about disability issues and how there's that intersectionality between their backgrounds and disabilities.

I really like the fact we're approaching that and we're thinking about that intersectionality.

It's always been there, but COVID is certainly making really, really putting it in relief, and making it clear how this impacts so many families.

>> ANN TURNBULL: Thank you Carmen for sharing those comments and thank you for your leadership in fostering parent and family leadership. Let's turn over to questions and see any questions, comments, on how we best support families, how we foster family leadership during this time of COVID, and during this time of our country coming to grips with a need to revamp and reform our system of policing and on criminal justice.

Comments? Darla, are there things in the chat box? No?

>> DARLA GUNDLER: One question people didn't understand was the early childhood of personnel center. Sorry about that. DEC is the Division for Early Childhood, which is a subdivision under the -- exceptional children. I apologize we use acronyms. I guess we forget that sometimes. Thank you for asking those questions.

>> ANN TURNBULL: Darla, tell them the mission of the early childhood personnel center.

>> DARLA GUNDLER: Mary Beth is the director. What we do is we work on supporting states to develop their comprehensive system of personnel development. One of the most important pieces for me is that works in conjunction with families and making sure families are part of the team. That's why they have the three family leaders that are part of this cohort. We have two cohorts so far. We're moving into our third cohort. It's providing family leaders the opportunity to grow their skills, but also to embed themselves in the workforce within their state, making sure we have impacts into the pre service, the in service, personnel standards, and understanding all of those pieces. That's really who is coming into our homes and working with our children.

>> ANN TURNBULL: If families are on here who would like to apply to be a part of a future Family Cohort or if there are professionals that would like to recommend their family partners, how might they do that?

>> DARLA GUNDLER: I just put my email in the chat box. You can have the families people me, and we can make sure to get them the information about this cohort because we're still accepting applications now.

>> ANN TURNBULL: Okay. One thing I would like to share with everyone is a very powerful panel that I listened to yesterday.

It was an archive webinar from Karen Map (phonetic), at Harvard, and does family partnership work.

There was an amazing second grade teacher named Emma. Some of you may know of her brother, Micah, featured in intelligent lives and an amazing person, self-advocate, a person with disabilities who is very active in the disability rights movement.

Emma's sister is a second grade teacher in a classroom. A project she undertook that I thought would be great for UCEDDs and LENDs is she sent emails to the families, to the families in her school, about what the special needs were during this special COVID time. She said -- and I can get this from the archive.

I invited her to join us so she could tell us about it, but she was tied up on something else today.

It was like a one-pager, something simple and quick to fill out about needs.

She sent that same form to approaches throughout the school district of what are the strengths that they have and would they be willing to be in a one-to-one match with families. When she gets the needs statement from the families, she finds a match of a person who has the expertise, the information, the resources that that family needs, and then shares it with the family, and then the family and that person get in touch with each other and share.

I was thinking gosh, UCEDDs are really set up to do that. I mean, you could send to the families in your area this invitation to let us know what your primary issues are right now and concerns, and then match that with your staff, with other people at your University, with other professionals in the area, as well as with family leaders and your parent training and information training center that could be exceedingly helpful. Isn't that super? That a second grade teacher who is still conducting classes every day with her students, she has online full class, as well as follow-up with individual students. She took the initiative to do that. I think it reminds us all right now with COVID and with our country that such a transformational point of social justice for each one of us to think what are the steps that we can take? What can we do to make a difference in one person's life? Or in several people's lives? All of us step up our game to do more and give more and care more so that this vision of health, from COVID, and justice, from our country's distress, that we can be part of the solution to that.

Does anyone want to share one thing you're thinking you might do? You know, what's a new thing? You're already doing so much, but if you did one more thing for social justice, for the safety and the health, especially of people of color in our country, what are steps that you can take? Let's all think that. We don't have to share it. Our time is almost up.

I'll share with you one opportunity that just fell out of the sky this last week for me. I thought oh my goodness, I don't know if I can do this. In Mr. Floyd's name, I'm going to give it my best shot.

That was getting a call from a center that focuses on the defense for people facing capital punishment, with a concern about an African American male, as Chioma has told us, or ones that often are at the greatest risk for involvement in suspensions and calling parents to come pick them up and the school to prison pipeline we've all heard about.

This young man fits the stereotype of that picture, of school to prison -- his father died very early. Six or eight children in the family, most of whom have a diagnosed disability.

He committed murder, first-degree murder, and is now at 23 years of age facing death penalty.

The lawyers were asking, can you help us review his special education records and see if there was things that were done or undone that contributed to this? As I reviewed the records and saw for the first time that he had issues with anger management, it was mentioned when he was about in 5th grade. There was no evidence of any intervention on that. He dropped out of school in 9th grade.

His number of suspensions far exceeded when IDEA allows. There was the functional behavior assessment, the behavior intervention plan was totally inadequate. You look at the educational system, and then you see now he's been in jail for 2 years, unable to make bond. His case will not come up until next year because of the backlog of the courts now over the last three months of not taking cases. Here, he and his family are paying the penalty of what was not provided to him.

I just said I've never been involved in a case like this, but I want to do everything I can on his behalf -- I want to meet him, and I want to visit him in prison, I want to meet his mother. I want to be part of his support.

I share that with you. Often, we're not ready to take on new things until we take them on and figure out how to do it. You know? We can't wait until we know how to deal with a case like this.

All of us have opportunities, typically not that dramatic of life or death, but all of us are going to have opportunities, and I think it is incumbent upon us, with the difficulties of the COVID impact and of what has been brought to our attention over and over again, and the country is now erupted -- and that's a good thing. It's way overdue.

All of us, we have to move from shock and outrage and move to action, and we all have to take action more than ever to hold the hands of the Karen's and the Doris' and the Chioma's and move together in unison to reform the educational system, the policing system, the healthcare system, every system where there has been systematic racism for 400 years.

Coming back to the dignity, when we do that, when we dignify every life, when we recognize the inherent dignity that people come into the world with, and when we, through our actions, not just our words, but through our actions, confer dignity on others -- that is what we are called to do in our world today.

I just say let's all do that and may our circle be unbroken as we create this new order where Molly's son does not need to move away for a year and a half to be treated with dignity, but can be treated with dignity in his own country.

So, that's my ending.

>> MOLLY COLE: Thanks to this panel. You have been spectacular and given us a lot of food for thought. I hope we all take away from this the opportunity to do things differently and better.

>> MARY BETH BRUDER: Thank you all. This panel gives me goose bumps every time I listen to them, and we get to listen to them through ECPC. I thank Molly and Darla for being such good parent leaders. Of course, I love Ann and Rud, and they know that. I'm so justice privileged that they are consultants to our UCEDD and our LEND. I want to end with what Ann said, which is let's be actors in the universe. What better way for all of our LEND students learning to be leaders and our UCEDD students and all of our staff to recognize that one person can make a difference, and that's what our job is. As we are creating the next generation, to not have to have the dignities that we have seen happen over generations for a lot of our children and a lot of our families.

So, I thank you all. On behalf of AUCD, you will get an evaluation. You all know how important that is, so please fill it out. Anna put it in the chat box. We will see you all next month at our next monthly. Also in the chat box, we love to get ideas of things you all would like to hear. Again, thank you all, and hopefully in the not so distant future, our ECPC family will be together again. We know -- yes, we've been learning how to do Zoom. We should mention for those who don't know the Division for Early Childhood will not be having our annual conference. It will be all online, virtual.

We look forward to 2021 when we will be together again, but in the meantime, there's lots of opportunities to learn from each other. So, thank you.

>> ANN TURNBULL: Bye everyone.