

## COVID-19 Behavioral Health Policies Affecting CYSHCN: What to Keep, Modify, or Discard? November 10, 2021

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Hello and welcome to behavioral health policies affecting children and youth with special needs, what to keep, modify, or discard. My name is Helen DuPlessis and I'm a pediatrician and principal in the L.A. office of health management Associates. I will be moderating today's discussion. We are recording this webinar, as you just heard, and it will be available on the Lucile Packard Foundation for children's health website in the coming weeks. I am ready to go to the next slide. Perfect. We are offering live captioning for this webinar today. You can access the captions by selecting the closed captioning button at the bottom of your screen or by clicking on the link that we just put into the chat function to view the captions. If you're having any technical issues with captions or anything else, please enter that into the Q&A and we will try to assist you. Next slide. We have truly outstanding three speakers today joining us. Their full bios, I will refer to you in the promotional materials, so we can use the time instead to benefit from their experience and wisdom. Margaret Comeau will be showing some additional insights about the effect of the pandemic on behavioral health. Debra Manners will discuss some of the service delivery implications from the perspective of behavioral health providers and Nicole Pratt will ground us in the realities of trying to access behavioral health services for her family. Thank you to all three of you and to everyone who has joined us today for making the time to share your perspectives. Next slide. We really want to have this be a dynamic and engaging conversation today, so we would like to encourage all of you to submit your questions in the Q&A box. We will be brief with our prepared remarks. Each of us will make some remarks and then we will get to as many of the West and as we can today. Next slide. Let's get started. In terms of context, the wide-ranging impact of COVID-19 is undeniable. I think we have all felt it, and the effects were arguably felt disproportionately by the poor, by ethnic minorities, and other vulnerable populations, including children and youth with special health care needs and I should point out today we are using the maternal and Child health Bureau definition that is listed at the bottom of your slide. So what happened in? The federal and state agencies organized a reasonably rapid response to the pandemic through the establishment of legislative and regulatory X abilities and in turn, the managed care plans, through their own administrative mechanisms. Most of these flexibilities were tied to the national public health emergency and on the next slide we were privileged to work, that is to say HMA was privileged to collaborate with the Lucile Packard Foundation for children's health on research assessing which of those policy X abilities -- flexibilities actually affected children and youth with special health care needs and their families and providers. In addition we made some recommendations about which policies should be continued after the public health emergency ends. We did this through detailed review of federal and state policy and through interviews with clinicians, with legal and family advocates, with research, program leaders and other public and private stakeholders. The report, including recommendations that are targeted at different levels of accountability, is available at both the foundation and the HMA website and the link has just been put in the chat. On the next slide, we are going to start by focusing on some of the really high level findings and themes and then we will briefly go over it deeper so we can stimulate

our panel discussion. One of the first findings was the real salient focused area of telehealth along those regulatory flexibilities. While most of the effects of telehealth or advantageous to children and youth with special health care needs and their families, they also should have shown a really bright light on the egregious disparities in access to technology and functional broadband. These telehealth enhancements were the focus of a July webinar that the foundation supported, the recording of which is still available on the foundation's website. One of the second findings was sort of a collection of flexibilities in another a number of other areas that was beneficial to the population. Some of the categories for those flexibilities included in Medicaid funding, to increase access, to maintain coverage, and the broadening of the federal match. Another category or the Medicaid eligibility enrollment flexibilities that impacted providers as well as beneficiaries, including things like deferral of redetermination of eligibility, maintenance of eligibility criteria, simplification and deferral of provider applications. We also saw a relaxation in a lot of the prior authorization requirements and we saw broadening in the scope of practice that allowed nonphysicians to deliver care and authorized services, including critical care services like medical equipment, without supervision. We saw expanded pay to family caregivers, including pay to legally responsible caregivers, so that term legally responsible caregivers, in the CMS world, centers for Medicaid and Medicare services, applies to spouses and parents pertinent to our population. Another key theme of our research was the behavioral health consequence of school closures and unemployment and isolation and the exacerbation of other social drivers of health such as access to food, social connections, all of which put really tremendous strains on this population and their caregivers. The next slide. You know, we often get so riveted on the medical complexities of children and youth with special health care needs that we forget that they are also susceptible to emotional and psychological stressors. These children and youth during the pandemic experienced disruptions in all of their routines and unlike many of us, they often could not exercise any kind of control over those disruptions. School closures meant no opportunity for socialization and for many, a cessation of critical, therapeutic services. Routine visits to doctors and specialists either ceased or were dramatically modified and format and frequency. The lack of respite care, lack of child care, in-home care services, and the massive underemployment affected our children as well as their caregivers. As previously mentioned, relative to other areas, there was a dearth of flexibilities focused on behavioral health. You know, we were largely, not completely, but we were largely caught off guard by this and did not really anticipate the profound behavioral health toll on children and families. On the next slide, these significant stressors that we just talked about took a huge behavioral health toll on this population that has gone largely underreported or at least we have been delayed in recognizing that. That was exacerbated by the fact that routine behavioral health screening in this population is often overlooked, under the best circumstances, and was most definitely lower priority during the pandemic and again, the policy options in this area, the policy options for flexibilities were largely limited to telehealth. So it hardly needs to be stated that the demands and the strain on family caregivers is additionally exacerbated by all of the demands for 24/7 care with the absence of respite. On the next slide, in addition to the other recommendations in the report we did make some specific recommendations to support behavioral health for this population and for their caregivers and I would like to really quickly highlight a few of those. From the perspective of what can be done at the federal level or by the centers for Medicare and Medicaid services, extending that telehealth reimbursement for behavioral health services, especially including audio only services, is a really strong recommendation. Last week, I should say, there was a rule included in the Federal Register to do this for the Medicare population and so we are now keeping our fingers crossed that the same rule will be established for Medicaid programs. Another recommendation we would like to see retained is finding creative ways to

incentivize routine behavioral health screening for all kids including children and youth with special health care needs. And we would love to be able to allow reimbursement to pediatric providers to screen caregivers of this population for behavioral health and social determinant needs in the same way that we are currently doing for Perry part of mood and anxiety disorder disorder. State actions to take could include some of the same plus increasing the training and confidence of primary care providers to deliver behavioral health services. We would also like to see made permanent the flexibility in the state of California at least, to transfer some of our dental health services administration act that MHSAs funds to meet local behavioral health needs in an emergency situation. On the next slide, you know, these challenges are all happening on a worsening backdrop of behavioral health issues for all children and youth, so much so that last month the American Academy of pediatrics, American Academy of Child and adolescent psychiatry, and the Children's Hospital Association declared a national emergency in child and adolescent mental health. You can see that prominently displayed on any of those organizations websites and I will point out that on the left side of this slide, those last two bullets underscore the dire circumstances in California and increases we have seen in our inpatient visits and suicidal ideation, et cetera. Some of the advocacy recommendations from that declaration are on the right side of the slide and are similar to the ones we have discussed with the addition of sustaining mental health care and primary care. That is been a trend that has been moving for the last decade or so. There is also a call to address the ongoing challenge of the acute and inpatient mental health care needs of children and youth. That in my mind needs to translate not only into acute community-based beds and psychiatric beds but to a full continuum of health services. With that as background I'm going to turn this over now to Meg Comeau to share some additional insights about the pandemic and what her organizations have been doing.

Thank you, Helen. I appreciate the laying of the groundwork and especially the detail around the recommendations from the report. I also want to thank the Lucile Packard Foundation for children's health or the invitation to be a part of this important and timely webinar. As Helen described a moment to go we are in a time of crisis regarding the mental and behavioral health of children, youth, and families and children and youth with special health care needs are at particular risk of pre-pandemic data from the 2019 national survey of children's health shows families of almost one quarter of children ages 3 to 17 reporting that their child had one or more mental, emotional, development, or behavioral health problem. Provider shortages, insurance but the gaps, and high out-of-pocket costs were significant problems before the pandemic and are expected to increase exponentially as demand for services increases now and post pandemic. Next slide. I'm going to be speaking today from the perspective of several sources including the excellent HNA report I hope you have all had a chance to read as well as the project I have been leading for the last four years called collaborative improvement and innovation network to advance care for children with medical complexity. Children with medical complexity or subpopulation of children and youth with special health care needs your especially high utilizes of healthcare services and often requiring medical technology. This -- funded by the maternal and Child health Bureau and focuses on care delivery improvements that increase the quality of life for children with medical complexity, the well-being of their families and the cost-effectiveness of their care. As part of this project between 2018 and 2021 we collected both quantitative data via family and provider surveys as well as qualitative data via a series of family focus groups. Specifically -- nine focus groups with parents of children complexity in 2019 and the remainder work was conducted during the pandemic's we have data we can use to compare the experience of families between the two time periods. In addition, the children with medical complexity collaborated with the -- pediatrics focused on the care of children with

medical complexity during the pandemic. Learnings from the learning discussions as well as the now is a participant surveys and focus groups served as a source of mission from the provider perspective. Next slide. So I want to preface my remarks by noting that I'm speaking in the past tense because I am reporting data collected in the past but the impacts I'm describing are ongoing. The pandemic and mental health -- children, families, and providers are still with us and will be for a long time. The bullet points on this slide highlights -- children with medical complexity drawn primarily from the family focus groups but also from the echo sessions. The whole families mental health needs were stressed by COVID-19. I need to focus on not just the child with medical complexity but also the behavioral health needs of his or her typically healthy siblings was also routinely reported by families. Families expressed high levels of dissatisfaction with distance learning although the necessity from an infection risk standpoint was easily appreciated by parents. One describe their child's individualized education plan which had been negotiated over months and with the involvement of lawyers as being thrown out the window with no compensatory strategies offered. Families describe not only physical but emotional isolation as they lost access to many of their pre-pandemic coping mechanisms. Coffee date with another parent, or even a break while children were in school was no longer possible. Families were not only prevented from leaving the home without risking exposure to COVID-19, they also lost often there in-home supports and services such as home nursing. Being on 24/7 with the associated increase in responsibility for medical care as well as the deprivation had a major impact on family stress levels and their ability to be resilient. Many families described being in competition with hospitals and even other families for medical resources their child required day-to-day. Such as gloves, masks, and vented supplies. The emotional distress experienced by families as a result of this change related to their relationship with traditional allies would routinely reported as a significant stressor. The risk of hospitalization was very scary for many families raising children with medical complexity. At only because of the disastrous health consequences and COVID infection because they worried in the event of care rationing, whether their child to be discriminated against because of the documented perceptions of quality of life for people with disabilities. They also worried that they would be prevented from being with her child in the event of a hospitalization. Families of children with medical complexity often serve as advocates, agile care providers, mental health supports, and patient safety sentinels at the bedside when their child is hospitalized. Next slide, please. The CMC coin in collaboration with the American Academy of pediatrics hosted a COVID-19 and children with medical complexity ECHO lecture in September of 2020 title supporting the mental health needs of children with medical complexity and their families at the time of COVID-19. The presenters were Dr. Christina Malik and Dr. Courtney sent sushi. This slide describes the major takeaways from their lecture, a recording of which can be found in a link at the bottom of the slide and in the chat box. It is reasonable to generalize these takeaways from children with medical complexity to the broader population of children and youth with special health care needs so all kids including those with special health care needs should be screened for mental and behavioral health needs. Providers may need to be creative and working with children and youth with special health care needs for example those were nonverbal or those with intellectual or developmental disabilities and interdisciplinary team based care is optional. Excuse me, not optional, optimal. Therapists should be matched to families needs and care should be trauma informed. There is a need to adapt what is working for children with behavioral health needs for the beginning pandemic, not just business as usual but in the context of what is happening and what is coming down the pike. Many states have some ports -- especially around pharmaceutical management. Next slide. There was a growing interest in and understanding of the need for integrated care for all kids before the pandemic. COVID-19 and its impacts of elevated that need to the point of crisis. Many of the

recommendations made in the HMA paper including those highlighted by Helen earlier which are focused on improved and expanded financing of care, can help accelerate the necessary structural changes required to better serve children, their families, and their providers from a holistic standpoint. The American rescue plan legislation passed in March of this year includes funding for a 10% increase in the federal contribution for home and community-based services covered by state Medicaid programs. States have submitted plans for using this additional funding to the centers for Medicare and Medicaid services and in a recent blog post the national Academy for State health policy identified three behavioral health laded priorities identified by states themselves and their plans including developing and enhancing mobile behavioral health crisis options, updating technology and data infrastructure and investing in the behavioral health workforce. A link to this blog post with specific details from specific state is found in the chat box. I'm going to turn the floor over to Helen who will introduce the next speaker. Thank you for the opportunity to spend time with you today.

Debbie is going to give us a perspective from large provider of behavioral health services.

Thank you. Just a little bit about Sycamores, we are located in Los Angeles County and we are the largest provider of children's mental health. We serve about 14,000 lives per year and we provide school-based mental health services in over 77 schools and so during the pandemic we needed to pivot on how we were providing services. Next slide. In looking at all the services that we provided and it was mentioned earlier in the slides, the spike in our children talking about suicide, so they had the idea and then they talk to us about it, which as you know, if you work with children and families and adults, often times they don't reach out and talk about their pain and so what we saw really quickly after the stay-at-home order was issued in March was a spike in talking about suicide, so just to do a comparison, prior to the stay-at-home order there was about an average of 16 suicidal thoughts reported per month and then we saw a spike to 23 so that is an average of 44% increase. Next slide. In the months leading up to the pandemic we saw about an average of two suicide attempts and during the pandemic 100% increase in the spike to four. We have a mobile response program, so we have staff who go out into the home and tried to do hospital diversion, crisis stabilization, or they will find hospital and hospitalized the youth. One of the other things that happened during the pandemic was there were no ambulances available for transportation to the hospitals and so sometimes the weight could be 8 to 12 hours. Next slide. Looking at the 47% increase in psychiatric hospitalizations, that really does not address how many we were able to stabilize when we were waiting for an ambulance. So during the pandemic, in addition to seeing a spike in psychiatric hospitalizations, the other issue that we really dealt with because many of our youth are under the jurisdiction of the Department of Child and family services, we really felt the need to do those services in person and so in retrospect now that we are returning back and doing almost 100% of our services back into the field, we have started talking about what an impact that had in the fact that we were continuing to do a lot of our services in home, and mostly because we had issues with our families having access to devices and broadband. Next slide. So, if you look at our services you can see that during the first three months, 20% of our services were delivered in person and then we really had an increase. Our services spanned -- I talked about how we have our school-based services, we have our intensive in-home wraparound services, and we also have a homeless program, which continued to be in person 100% of the time and we also had a residential treatment program that of course was also 100% of the time. Next slide. So the spike in mental health services, and we continue to see this spike, was 32%. We continued to see a spike in services. We are unable to meet the demand currently because of workforce shortage issues. We have

looked at our turnover and it is about 30%, one of the highest we have ever seen in probably the 30 years I have been here, and so that is really affecting access to care. So from a system of care service model we are really talking about how do you kind of begin to triage. We did a little bit of that early on in the pandemic but we are continuing to see the need to do that. Next slide. So during the pandemic it was important to us that we made sure that we were meeting the needs of the kids and the families that we were working with, that we were able to provide good quality care, and that our employees felt like they were doing meaningful, effective work and getting good outcomes. We continue to do surveys of our staff as well as our caregivers and our community partners who are -- Department of Child and family services and you can see from this slide that 90% of our caregivers were satisfied with the service and a little bit about our services, we have peer support, we have a partners, we also have youth who have substance abuse issues or who grew up in the foster care system and so they really work as a part of that team and were really there to support the caregivers during this time. Our staff who really, many of them are in their 40s and they had children at home and so they were really managing homeschooling their youth and doing telehealth and then going out into the community's providing services in the evening, and so wanted to make sure they were doing well. We made a decision of the beginning of the pandemic that we would keep every employee employed and we also started a COVID relief fund so that any of our employees who maybe had economic issues or lost a loved one, they could apply for some economic relief from our organization. And then we surveyed our community partners and 90% of those felt like they would continue to refer their consumers to our services. Next slide. So, I'm going to turn it over to Helen.

Very good. Thank you so much, Debbie. We will hear from Debbie and Meg and just a little bit but we want to hear from Nicole, and you will see her virtual background aptly lays out what she has been up to but we want to hear from the family perspective. Nicole?

Yes, hi and good morning over there and good afternoon where I am. I am Nicole Pratt. I live in New Jersey. I work for the parent center here in New Jersey but I am here talking to you from my parents hat today. As you see on the screen I am a single parent of two young adults now and I have a daughter who is now 27 who just graduated from her college this past May but when she was a teen dealt with mental health services and one of the things I thought about when the pandemic hit even though she has been stable for seven years, how is the pandemic and going to college at home going to affect her because socialization was one of her big things that she greatly improved upon over the last couple of years when we moved from one part of the state to another. And we had several conversations with her about that and how she was feeling and urged her to contact the mental behavioral health services at her college that was offered. I'm going to talk to about my son. Jordan. Jordan has a developmental disability and his diagnosis is mild cerebral palsy with a mild developmental delay. He just turned 21 in July and just graduated from his high school because he went through 21 and I was being serviced through the developmental disability system, but Jordan had been getting mental health services for the last four years, 3 1/2, four years of service school due to the loss of his grandfather a couple of years ago and it was important because I saw that he was having some bouts of sadness and some issues with depression and when the pandemic hit and his school went virtual, for the first couple of months he was okay and then after a while it was really affecting him even more and so I had a very good relationship with his counselor at school and we communicated with her because he was voicing that he was really sad and wanted to go back to school and things like that so I kept really close touch with his counselor at school and then when graduation was coming up upon us and this past June I said to her, because he was still having bouts of sadness about his father even though

they went back to school, they went back to school part of the time and he was still having some sadness and feelings about not really being in school the way he wanted to be so I asked his counselor and I said, you know, do you think I should still continue behavioral health, mental health services and she said definitely, he really needs it and it has been a big help to him. I said okay, so three or four weeks before he graduated I put my mom advocacy hat on and started looking up his insurance. He has a Medicaid HMO here in New Jersey and I started researching and I started looking at the mental behavioral health organizations that were listed under his insurance and I made sure that they said that they serviced young adults, children with developmental disabilities because that was really important to me that I had a service provider that also understood his developmental disability. So I start calling and one place did not call me back and then I get in touch with another place where was familiar with their name and I was like okay, I know who they are. So I call them and I explained to them about my son and explained to the lady what I'm looking for and so the first lady that answered the phone said, well, I don't know if we service people with disabilities here. So my eyes were bulging out of my head. She did not really see me but I was sitting there for a second going she really does not know who she is talking to by telling me this and I said well, let me speak to the supervisor. Let me speak to your supervisor. She's like okay, hang on. What she did was hang up on me so what did I do? I called back. I called back and I said you hung up on me. No, I didn't. Yeah, you did. Let me speak to your supervisor. She must've said something to the supervisor so the supervisor got on the phone she had an attitude and I explained to her my situation. My son is going to be graduating. He does have a developmental disability but he is able to facilitate conversation and I need to have them continue mental behavioral health services. So she says well, I need to speak to him. I said well, you can but the information that you need, I need to support and speak on his behalf. Well, we can provide many services if we cannot speak to him and I said well, I am his mother and I providing support to him so are you telling me that you are not going to service my son? She says I don't know if we will be able to service them here. I said so you're telling me that you're not going to be able to service my child is that what you're saying? You know that is discriminatory. She said no it's not. I said yes it is. I said you say on the information that you service individuals with developmental disabilities but here you are telling me you cannot service him because he has a developmental stability. I said that is very discriminatory and so I hung up because I felt myself going somewhere else. So then I went through, plow through, kept researching his insurance and found we have our here in my county. We have ARC in every county in New Jersey and I found they had a behavioral health program and it was great because I knew that they would more than likely provide service to him and that is were ultimately I was able to get the behavioral health services which is being paid for through his insurance for my son which he gets once a week through a telehealth model and that he also gets to see the clinician every three months just to keep updated. So with all of that going through that, I am a single mother, I have my own health issues, I have survived massive violence when my children were younger, working with families and supporting our families with the work that I do at SPAN, I was beginning to feel very overwhelmed and stressed. Extremely. I started talking to some people at work and I said you know, I feel like I need mental health services. I said because just keeping my children healthy, keeping myself healthy from not getting sick, working, I love the work that I do, but I also know that I have to take care of my mental health and take care of my health in order to be able to support my children and provide support to other families so I say that as parents of children with disabilities or mental health and special healthcare needs we have to be our advocates for our children even when they are young adult. And also remember to take care of ourselves and take care of our mind, take care of her body, take care of our hearts, which are our children. Thank you and thank you for having me here today. You are welcome.

Thank you so much, Nicole. That was really wonderful. We have got plenty of time now to open up the webinar for questions. There are number that are already in the Q&A box and we will be going through those so just a reminder, if you have questions enter them into the Q&A box. While we are getting to those, let me offer one that is a lead-in from one of the -- you know we spoke about the dire situation of our behavioral health system for children and youth in general but especially for those with special healthcare needs. So I'm asking now the entire panel, are there opportunities here you are aware of on the horizon and what can we do to advance those opportunities to see to it that something is done to address what is obviously a huge mismatch between the need for and the supply of behavioral health services, particularly for children and youth with special healthcare needs. I am opening that up to the panel as a whole. Meg, do you have a thought?

I do have a couple of thoughts. Specifically most of this kind of happens on the state level so there are federal supports that are available and I think they get a lot of attention but it tends to happen more on the individual state level and so expanding pathways to coverage, whether through private insurance, mandated benefit laws, or through Medicaid expanding access to Medicaid, especially through home and community based service waivers is one way to address benefits and benefit issues. Another thing to think about is to look further upstream and see if there are things that can be done in the area of the workforce, so enhanced reimbursement for services provided. Reimbursement for training and national development and education are really important. Another thing that is less recognized is training for families and education for families as well. And that can be incredibly important in terms of making sure that the entire family is looked at holistically, not just the individual child, but their individual mental or behavioral health problem and they are seen as all of their health included in the thinking and strategies and the entire family is including included in the thinking and strategies. Those are just some thoughts off the top of my head. You know, I keep thinking about the role of the school because that is where kids end up at five years old and sometimes sooner. What role they have in really just doing screening and assessment and also having behavioral health providers located at the school so even if there is an assessment that is done or screening tool, then there is not a linkage in referral but actually a warm hand off, so they make sure there are some services that are provided and they include the family and so once there is an assessment done of the child, the assessment or the screening goes out to the family because as Nicole stated, it is really the whole family and mental health issues affects everyone. And so I really think the focus needs to be right now on the schools and as kids are returning back to school, we are seeing that the schools are overwhelmed with what they are finding in the children as they are returning. A good points and Nicole, I know you have a comment but I just want to tie Deborah's comments into a couple of questions that came up in the Q&A box one from Beth that you have addressed about behavioral health screening. She asked the question about through school nurses but they are our whole host of personnel within the school system including school-based health centers as those are accessible on campus who may be engaged in that. And then Michael Butler also asked a question about how the ongoing expansion of school-based mental health might provide a partial solution. Any additional comments related to that?

I think someone also put in the chapter schools are overwhelmed and we're seeing that in the schools where we are providing services. And what we found to be most effective is to be integrated with the schools, so the kids and the staff and the families would never know that our staff art school staff, right? The ability to be there and really work as a team is really important to support the teachers and to support the administration so that is the other role of

school-based mental health providers is to educate everyone on what is it that you need to be looking for in your classroom and what you need to refer immediately for screening or for assessment .

Nicole?

I saw someone put that in there about ESPER funds. In New Jersey a few years ago, because they kept seeing a spike of children with mental health problems before the pandemic a couple of school districts started to partner with community-based mental health places because one, parents were struggling to get an appointment with a psychiatrist when they made the call and said your child needs to be clear or insurance, they could not afford it because many psychiatrists do not pay payment or you could not get a community-based one from the hospital because you have Medicaid and you have to wait. With some school districts, they started to partner with mental health agencies and get children screened Tsanais fast-forward and have a pandemic and everyone is home and everybody begins to come back and so what we did at SPAN, we had a short summit over the summer and we invited the Department of Education to find out how are they spending their -- funds. Now there are schools that have social and emotional programs come, those funds -- they have to enhance with schools already have or schools putting in social and emotional learning which encompasses more mental and behavioral health supports in school so that is what is happening in New Jersey but the issues are also still rising with insurance. And so if you have private insurance, trying to find a psychiatrist or mental health provider that you can afford and then if you have a Medicaid based insurance, HMO, well, then you're kind of pigeonholed into which ones you can actually go to. Many of them, whether they are community-based mental behavioral health services or hospital-based, so definitely Meg pointed out that the advocacy is at a state or national level to ensure there is more funds and if any bills are coming out and that is really important. That is why it is important that parents and everyone and professionals tell the story's to ensure that people hear what is going on and lawmakers hear what is going on and they can say okay, we need to be put more money in mental health. Every year we hear that but it is still not enough and so we have to keep telling our stories and advocating whenever we can. It is really important that we keep getting the stories out there and parents not being able to be afraid to tell their story because that is what makes a difference.

Yes, and I'm seeing sort of a number of people in the chat and they have talked about the long, long, long wait list for waiver services and other kinds of services and how significant that is and I think you're absolutely right, you have to keep telling those stories keep pushing. Absolutely. A couple of questions or comments and I would love to sort of throw out where does primary care fit into this? Our pediatricians part of the solution or other child health providers part of the solution to behavioral health service crisis and what needs to be done to best position them to be part of that solution?

Well, pediatricians are part of this because often times what they can do is do a screening and then work with the family around kind of what the issues are and helping them to get some treatment or some type of intervention. It seems in many situations family members are more comfortable talking to their pediatrician than they are with someone else.

So, one of the things I think about when I think about the role pediatricians is so many of them are overwhelmed with all kinds of different things now, but those mental behavioral health needs land on their doorstep anyway and so the need to provide more interdisciplinary

support around them, if they're practicing in the context of a community-based medical home that being able to have resources around them can help support the work they are doing with patients and families. That's integral to being able to improve the quality of care and better outcomes. I think one of the things I mentioned was to have consultation services available, so child and adolescent Akai interest psychiatrists who can help pediatricians with pharmaceutical management is a helpful thing and increases confidence of community-based pediatricians to be able to provide quality care to these kids and it is a patient safety issue but also helps extend that workforce a little bit in ways that can be important.

Yeah, and I would like to share that I mentioned in my earlier comments that the move to integrate behavioral health and primary care is over a decade old now and the reality is it has been a little slow coming to child healthcare and indeed the notion of having in-house services with social work and other therapists and paraprofessionals who can provide support, other parents who can provide support and be some of those wraparound services and facilitate the connections to an navigation through the systems and referrals to the degree that they are accessible and pushing on those waitlists is really vital. We have sort of gone from the old school community pediatrician that did everything to now in the advent of managed-care, very focused, anticipatory guidance, acute and chronic needs -focused pediatricians and now we are sort of moving back full circle to that holistic approach that is at the bedrock of child healthcare. Lots of important conversations. Here is kind of a disturbing one. Jerry Clark made a comment about the trend of families being coerced to give up custody of their kids in order to access optimal services , particularly for impaired kids . Can you will comment about this trend and what can be done to stop it?

If it is okay for me to jump in for a second, this is not a new phenomenon. This has been happening for a really long time. One of the drivers behind it is kids in foster care are automatically eligible for and enrolled in Medicaid and Medicaid through -- child health benefit pays for mental and behavioral health services to a greater extent than private insurance and certainly being uninsured. There are several strategies that states use in order to try to mitigate some of this risk. One is to pass state laws that prohibit this kind of situation from happening to begin with and another is voluntary agreements between families and the state that the family will retain legal custody of the child but the child will be eligible for Medicaid services under the Medicaid plan. Another is around states really devoting specific time and attention to increasing the workforce so looking back upstream, not waiting until they are drowning but keeping them away from the river to begin with, increasing the workforce and having enhanced reimbursement and funding for training so that there is a -- in order to meet the need before it gets to a crisis state. And certainly expanding access to Medicaid through pathways such as home and community-based service waivers, you have to address the issue of waiting lists around that but that's another way, Medicaid buy-in programs is a potential state strategy that can be used to expand eligibility for Medicaid for kids so they can get services, screening, get treated before it becomes a crisis state where their families have to look for external help in getting them services they need.

Nicole, did you have a comment about that?

Yeah, I do know that does happen and with the Medicaid, Medicaid is a really big issue and every state has a Medicaid program and I was reading the comments about the one mom talking about the Medicaid waivers and not being able to get services and in New Jersey we have a system of care, a statewide system of care which has been now around for about, let me see, 16 or 17 years. It is a program that has morphed and changed over time that provides

in-home behavioral health services for families and children and children in child welfare so they try to avoid not taking the child away from the family needs those services. So the first thing they do is they want to ensure the child welfare system ensures that the family is getting -- if the child is ending up in the system but the family is getting the services pushed into the home, if it is access to services, maybe the family is struggling to be able to make the call or a variety of other things that could be going on, so the system here is set up to ensure that the family is going to get the support they need and the child gets supports. If the family is unable to, then they may look at, then they will look at possibly removing that child but in New Jersey, they have made it the last resort. It has been a long-standing thing to change that way of thinking to keep children, you know, not pulling children out of the home, but with the parent or another family member, so I think each state from what I'm reading, people are saying what they have is very different than how the systems look, especially around mental behavioral health services for children and for families. Again, he goes back to that advocacy piece. When Medicaid has hearings, if that is something in your state that is happening, then why is it not, we are not looking at ensuring that the families are getting the right support services instead of saying to a family, when you give up your rights which does not have to be the case. It's about getting the family the right supports and services.

Yes, definitely.

Thank you for that. Shifting a little bit, I love the comments. There's so much to talk about and we could've scheduled this for I think three hours and still not have enough time. One of the other questions that came through was about we are sort of back workforce and integration, so what are the physical barriers to integration of behavioral health with primary care and I would like to offer some additional thoughts about that and encourage others to add to that. Clearly Meigs -- make is underscored the notion of low reimbursement rates and that combined with stigma is an ongoing challenge. In the safety net, particularly in federally qualified health centers, rural health centers, there are prescriptions against same-day billing for more than one kind of visit. If someone comes to see me as a pediatrician in a community health center and make a referral to a psychologist or the psychiatrist was also part of our center we cannot bill for both of those visits. We are only allowed to bill for one visit per day and that is a huge massive disincentive. The other challenge, and I will own this is a physician, but it is a larger health system challenge, is we alluded earlier to the notion of needing to think more broadly about who can provide behavioral health supports and services. It is not just physicians. It is not just psychologists. Being able to train and utilize an increasingly effective paraprofessional and pure workforce, not all of whom are recognized and were allowed to build. Other thoughts?

Weise hired our first parent partner in 2001 and we have had robust peer support program. In a residential program we hired youth grew up in foster care who were in the probation system, to work with our kids and our residential program. What I love about peer support is their ability to do engagement and you know, engagement is opening the door and it is just so, so important and now in California, peer support is recognized, but they can bill Medicaid Medi-Cal and they have been able to for as long as we have employed peer support and it should not, it should not be an issue, but they are incredibly valuable. Especially when we are working with families who do not want anyone to know they have a child who has a mental health issue. And they don't understand it. And so they will talk to the parent or the teenager before they will talk to the psychiatrist or the psychologist or the social worker.

Meg, if we have a minute for one more comment, if you are hiring professionals from the community it can also address the issue of cultural humility and cultural accessibility and so I think that is incredibly important when it comes to the effectiveness of the treatment and the service provided as well as improving the outcomes.

We have hired, we have a family resource center in the community and we have hired people from the community to be health promoters, but we knew that what we really wanted to talk about with mental health but because of the stigma we started talking about physical health.

And I want to add that peer support, we do that here in New Jersey and a variety of different levels. It is part of our system of care. As you mentioned, it is such a critical piece because that person, I may meet the parent and I will tell the parts of my story and then at that point once I talk to them they may be like, maybe on the fence to contact a clinician but after I have shared my story and given them that support and say this is how we can do this and I can help you with that and help you through that, and it is just better. It is more culturally effective to have someone, not that the professional is not, sometimes having that family or that person or that youth that is been there and gone through it, to be able to talk about it and the experiences and if it lead them to getting those professional services are so critical and so important.

Absolutely. Well, my goodness that is all the time we have for questions today. We are going to make every effort to address unanswered questions and provide that information to you in printed form with the rest of the materials. If you would like to read the full report that we reference today we are putting that link back into the chat yet again and I would encourage you to visit the foundation website to learn more about their work with children with special health care needs and access resources and I also just want to thank our panelists . You are all wonderful and everyone who joined us today and wish all of us -- you continue support and empowerment in carrying out the good work that you all are doing. Don't stop. We have to keep pushing. This is a huge issue. Have a great day everyone. Thank you for your participation.

Thank you. [Event Concluded]