# ASPR TRACIE Webinar Transcript
# Impact of COVID-19 on Children with Special Healthcare Needs Webinar
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Shayne Brannman: Good afternoon and good morning to others. On behalf of the U.S. Department of Health and Human Services, Office of the Assistant Secretary for Preparedness and Response, I'd like to welcome you to ASPR's Technical Resources, Assistance Center, and Information Exchange webinar titled, "The Impact of COVID-19 on Children with Special Healthcare Needs," the fourth and last webinar in our series, "Hidden Consequences: How the COVID-19 Pandemic is Impacting Children." In this series, ASPR TRACIE is partnering with ASPR's Pediatric Centers of Excellence to discuss how the COVID-19 pandemic is affecting children.

Before we begin, we have a few housekeeping items to note. The webinar is being recorded. To ensure a clear recording, everyone has been muted. However, we encourage you to ask questions throughout the webinar. If you have a question, please type it into the questions section of the GoToWebinar console. During the question and answer portion of the webinar, we will ask the questions we received through the console. Questions we are unable to answer due to time constraints will be followed up directly via email after the webinar. To help you see the presentation better, you can minimize the GoToWebinar console by clicking on the orange arrow. Today's PowerPoint presentation and speaker bios are provided in the handout section of the GoToWebinar console and will be posted along with the recording of this webinar within 24 hours on ASPR TRACIE. The opinions expressed in this presentation and on the following slides by nonfederal government employees are solely those of the presenter and not necessarily those of the U.S. government. The accuracy or reliability of the information provided is the opinion of the individual organization or presenter represented.

My name is Shayne Brannman and I'm the Director of ASPR TRACIE, and I want to welcome new and old friends to this webinar. I want to thank you for what you do daily to enhance the preparedness, response, and recovery activities of your healthcare entities and communities. Your role is so vital to addressing the daily and arduous challenges being presented. So your willingness to spend the next hour with us to further advance your knowledge is noteworthy. I also want to convey my heartfelt thanks to our awesome lineup of panelists and moderator for this webinar. Your willingness to lend your precious time and share your substantive expertise so others might benefit is commendable and genuinely appreciated. And lastly, thanks to the ASPR TRACIE crew for coordinating this webinar.

For our new friends to ASPR TRACIE on the webinar today, this slide depicts the three domains of ASPR TRACIE: Technical Resources, Assistance Center, and Information Exchange. If you cannot find the resources you are looking for on the ASPR TRACIE website, simply email, call, or complete an online form and we will respond to your inquiry.

This next slide depicts many of the virtual resources that are available to you. So, please check them out and return often, as new resources are continually being added or updated.

Before we begin the presentation, it is now my distinct pleasure to introduce Dr. Andrew Garrett, who serves as a Special Assistant within ASPR, for some brief opening remarks. Andy, if it hadn't been for your leadership, we wouldn't have been able to pull off all four of these webinars and this entire series. So, thank you for that. And now sir, over to you for some opening remarks.

Andrew Garrett: Great. Thank you Shayne. And just one of a team, we all did a good job I think getting this out to a great audience. So, welcome one and all. My name's Andy. I'm a Pediatrician who is specialized in EMS, disaster medicine, and public health. I'm also a Senior Advisor here at ASPR where one of my roles is as the government liaison for the Pediatric Disaster Medicine Centers of Excellence pilot projects. On behalf of our whole team and the Assistant Secretary for Preparedness and Response, Dr. Robert Kadlec, welcome to the last of our four-part webinar series that has focused on this important issue: How the ongoing coronavirus pandemic is impacting the health of children? Over the past installments, we've seen in broad focus that has encompassed the biological, sociological, and psychological needs of children in disasters. Those past presentations are available to view online, by the way, if you missed them.

Children under 18 represent about a quarter of the U.S. population, and they are at a disproportionate risk during disasters of all kinds. It's really important to identify and plan for this population and through all the phases of the disaster lifecycle, which you guys know are preparedness, mitigation, response, and recovery. Compounding this challenge for whole community care, approximately 12 million children live below or near the poverty level in the United States, and children with special healthcare needs are present in about one of five households. It's the role of all of us from the federal government to the state, local, tribal, territorial, public, and private organizations as well as individuals and families and other stakeholders to purposefully prepare to meet the needs of all children in a disaster.

About a year ago, ASPR funded two Pediatric Centers of Excellence in a pilot project to assess the feasibility of regional children's hospitals serving as the focal points for raising the bar for pediatric disaster preparedness in an area and catalyzing the increase in availability of medical and behavioral health services that can be made available for children in their time of need. The first center, the Eastern Great Lakes Pediatric Consortium for Disaster Response, is led by Rainbow Babies & Children's Hospital at Cleveland. The other center, the Western Regional Alliance for Pediatric Emergency Management is led by UCSF and the Benioff Children's Hospital. And the work from these centers just in the first year will really inform excellent pediatric disaster healthcare in their region as well as nationwide and beyond.

The sharing of this type of information that we're going to talk about today from pediatric experts to a wide audience – and by wide audience, I just confirm that that’s potentially over a million people by the time this is distributed amongst all the stakeholders – is one of the reasons

that ASPR is supporting these centers of excellence. It's our hope from ASPR that you will take this information and use it to assess areas for improvement in your home community.

Thank you for investing your time to participate in today's webinar, and thank you for what you do every day to advance the nation's disaster health security for every member of your community. Lastly, we are grateful to Shayne and Audrey, Dr. Hick, and the whole TRACIE team for their hard work for keeping this information platform alive, current, and very relevant. Thank you to our PIs for the Centers of Excellence, Drs. Chris Newton at UCSF and Deanna Dahl-Grove at Ohio. And to today's speakers, thank you for all your time preparing for this. Lastly, but not least, thank you to Dr. Mike Anderson, a fellow pediatrician assigned to ASPR, who is helping ensure that children are well represented in our government's disaster preparedness efforts.

All that being said, I'll hand you back over to Shayne. And thanks again.

Shayne Brannman: Thank you Dr. Garrett. It is now my pleasure to introduce Dr. Chip Schreiber with the UCLA Medical Center to provide an overview and update on the ASPR Pediatric Centers of Excellence. Sir, over to you.

Merritt Schreiber: Thank you so much, and greetings everyone.

Next slide, please. So, we are just very excited to be part of these presentations facilitated by ASPR and TRACIE. And I just wanted to say just a couple words as the series close out. This effort to build regional pediatric disaster centers and capabilities, it's really been a dream, longtime in the making, and now it's a reality. So, this idea to have regional capability that includes mental health and also focus on special healthcare needs, children and youth, is really something that many of us have been working toward for a long period of time. And I just wanted to do extend -- add my voice to the -- thanks to Dr. Kadlec, the ASPR team, particularly Drs. Garret and Anderson and others who have been working behind the scenes for a long time to make this possible. And then to our two leaders, Chris Newton and Deanna Dahl-Grove for leading this effort the past year that started before COVID, but has definitely been very, very responsive. So, we would definitely encourage you to have a look at the resources that TRACIE has put together. And that's just a screenshot there of the WRAP-EM website. And again, also thanks to Dr. Hick and the TRACIE team for making these presentations available.

Next, please. So, I also serve as the Mental Health Workgroup Lead for the Western Pediatric Center, and I just wanted to just very briefly share with you some very exciting developments we've had in the past year. We have the ability to generate real-time mental health situational awareness across the WRAP-EM states, and actually we've partnered from the very, very early days with the Eastern Great Lakes Center, and that mental health situational awareness using evidence-based indicators is integrated across both centers. We're working now, also both centers, on something new for parents on coping in the context of COVID-19, and we've also been able to provide specialized mental health reach back to some of the states and entities within our territories.

Next, please. So, the situational awareness that's really tied to one of the key aspects of the pediatric centers, which is to create a common operating picture, situational awareness, to inform shared decision support and crisis standards of care when we have to make difficult choices about allocation and prioritization of mental health resources. We've had very broad sector engagement; emergency room, children's hospitals, state agencies, mental health teams, deployable assets; really from across many, many states. In June, we were able to host a tabletop where we generated real-time population-level metrics using our triage system. And we've actually been able to adapt that kind of in the real-world context of COVID-19 and we've included the ability to look at ACEs to some extent; we're piloting that now. And we definitely have seen in some of our -- some of the states and counties within our area very extreme compounding of events; fires, floods, COVID-19, and wildfires that continue to be in my own county today as we speak. So, we're able to now do that in a hybrid way looking at COVID, natural disasters such as wildfires and hurricanes and other events, and also the burden of preexisting challenges such as ACEs.

Next. And just to close out, this is just the image of our tabletop we did. You can see the wide geographic involvement across the U.S.. Heavily weighted obviously in the Western States where WRAP-EM is based, but also with partners in EGL, in Ohio and Michigan, and then others that we've been able to develop relationships with that are not in our current regional scope. And this is kind of just an image of the real-time capability, shows relative scaling of risk and presumptive resilience for children in a simulated multi-hazard event.

Next. So, thank you very much and I look forward to learning from my colleagues today.

Shayne Brannman: Thank you Dr. Schreiber. I will now turn it over to Dr. John Hick from Hennepin Healthcare, who will serve as moderator for today's webinar. And John also serves as ASPR TRACIE Senior Editor. John, let's get started.

John Hick: Thanks so much Shayne. It's a pleasure to be with you today and a pleasure to host all of you. So, good morning or good afternoon depending on the time zone that you're in. And with that, we'll travel out to the Pacific Time Zone and talk with Anna Lin from Stanford Children's Health, who will talk about social determinants of health and the effects of COVID-19. Anna, thanks for being with us today.

Anna Lin: Thank you John. I would like to thank the ASPR TRACIE team and the Pediatric Disaster Centers of Excellence for giving me the opportunity to speak to you today.

Next slide, please. I will be speaking to you about children and youth with special healthcare needs, social determinants of health, and the impact of COVID-19.

Next slide, please. As defined in 1998, children and youth with special healthcare needs are those who are -- have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally.

Next slide, please. The National Survey of Children's Health screens for children with special healthcare needs by asking if the child has one or more prescription, requires more than average medical mental health or education services, has a functional limitation compared with others of the same age, uses specialized therapy such as occupational, physical, or speech therapy, or needs treatment or counseling for emotional or developmental problems. These are due to a health condition that has lasted or is expected to last at least 12 months.

Next slide, please. As you can see, we have seen an increased prevalence of children with special healthcare needs from 12.8% in 2001 to now where nearly one in five children has special healthcare need.

Next slide, please. We also see increasing prevalence in chronic medical conditions such as asthma, diabetes, and obesity, medical complexity, and behavioral mental health learning or developmental disabilities. Racial and ethnic disparities are also present, not only in the prevalence, but also the severity of chronic physical and mental health condition. For additional information on racial inequities, please refer to Dr. Beck's presentation from October 16th.

Next slide, please. We will now apply the social determinants of health to children and youth with special healthcare needs.

Next slide, please. The World Health Organization defines social determinants of health as the conditions in which people are born, grow, work, live, and age, and the wider set of courses and systems shaping the conditions of daily life.

Next slide, please. Although research surrounding social determinants of health dates back to the 1960s and 1970s, it hasn't been until recently that we have used them as a framework to shape public policies. This framework has been used by the U.S. Department of Health and Human Services to set goals for Healthy People 2020 and then again for Healthy People 2030. The five domains include economic stability, education access and quality, healthcare access and quality, neighborhood and built environment, and social and community context.

Next slide, please. Delving into some of the data provided by the National Survey of Children's Health, children with special healthcare needs do have disparities, which existed prior to the COVID-19 pandemic. These have decreased overall general health, more medical complexity, more functional difficulty, and health conditions that moderately or consistently affect daily living when compared with children without special needs. A greater proportion of them also report two or more adverse childhood experiences or ACEs. There is a dose-dependent relationship with a number of ACEs and poorer health outcomes. Dr. Burkhart will be speaking about ACEs in detail later on in this session.

Next slide, please. In terms of economic stability, families of children with special healthcare needs answer being at or below 200% of the federal poverty level more often than those of children without special healthcare need. These families also reported having more out-of-pocket expenses, difficulty paying medical bills, needing to leave jobs, cut back on hours or requests leaves of absence, and receiving food or cash assistance. Even prior to the pandemic, families of children with special healthcare needs already had more financial stressors. The

economic impacts of the COVID-19 pandemic were discussed by Dr. Ronis on October 16th. To highlight this effect, in one patient population, about one-third of pediatric centers treating children with intestinal failure requiring IV nutrition needed to address COVID-related food insecurity in addition to their patient's primary medical issues.

Next slide, please. Data shows that children with special healthcare needs access special education more than those without and also report seven or more missed school days more often when compared with children without special needs. In general, disruptions to routine from school closures can cause all children to have worsening behavioral issues or regressions. Dr. Ievers-Landis spoke about this on October 16th. For children with autism, these types of disruptions are magnified and can induce worsening repetitive or restrictive behaviors and decreased needed social interaction. And a rush to transition to online learning platforms, accommodations for those with functional limitations such as hearing or visual impairments, as well as those with individualized education or a 504 plan, may have been overlooked. Our institution and others advocated for children by addressing loss of school days services including school food programs and specialized therapies such as mental health services and occupational, physical, and speech therapy. The American Academy of Pediatrics has taken a strong stance for all children regarding school reopenings with the statement that all policy considerations for the coming school year should start with the goal of having students physically present in school.

Next slide, please. It should come as no surprise that children with special healthcare needs have increased healthcare needs. But in addition, families of children with special healthcare needs report decreased effective care coordination. Those who experienced inadequate care coordination reported having public health insurance or being uninsured and living at or below 200% of the federal poverty level.

Next slide, please. The COVID pandemic has reshaped the delivery of healthcare. We have transitioned many of our outpatient clinic visits to phone or telehealth visits. This increased access to healthcare for some of our most vulnerable patient populations such as those with neuromuscular disease and including those who would prefer delayed or non-access of care over the risk of infection exposure. Taking innovation even further, a case report of two patients with spina bifida cited the use of virtual reality to complete home physical therapy programs. The use of virtual platforms has improved care coordination and engagement with patient and allowed for parent-mediated interventions for children with autism. On the other hand, children requiring intensive outpatient therapy or residential programs have been negatively impacted as the pandemic forced closure or transitioned to online venues, which cannot replace the structure of these programs. Locally, we have seen a surge on our inpatient eating disorders unit where we have had to increase the threshold for admission and decrease the threshold for discharge in order to accommodate this vulnerable population of children in adolescence. Anecdotally, these patients are presenting with more acuity and requiring longer hospitalization. In preparation for the surge of COVID patients, many hospitals canceled elective procedures. For patients presenting with symptoms of inflammatory bowel disease, this has changed the diagnostic approach for endoscopy and colonoscopy with direct visualization and histology have historically been the gold standard for diagnosis. Also, management changes included the use of diet-based intervention to delay the initiation of steroids and other immunomodulation therapies until these definitive diagnostic procedures could occur. To protect healthcare workers and

patients, most hospitals implemented strict visitor restrictions, which may have further burdened families. In some cases, families may have had no choice but to separate from their hospitalized child, which can already be a traumatic experience. Delivery of home health has also changed. For example, without appropriate personal protective equipment due to widespread shortages, families have had to alter the way they manage their central lines at home, which includes reuse of gloves and other supplies. This in turn increases the risk of central line associated bacterial infections, which can be life-threatening. And last but not least, there was genuine concern from families about the ethical provision of care and resource allocation. COVID-19 prompted many states and institutions to revisit their crisis standards of care. With ventilator shortages and limited supplies of Remdesivir families worried about their child with special healthcare needs not receiving equitable care.

Next slide, please. We will skip the neighborhoods and built environment to spend some time on social and community context. Looking at pre-COVID data, mothers of children with special healthcare needs reported overall decreased general mental health and physical health when compared with mothers of children without special needs. We also saw more parental aggravation and difficulty dealing with day-to-day demands of raising children as well as decreased family resilience. Compounding these pre-COVID disparities, shelter-in-place policies, which are needed to stem the pandemic also resulted in the isolation of many families of children with special healthcare needs who may have relied on extended family, home health professionals, other community members, and school for respite. Financial stressors from COVID-related employment loss and food insecurity have also weighed in on these families. True anxiety for infection exposure may have aggravated underlying mental health issues. The social networks that parents have generally relied on may have been disrupted, and these normal coping strategies may no longer be available.

As you can see, all of these social determinants are intertwined and impact our children with special healthcare needs. The full impact of this pandemic may be unclear for years or decades to come. I agree with the epithet that we are living in unprecedented times, but I would posit that we have an unprecedented opportunity to form interdisciplinary partnerships to support our children with special healthcare needs at the individual, community, and systems level of care.

Thank you for your attention, and I will turn it back now to Dr. Hick, the moderator.

John Hick: Thanks Anna. So with all of these social determinants of health are being changed fundamentally with COVID-19. Is there a domain you're most concerned about and what should we be doing to evaluate and intervene in that domain?

Anna Lin: Thank you for the question. I think, for me, when you're looking at Maslow's hierarchy of needs, really having the economic stability and helping families socially is going to be most important. When -- I think we've seen a lot of food insecurity with our patients with special healthcare needs as well as employment loss. And the financial impact on these patients make it really hard for the families to actually focus on the actual medical issues at hand. And so, really supporting those families is important to us and engaging our social workers as well as our care coordinators to actually facilitate, whether it's transportation or gas cards to help them come to clinics or other types of resources.

John Hick: Thank you. The logistics have just become so much more complicated with COVID. So, well, we'll move across country here to the Midwest, and Rainbow Babies & Children's in Cleveland with Dr. Kim Burkhart. Kim, thanks so much for taking the time today.

Kimberly Burkhart: Hello. Thank you for the opportunity to speak. I'm Dr. Burkhart, a clinical psychologist at Rainbow Babies & Children's Hospital in Cleveland, Ohio. I serve as the ASPR Eastern Great Lakes Co-Chair of the Behavioral Health Workgroup. My area of specialty is in working with children who have developmental disorders and who have also experienced trauma.

Next slide, please. Developmental disabilities are deficits in areas that may affect thinking and learning, language, motor skills, behavior, and adaptive functions such as self-care, communication, and social skills. Some of the most common developmental disabilities include autism spectrum disorder; fetal alcohol spectrum disorder, which some studies suggest can affect conservatively 5% of the population, making even more common than autism spectrum disorder; attention deficit hyperactivity disorder, Down Syndrome, and rare genetic disorders. Some studies suggest that children with developmental disorders are up to 10 times more likely to experience trauma or adverse childhood experiences. Some of the reasons for this include that there's increased risk because of behavioral and emotional dysregulation, communication challenges, confusion related to appropriate boundaries, and increased dependence on others.

Next slide, please. Types of traumatic experiences that youth with neurodevelopmental disorders are particularly susceptible to are child maltreatment, various forms of abuse and neglect, foster care placement, and bullying. Worldwide, three in four children aged two to four years old are regularly maltreated. Like all other youth, children with neurodevelopmental disorders are also exposed to community violence and natural disasters. There's evidence to suggest that children with special healthcare needs are more negatively impacted due to increased difficulty adapting to changes and increased need of behavioral and medical services. It goes without saying that youth with special healthcare needs have been particularly affected by the pandemic.

Next slide. Maltreatment early in life damages the brain's physical structure by impairing cell growth, interfering with the formation of health circuitry, and altering the neural structure and function of the brain itself. Trauma affects the development and interconnection of the hippocampus and amygdala as well as other important brain structures. Also, higher cortisol levels are present, which is associated with hippocampal reduction. Accelerated loss or metabolism of the neurons in the hippocampus has a direct effect on memory, learning, and processing spatial information. Trauma may result in interference with activation of presynaptic and postsynaptic neurons and pruning of synapses. This leads to disrupted neural development, which results in social, emotional, and cognitive impairment. This then puts those at risk for adoption of health risk behaviors such as substance use and abuse. These individuals are more susceptible to disease such as cardiovascular disease and obesity, disability, social problems and various forms of autoimmune disorders and cancers. Research shows that individuals with five or more adverse childhood experiences die 20 years earlier than their same age counterparts who have not experienced adverse childhood experiences.

Next slide. When reflecting on ACEs, two adverse childhood experiences that are specific to the pandemic include traumatic separation from loved ones due to COVID-19 and traumatic grief due to loss of a loved one. Traumatic distress may also be experienced due to worrying about the health and well-being of caregivers who are first responders or essential workers. For children who have previously experienced traumatic loss, seeing death covered by media can serve as a trauma trigger. For those children who have experienced abuse, wearing masks and even being isolated can also serve as a trauma trigger.

Next slide. As I've said, being a child with special healthcare needs or with neurodevelopmental disorders, in and of itself, can serve as a risk factor for adverse childhood experiences and maltreatment. You take into account parent risk factors and the fact that some neurodevelopmental disorders have a higher genetic loading, and this increases children's risk exponentially. Moreover, severe mental health issues are associated with increased difficulty maintaining a job and can result in financial instability and living in impoverished conditions. In addition to parent risk factors associated with medical health, mental health diagnoses, we also need to consider that the risk increases when the parent has experienced maltreatment and/or lack of awareness of age-appropriate developmental expectations. Of particular interest, two of these risk factors, breakdown of support in child rearing and isolation have occurred as a result of the pandemic as has financial hardship for many of the families that we serve.

Next slide. There has been between a 30% to 50% decrease in child protective services reports during the pandemic. This has been attributed to the fact that one in five of those who report child abuse related concerns are teachers. With increased isolation, there's been less contact with mandated reporters. A study conducted early in the pandemic indicated that 61% of parents yelled at their children in the last two weeks and one in five spanked their children. Moreover, in a manuscript currently in preparation, Knox and colleagues found that hitting and slapping increased from 11.66% to 61.9% from March to June and insulting children increased from 7.42% to 63.3%. There is not yet a research based on how the pandemic has impacted harsh parenting or use of corporal punishment on children with neurodevelopmental disorders or children with special healthcare needs. Based on the data that has been collected, we would suspect that it would equally affect, if not more so, children with neurodevelopmental disorders.

Next slide. One strategy to prevent and intervene in response to child maltreatment is through providing positive parenting strategies. The ACT Raising Safe Kids Program was developed by the American Psychological Association, Violence Prevention Office. ACT is a nine-session two-hour group education program focusing on caregivers of children from birth to age 10. It is considered a primary violence prevention and intervention program. ACT is rated by the California Evidence-Based Clearinghouse as having promising research evidence and is listed as effective for parent skills training by the U.S. Department of Health and Human Services, Compendium of Parenting Interventions. The Centers for Disease Control and Prevention also named ACT an effective child abuse prevention strategy for enhancing parenting skills to promote healthy child development.

Next slide. Dr. Michele Knox, who is a Master Trainer in the ACT Program out of the University of Toledo College of Medicine and Life Sciences in Ohio, and I received funding to create a remote implementation guide for facilitation of the ACT Program. The goal of this

funded project is to determine the feasibility of the remote implementation of the ACT Program, conduct the program of fidelity at multiple sites, offer violence prevention and intervention for urban and rural families, gather report outcomes and characteristics of parenting, and to complete and disseminate an ACT remote implementation manual. Essentially, the purpose of offering remote implementation is to mitigate the impact of economic hardship, illness, and other stressors related to the pandemic on parenting and to promote social connectedness and to provide support.

Next. The ACT Program addresses five components: child development, nonviolent discipline, anger management and social problem solving, effects of media on children, and methods to protect children from exposure to violence. Parents with unrealistic expectations for young children easily become more frustrated. Parental understanding of child development also relates to the extent of parental monitoring, which is a protective factor against violence. The ACT Program addresses misattributions, characteristic of abusive parents, and helps parents to understand why children misbehave. The program also teaches parents what to expect from children at various developmental stages and how to use skills to guide children's behavior based on their developmental level. The secondary address is use of nonviolent discipline, or in other words, the use of positive and age-appropriate discipline. Research suggests that corporal punishment is often the first step in the cycle of physical child abuse and that corporal punishment and physical child abuse may not be distinct constructs or rather varying degrees of violence against children, which fall in the continuum. In addition to its strong association with eventual child abuse, meta-analysis representing research of more than 100,000 individuals in over 100 studies on the topic has confirmed that spanking and other forms of corporal punishment are related to increased aggressive and delinquent behavior in children or parent-child relationships, worst child mental health, increased adult aggression and criminal behavior, decreased adult mental health, and increased risk of abusing once on spouse or child as an adult. The ACT Program also teaches anger management and social problem-solving skills that are developmentally appropriate for both parent and child. In keeping with social learning theory, parents are taught to manage their own anger and model anger management techniques for their children to increase the likelihood of children's use of effective strategies. In addition to modeling, parents are guided in ways to teach their children to use developmentally appropriate methods, to manage anger and to solve social problems. The relationship between media violence exposure and childhood behavior problems is now well established. Research on the effects of violent television, movies, and videogames reveals unequivocal evidence that media violence increases the likelihood of aggressive and violent behavior in youth. These effects are evident in both, the short- and long-term. When children are aggressive, the overall risk of family violence increases. As a result, the ACT Program educates parents about the risks of media use and trains parents to reduce children's risky media use. Overall, violence exposure is considered a form of child maltreatment. The ACT Program educates parents about the impact of violence on children and teaches them multiple strategies to protect them from violence in the home and in the media.

Next. For those who do not have access to the ACT Raising Safe Kids Program or another form of parent training, but who need assistance in managing parenting stress and to make important decisions about their child's schooling, socialization, and medical care, Dr. Schreiber has created the 'anticipate, plan, and cope' approach along with the ASPR WRAP-EM and EGL groups. Dr.

Schreiber and I are in the process of adapting 'anticipate, plan, and cope' for parents of children with special healthcare needs. This self-guided decision-making approach helps parents anticipate challenges, plan to manage challenges by creating a family resilience map, and to cope by identifying and using new coping strategies. This strategy, which is designed to help parents inoculate against stress, is promising for mitigating harsh parenting.

Next. For general resources on positive parenting support, please consult AAP's Healthy Children website, the American Psychological Association, and the National Child Traumatic Stress Network. Thank you.

John Hick: Thanks, Kim. Is there a population of children within those categorized as having special healthcare needs that you're particularly concerned about during the pandemic?

Kimberly Burkhart: Yes. I'm particularly concerned about children who have neurodevelopmental disorders that are associated with emotional and behavioral dysregulation and executive functioning deficits, such as fetal alcohol spectrum disorder and prenatal drug exposure. Specific parenting skills are needed. There is already an increased likelihood that these children have been removed from their home and placed in foster care or in the care of multigenerational family members. In addition to parenting challenges that caregivers may or may not be equipped to handle, these children often have individualized education plans. It's often challenging to implement these IEPs virtually. Challenges also present then with educating the child which increases the frustration of both parent and child, which can then lead to increased harsh parenting.

John Hick: Thanks. Thank you, Kim. And now from the Midwest we'll go back out to California, and USC and the Keck School of Medicine, and Dr. Rita Burke to windup our formal presentations. Rita, thank you.

Rita Burke: Thank you. Thank you to ASPR and thank you to the WRAP-EM and EGL group for the opportunity.

Next slide, please. So, when it comes to disaster preparedness, the traditional guidance continues to apply with some added considerations. First, make a plan and practice your plan, make sure you're planning for this medication, batteries for electrical equipment, AC adaptors for small electrical equipment or assistance devices that your child needs. If possible, let your child help make the plan and being involved; this is a great way to familiarize them with the plan. Healthcare providers can work with families of children with special healthcare needs to make sure that child's needs are covered in the family emergency plan and to identify support networks in your community. In addition to the traditional disaster kit, keep a copy of all medications handy. Talk to the child's physician about medications and how to get an emergency supply of medication and make sure that you have all the supplies necessary for your child's needs. When it comes to staying informed, it's important to know what's happening with each of your family members and have a plan for when you're separated during the day. The likelihood of a disaster happening during the day when you are separated is very high. Know the emergency planning of your child's school and keep your emergency contact information up to date. Have a close family friend as an extra person who could pick up your child if you or someone else in your

family is not able to do so. Have someone that your child trusts and is comfortable with in the event they are not able to contact you.

Next slide, please. Enacted in 1975, the Individuals with Disabilities Education Act, also known as IDEA, formerly known as the Education for All Handicapped Children Act, mandates the provision of free and appropriate public school education for all eligible students aged three to 21. Eligible students are those identified by a team of professionals as having a disability that adversely affects academic performance and as being in need of special education and related services. Right now, we know there are about 55 million children that are missing in class instruction. Of those, about 14% or a little over seven million have special needs and require services in public schools. So, we know that these students are missing their physical speech and mental health therapy, and we heard from Dr. Lin about the social determinants of health. So, this adds an added layer to the complications that we're seeing in the pandemic.

Next slide, please. This is data from the Pew Research Center that shows the change in percentage around disabled student population across states. Starting around 2017, we see an increase in the percentage of disabled students that require services from public schools in each state.

Next slide, please. This is data from the National Center for Education Statistics that shows the percent of students by disability. So, we've heard that nearly one in five households has a child with a special medical need. This includes some chronic/acute life-limiting illnesses like cancer, autism, genetic conditions, and those who may have visual and auditory differences or suffered trauma. Now, let's think for a moment about the current shelter-in-place order that's still in place across many states, and that is the current setup for many students right now. Children with autism may have difficulty sitting still and may need more physical movement. Those with sensory impairments may have a really hard time interfacing with the current tools that are used like Google Classroom and Zoom. Interruption of the requisite therapies that we talked about can have long-term consequences on children with developmental disabilities and keep them back. Cessation of regular physiotherapy may worsen functional ability and cause complications. Lack of a daily schedule can be challenging for children with autism, resulting in irritability and temper tantrums. No kids right now across -- nationally are struggling in this virtual setting, but it's even more challenging for children with special healthcare needs.

Next slide, please. Now, I want to take a moment to pivot and to discuss some of the work that we've done with our local school districts in collaboration with our local public health department here in Los Angeles. We used a mixed-method approach where we administered a short survey to parents that have shown special healthcare needs about basic preparedness and also conducted focus groups. So, what did we find? Here, this is a selected summary of the survey results and I want to bring your attention to some key findings. First, not surprisingly, we found that only 15% of parents had an emergency plan. When we asked them why, the majority said they felt it was too difficult to complete. We also found that only 15% had an emergency kit for seven days, although a greater percentage had a kit for three days, with the same reason that this was too difficult to complete. Keep in mind that for many of these children this could be a matter of life and death.

Next slide, please. Now, here I'm going to show some of the qualitative results that we found, some of the quotes to illustrate the points that I mentioned around having a plan, making a kit, and staying informed. Also, we conducted a study before COVID hit, the themes that I'm going to discuss are still relevant right now, perhaps even a little more so.

Next slide, please. We found that medication is certainly on parents' minds and they recognize the importance, but they're not sure how to secure the additional dosages from their physicians, and it highlights the challenges they face in creating a kit for their families and children.

Next slide, please. Parents also recognize the importance of being prepared, but it's not something that's taught or readily available to them. There's a lot of confusion about all the information that's out there. There's a lot of information and they are confused and not sure about what information is accurate and what is a reliable source.

Next slide, please. Parents recognize the importance that they need to act and they may have taken those steps in the past, but due to certain challenges, bandwidth, they are unable to update those plans and to take the necessary steps.

Next slide, please. A surprising finding was the lack of communication between parents and schools. This is one example, but overall parents thought that schools somehow knew about the specific needs of their child and the schools were certain that parents would come to them with their child's specific needs. We discovered this huge gap that existed in communication between the parents and the schools and may potentially have the children with special healthcare needs fall through the crack. So, we realized that this was a key issue that needed to be addressed.

Next slide, please. Based on that information, we created a resource for parents with children special healthcare needs, and I've included the website where this can be found on our partner at the Los Angeles Children Public Health Department. We developed a one-page guide where it organizes the necessary steps into more manageable pieces. The first step encourages parents to communicate with the school, learn what their plans are, and what is available to them. Next, we describe some steps that they can take in order to be more prepared. Once they have done that, then we offer some additional steps that they can take for their child's specific needs. This was based on feedback from the focus groups that we conducted with parents who wanted additional preparedness information that was brief and almost like a checklist that they can go through and check off as they completed each item.

Next slide, please. Thank you so much, and to that I turn back to our moderator.

John Hick: Thanks, Rita. With all the changes to classroom learning like hybrid and online that we're seeing during COVID-19, what do you see is the major challenge for children with disabilities that require specific attention?

Rita Burke: It's a good question. I'm really concerned about those with learning disabilities and sensory disabilities because the current learning environment makes it much more challenging for these students, and we really don't have any accommodations that can in any way alleviate

those challenges, and as a result they may be left behind depending on how long this online or hybrid learning continues. So, those two groups are really my biggest concerns.

John Hick: Great. And I have a question, Anna, for you. How do you people access the materials of the ACT Program?

Anna Lin: I didn't talk about the ACT Program.

John Hick: Oh, I'm sorry. That's for Kim. My bad.

Kimberly Burkhart: No, that's perfectly fine. So, you can access the basic components of that program through the American Psychological Association's website and just typing in 'ACT Parents Raising Safe Kids'. And across the country there are different training sites and different organizations that are listed that offer groups. And as I mentioned, this is the first study that we're doing looking at remote implementation. Right now, we're focusing on the State of Ohio, but soon we will find out if we receive funding to broaden that to across our country.

John Hick: Great. Thank you. And now a question for Anna. Have there been an opportunity with state-based Medicaid waivers for home - and community-based services to leverage those to support families during COVID-19 specifically as it relates to remote learning or for physical supports or activities of daily living?

Anna Lin: I don't know the answer to that question because that's a little bit outside of my wheelhouse. I would say that anything that we can do to support our children with special healthcare needs and their families is really important. I know that locally we've actually worked with our schools to actually provide school-based food services and a mechanism of delivery to the family so that doesn't provide an additional hardship or burden for them. And I'm sure there's other agencies that have actually reached out for that. Maybe one of our other panelists may have more insight onto that.

John Hick: Great. Kim, Rita, or Chip any other thoughts on federal other programs that are special and/or being leveraged to provide additional support?

Rita Burke: I can speak to what's going on in Los Angeles for our public health schools that have really stepped up and meet needs that are generally outside of their scope. So, they have set up food distribution sites to ensure that children who are experiencing food insecurity will not have to, and so that they have sites where they can pick up food. They've also started some other programs to try to kind of bridge that gap of the services that students with special healthcare needs are not receiving due to school closures and online learning, and so enacting telemedicine type of services.

Merritt Schreiber: And John, I can make a comment.

John Hick: Yes, please.

Merritt Schreiber: Yeah, so we have an initiative separate from the ASPR Pediatric Centers that's funded by SAMHSA. And it is focused on a rural -- a set of rural school districts in Sonoma County that have been hit by multiple presidentially-declared disasters, plus there's a significant ACEs burden and likely special healthcare needs burden also in those communities. And that is a stepped continuum of care, a telehealth initiative that is using trauma-focused CBT to reach families that because of COVID are impacted and also not able to access traditionally available services. So, we're really excited about this new initiative that SAMHSA has funded.

John Hick: That's great. And I'm glad you touched on that Chip and I'll throw this to you first and then open it up to our other panelists. How are we providing the more routine therapies or assessments for children that are in need of them, right now, not only with difficulties with in-person visits, but also just access to transportation and other services that are needed to support those usual visits? What are we doing to do things differently and yet still meet the needs?

Kimberly Burkhart: Well–

Merritt Schreiber: I'm sorry, go ahead.

Kimberly Burkhart: Thank you. The majority of my clinical practice is done virtually, either through HIPAA compliant Zoom or Doxy.me, we're doing evaluations that way as well, and there's been modifications that have been done to standardize testing protocols, including some that evaluate for autism to provide a telehealth modification.

John Hick: Great. Other comments on different delivery of services or learning?

Anna Lin: Yeah. I do agree with the telehealth, that actually has been a boon in terms of access to healthcare which we had the capability prior, but we really never used it to the extent that it has been used in this pandemic. We have actually, especially not just with our children with special healthcare needs, but our children with medical complexity used telehealth formats to actually engage multiple providers at the same time so that we can actually improve the care coordination for these patients.

John Hick: Great. I want to finish out -- oh, go ahead.

Merritt Schreiber: No, I was just going to echo that. I think that the whole aspect of the telehealth specific to kids with special healthcare needs and children in general, we really need to understand that better. I think it's definitely the case that in the mental health realm such as our SAMHSA project in Sonoma County, we've been able to actually improve some service delivery using telehealth because there has been an increased availability of telehealth services. And more generally just telehealth for children in disasters. WRAP-EM has a telehealth/ telemedicine working group that's led by UC Davis and a group at Oregon Health Sciences University. And I think we're going to see some data coming out, some survey information, kind of looking about how telemedicine for kids has been adapted around COVID. So, standby for those findings to come out.

John Hick: It's one of the biggest public health experiments we've ever conducted, right? So, this is all going to be interesting. A couple questions around equity, and I'll start with one for Rita. Is there a socioeconomic disparity associated with ability to create disaster kits at home?

Rita Burke: Well, absolutely. And there's a lot of data out there that supports that because if you think about what goes into a kit and we're asking people to do. So, for example, have at least seven-day supply of food, of water/light, that if you are living in a situation where you're food insecure, so you're not even sure if you're going to be able to put dinner on the table tonight, how can we ask you to think about having a food supply for seven days, let alone when you can't even be secured what you're going to have for dinner? So, we know that there is lot of disparities when it comes to creating disaster kits and, trying to come up with creative ways about how to help and empower people to do that. And I think a lot of times people get discouraged because it seems like such a huge undertaking by trying to divide into more manageable pieces and just focusing on one small piece. Even just being aware of it is the first step and may already increase their preparedness.

John Hick: Yeah. You can't fill the gaps until you identify them, right?

Rita Burke: Exactly.

John Hick: Someone else had a comment about that? Otherwise, I want to throw out a question a little bit more broadly about equity and especially our communities of color and how children with special healthcare needs are not getting needs met within those? Are there any specific programs that are available currently or any policies that we should be pushing for in order to make sure that we are maintaining fair and equitable access for our at-risk communities?

Anna Lin: I think one of the things that we may consider was making sure that if we're trying to support telehealth or virtual visits that our patients actually have the ability to -- and the internet bandwidth and the software to actually participate in that form of telehealth access. I know that locally we've had a lot of families who have some socioeconomic issues be provided with internet services. And this is also with respect to school services as well which are largely online and distance learning at this point. And so, just kind of being supportive of that so that we can actually have equitable access to both healthcare and education is going to be really important.

John Hick: Yeah. I'm glad you mentioned both healthcare and education. I think we struggle with both. Other comments on -- from an equity lens, and -- and this doesn't have to be just communities of color, it could be rural/urban, it could be other inequities, but I think COVID is laying bare a lot of -- and exacerbating a lot of these things that we're going to have to really take a close look at how programmatically we create public-private partnerships to solve some of these. Other comments?

Rita Burke: Just one quick note about telehealth. I think you are correct and that this is one big public health experiment and we found that it has alleviated access for some particularly vulnerable populations, and perhaps we can start thinking about how do we continue these telehealth programs even after there may not be as critical of need for them because the pandemic subsides.

John Hick: Great. Well, that's all the time we have today. But Chip, Anna, Kim, and Rita, thank you so much for a great dialog, great information. I will turn it back over to Audrey Mazurek for closing comments.

Audrey Mazurek: Great. Thank you so much Dr. Hick and thank you again to all of our speakers. As Dr. Hick said, that is all the time we have for today. Again, this webinar was being recorded and the answers to the questions that were submitted, but were not able to be asked during the live webinar will be answered directly with you via email. On behalf of the ASPR TRACIE team and the ASPR Pediatric Disasters Care Centers of Excellence, thank you for joining today and have a great day.