

A Family-Centered Research Agenda for Supporting Caregivers of Children with Special Health Care Needs

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Hello and welcome to today's webinar. A family centered research agenda for supporting caregivers of children with special health care needs. Next slide? My name is Ryan. I am a pediatrician at the University of Wisconsin, Madison. I am thrilled and honored to have the privilege to be moderating today's engaging discussion. We are recording this webinar and it will be available on our website in the coming weeks. Next slide? Joining me today are three distinguished experts. For Hoover, the project director at Family Voices, Renee, chair of pediatrics and pediatrician in chief, General Peter Italic -- and Debbi Harris. As you have seen in the biographies, each member of today's panel has unique and specific expertise in the subject matter for today's webinar. As the lead author of the article behind today's organization, Clarissa will help us with this. Then we have highly insightful and thought-provoking perspectives, and following this discussion, I will be back to moderate the dynamic question-and-answer section. Next slide. We are offering live captioning for this webinar. You can access the captions by selecting the closed captioning button at the bottom of the Zoom screen or click the link in the chat to view options. If you're having any technical issues, please enter them into the Q&A and we will try to assist you. Next slide? Ask the questions. We want this to be an engaging conversation and encourage all attendees to submit questions in the Q&A box. We will try to get as many as we can get through today. Next slide?

To orient us to how we got through today's webinar, I will share a brief background. Today's webinar dives deeper into one section of the national health systems research agenda for children and youth with special health care needs. This was developed as part of a five-year collaborative agreement with maternal and health bureaus -- the purpose behind this agenda began with acknowledging the key outcomes that proved stubborn for this population. Despite having a larger volume of research output, along with guiding materials like these outcomes and the standards for systems of care for children and youth with special health care needs led by the Association for Maternal and Child Health Programs and Health Policies. The promise for having a national research agenda is it will complement these efforts that is shining the spotlight on family priorities and coalescing stakeholders around a cohesive set of research priorities and standards. Next slide? The framework for the national research agenda began in 2018 and was developed through engaging hundreds of stakeholders over a series of complementary processes, including divisions of open ended ideas and robust prioritization method called the RAM UCLA Appropriateness Methods. This background was published in 2020 and now we have this summary of each of the six key resource areas published as a series of articles and academic pediatrics with support from other foundations each article summarizes key knowledge gaps in recommendations for future research in one of the six topic areas. Webinar in December discussed healthcare transitions and today, we are discussing the second of these topics, caregiving at home. Other topics will be discussed in future webinars. With that, I will turn it over to those you want to hear from, beginning first with Clarissa.

Thank you very much, Ryan. So, I wanted to start by talking about how we conceptualize caregiving for this research agenda. We are focused on children and youth with special healthcare needs in terms of the expertise. We are little more focused within the medical complexity subset of that larger definition, but we are really thinking about those who have special healthcare needs. Really, a key distinction that we want to make is between the idea of caregivers and who they are and what they need, and the work of caregiving, as an activity that contributes to the well-being of children and those with special healthcare needs. We want to have everyone thinking about the fact that caregivers -- they are to caregiving as doctors are to medicine. Are two different areas and the national research agenda addresses these two topics separately. Types of caregiving include family caregiving, which may be either paid or unpaid -- often unpaid. Professional caregiving that happens in the home health setting. And there is institutional caregiving that happens in the institutional setting. Next slide, please. For today's topic, we are not really talking about caregiving or professional caregiving in the institutional setting. We are focused on home health, including family caregiving, unpaid and paid, and to some extent, professional caregiving that is provided within the home. Next slide, please. So, I mentioned that we are thinking about caregivers and caregiving as two separate things. I want to do a brief discussion about the article on caregivers and family support and family health. It -- it is not a phrase we prefer, the word "burden." We think it is the labor of love. It is parenting. It is family love. It is not that different from parenting or family care that happens for other children, other than the intensity and difficulty that it presents. The article on caregivers is a resiliency orientation. We are focusing on the resilience that families bring to their situations and how they contribute to their own health and improvement, and the needs of the family in general. That is another version of a strength-based orientation that we are focusing on, this topic of resiliency. It is thinking about giving caregivers support and it being an opportunity for emotional support or an opportunity to recognize the special needs that caregivers have because they are caregivers. That is an area that definitely overlaps with what we will talk about for the rest of this session because caregiver support can't address the personal needs or address caregiving related needs -- work-related needs. If we will conflate those two different kinds of support into the same types of interventions, we have to keep in mind it is two different things. The emotional needs caregivers have because they are caregivers, and the work they do because they love their children. Finally, one of the things that is a big interest is thinking about how caregiver health and sibling health and other health impacts the health outcomes of children and youth with special healthcare needs. Again, distinguishing caregiver health from caregiver work. They are both very important but we want to be keeping in mind, especially with research, that they are not the same thing. There are different issues involved. Next slide, please.

So, for the remainder of this presentation, I will focus on the caregiving paper. Not the caregiver paper. These are the two questions that were generated in the research agenda process that Ryan described earlier. How can the optimal level of home support, including home healthcare, that a family needs to improve child and family outcomes be determined and achieved? And how does reality uniquely affect children and youth with special healthcare needs and what are effective interventions to support them and their families living in rural settings? Next slide. In order to respond to these research questions, I want to start out with a general recommendation. One of the reviewers in the article called us on the fact that this was not completely clear, so I am making it very clear the article is in bold and the presentation gets its own slide. All the projects from the research agenda and the projects suggested from our paper and projects that are suggested in other articles in this supplement

should be carried out with youth and family partners and with the intent of being family driven. Family engagement, youth engagement, community engagement will be an essential component of how all of these things come to be and how they are successful with our goals. Next slide, please. so, in terms of our recommendations for how to respond to the two research agenda questions on caregiving. Our first research concept was to develop a conceptual model of caregiving that acknowledges the volume and sophistication of connections and resources needed to care for children with special health care needs at home. So, in order to start thinking about what this model would look like, I am taking a personal example. Eleanor is my daughter. You can see pictures of her there, when she was maybe four years old, and then when she was a new driver at the age of 16. She is now approaching graduation. Who takes care of Eleanor? Herself, about 1 1/2 hours a day. Her father, every day. She is currently living at his house full-time, so he takes the rent of it. Her mother, most today. Her boyfriend, most days. All of those numbers are related to healthcare only. Are not talking about general care or love or friendship or anything. She sees a therapist once a week. She sees her teachers, of course, most days and I think about her health needs pretty often as well. She has a care coordinator specific to her health care needs, who I would guess probably need to work on issues relating to her about once a month. All other healthcare providers combined -- they are every three months or less. That includes the rest of the specialist who deal with her healthcare condition and home health and other needs of that nature that she has. Eleanor does meet the definition for medical complexity, no matter what you look at. But she is kind of on the edge of that. You would have to look at each individual definition and say, yes, I guess that does apply. We will hear from Debbi, whose son is so much more complex than Eleanor, and it is really just a different world, relative to what our experience is. That was our first research idea. That is just a little bit of thinking about what that model might look like conceptually. Next slide, please.

So our second research suggestion, in order to respond to the research questions, was to do social network analysis, to quantify the relationships and pads of the conceptual model and introduced -- we are covering contributions key to health outcomes. So, here, again, I wanted to share an example. This is a violin lesson. What does that have to do with health? The violin teacher was not listed on the previous slide because Eleanor is not taking those lessons anymore, but for much of the last 15 years, she would have been in that list of weekly contributions to Eleanor's health. These are some of the ways that she contributes. She gives us a chance to be vulnerable or normal and take more important activities. That is important for those that are not necessarily experiencing unusual needs every single day. It is willing meaningful to us. Working for medical trauma. If you see this little guy in the photo, he is obviously a beginning violinist. If there was a teacher, she would have her hands all over him. She would be straightening him up and repositioning his hands and repositioning his violin. With Eleanor started taking violin lessons, every single time, somebody smiled and reached for her, she would visibly cringe and shrink away because the friendly people who reach for you are going to hurt you in her world. Is the number of shots and other procedures that she had over the years of doing violin lessons, she learned happy people are helping you, which I think also extends back to accepting some of the things that she is going through in the healthcare realm. Then mandatory socializing. Or reason to get out of the house. It is hard to express how important that is in the lifestyle we are living. You will have to take my word for it. I think Debbi will illustrate that very well. A weekly consultation when we are in violation lessons. This was the only person sitting down with me every week, to talk about her development and needs. When I say she was a healthcare provider, like, it was just really, really important to have her input and help. Finally, having a task that is challenging without

being life-threatening and learning to enjoy striving for something, rather than everything being so fraught. Maybe even Regent, as term -- next slide, please.

Our third recommendation in terms of responding to the research agenda is to do randomized controlled trials. And this is recommending this method and applying it in a lot of different ways, particularly as it relates to health equity. So, to go back to what the paper says again, approaches for remedying health inequities by supporting the work of diverse family caregivers needs backing from a strong evidence base. That is what the trials are therefore co-. Not just to answer the big questions that apply to everybody, but to answer the questions that are incredibly important to smaller groups, to subsets of the community. What does the evidence say? Here is some of the evidence that I would have. What does it mean to me? What does it mean for where I live, for my race, for my rare, genetic condition, for my work schedule, for all of the things that make things work out differently for me, compared to the idealized or average situation? Does the evidence answer the questions that I have? Does it really matter whether it is special healthcare needs or q8h? Those are pharmacist abbreviations. Tid means three times a day, but q8h means every eight hours. A lot of people writing prescriptions might consider those to be interchangeable in an institutional setting. They are but it is happening every eight hours. If you start a dose at 4:00 in the afternoon at the hospital on the first day, they will wake you up at midnight every single day to give you the doses eight hours after four hours and then they will come to you again to give you the next dose eight hours after that. That is the entire time you are there. At home, we do not necessarily do it. We have it when the kid gets in the car or after school or when they get up in the morning. First thing I do is hand them the dose. The second thing I do is say, hey, how was your day? And then before bedtime. It is not too different from eight hours but is a little difference. I give her a dose and I take an hour of "me time." Then I fell out of the forms in order to get a 2:00 dose an hour before school gets out. Trying to go through that quickly but I hope I am painting the picture of how big a difference that small change makes. The last kind of question I have for the evidence is, are we choosing questions that are easier to answer over questions that need answers? Are the limitations of research driving what research questions we are asking? Or is the idea of trying to benefit everybody rather than benefiting those experiencing health inequities and really need the answers driving our questions? If we find that the tail is wagging the dog, rather than the need of answers pushing what research can do, how can we push everything to make sure those questions are getting answered? That said, I'm going to hand it over to René. Thank you very much for your time.

Thank you. To transition from that wonderful topic. That was really framing the work that we do. I want to talk from the healthcare provider perspective. I like to see patients in my practice. One of the things with his work that I have reflected a lot on and for many of you in the healthcare sector, you might think about this a bit -- through the course of my day of seeing patients, I am often very aware of who is at the front desk or my Medical Assistance and my nurses. If I do not have those registering patients, helping me with -- helping me with some of the activities, I am not able to see patients. I am not in a position to take on multiple roles within my practice. I do not even know how to register a patient and I do not have access to that in my electronic healthcare record. I do not have access to order certain things that our nurses do or administer. I cannot even take on those roles. I think it is an important caveat. I think about what we are talking about with caregivers and the caregiving at the great analogy that Clarissa presented. When we think about, often, when I see parents in practices and I think about the medical complexity and I think about the first time I might meet a new patient or a parent, who was coming out of -- let's say the NICU or they might be on a respirator. But I often say is, in many ways, we sprinkle pixie dust on you and we give you a

couple of weeks of training in the hospital. Sometimes, I have a great dialogue with parents where they might say to me, I have no interest in ever wanting to do anything medical. We find ourselves, where many of our parents are becoming a caregiver are doing the caregiving because, you know, they love their children and will do whatever is needed. When we think about that in all the roles we practice and the amount of training and schooling and it is all by choice at the outset, the situation sometimes -- I think a lot about caregivers and our children and youth with special health needs. They go home and, as we move along, our caregivers are now taking on the roles of, many times, physicians, nurses. I said to a parent, you have trained more of this than I have within 20 years of being a pediatrician. They are taking on these roles. Also, often, they are working closely with home care agencies. Let's say they have home care nurse who is called out or unable to come. They are also managers. They are managing schedules. They have phones. You know, they have phones and numbers that might be very dedicated to managing staff in their house or managing multiple nurses. They have calendars and they are managing schedules. Not just their own and their family, but multiple therapists of people coming in and out of the house. They often also -- you can keep going through. They find themselves also in situations where I think about the recent pandemic, where we pivoted to virtual. We have children and youth that we have receiving occupational therapy, speech therapy -- now it is through Zoom. They are becoming physical therapists. So often, I have had parents talk about how caregivers, how they are finding themselves, you know, doing maneuvers. They're not trained to do it and it is very intimidating to be on the screen, assuming the function of a therapist. They are also managing medications, refills, getting prior authorizations. Thinking about, do they have the equipment needed to administer those medications? They might think about the virtual world. With COVID -- some of our families are homeschooling, whether they are homebound or virtual, and assuming, you know, it might be individualized education plans. They are also thinking about medical equipment, understanding it in a realm where I often think about some of our families -- their living rooms or houses have become mini-ICUs. They have plastic containers -- they have to store 30 feeding bags that are coming every month and sometimes the equipment is incorrect. They have to think about access or not enough. Thinking about transportation, where maybe they have to either convert their own vehicle or think about, if they do not have that option, how they will get to appointments and to school and to participate in family events and be part of their communities. Also, just thinking many of our families, as Carissa said, thinking about siblings. There are chronic medical complexity is that you might be managing. We layer all that on. We think about the COVID pandemic. COVID -- think about all that going on and now you have a pandemic, where maybe your shift of nurses cannot come or you do not necessarily want nurses in. You do not know if they are vaccinated or you cannot control that or you do not know if they are tested, and now you have someone in your home. Or maybe they are calling out and you cannot get to your job. When I think about our staff in the hospital, and they call out, or I go on vacation, I have paid time off. Our caregivers do not have that. You know, I think about many of our family members during the pandemic. They were, at times, finding themselves finding themselves doing 24 hour a day care. Go to the next slide.

In the article, one of the figures I think is really poignant to me, that underscores a lot of what Clarissa eloquently talked about is this framework. It really conceptualizes the healthcare services and research, based on whether they are family centered, system centered, neither, or both. If you look at the bottom right-hand corner, where it is family driven and circled in red, that is the best quality of the family centered care. It means our families have primary decision-making capacity in the care of their children. This also includes the procedures, the

policies, the relationships, everything governing that care for their child. That family driven approach and research really focuses on the needs and the goals of the family as the driving force, shaping the healthcare system and the family caregiving of the child that we are all caring for. I really like this figure and I think it drives home a really important point about family driven care as we think about the research agenda. You can go to the next slide. I wanted to talk a little bit about, you know, as we think about the research and this relationship that we think about with families and home health and the health care systems, and really this conceptual model for us, as we think about -- hopefully you can see or view the paper. We are talking about reframing, looking at things holistically. Part of that in the research agenda is understanding, acknowledging, and honoring the caregiver work, and I think it is really important, just to underscore a point that Calista made where can they take away the idea of the caregiver as a burden? Thinking about goalsetting and care mapping. Really thinking, you know, we want to understand that family driven approach, focusing on research, where we look at the resilience, that families are, you know, responding to the role that they have on their child's health and looking at research that also looks like the relationship between families and the various home health, other partners and systems that are needed to help care for the children. And, when we think about the assessment and measurement. Some of the things that are mentioned in the article are things like technology and telehealth. Thinking about things like inequity or equality. Thinking about the digital divide. Thinking about that rapid pivoted to telehealth that we all saw during the pandemic. When we think about technology, we are looking at what Clarissa pointed out, thinking about technology and telehealth and ensuring that it is equitable and that it is adaptable and it is affective. It is not enough to give, you know, a family, you know, a powerpack for Internet and not really understanding what it would do and really thinking about access to care, access to services for our children. Families living in rural areas. Also, thinking about transitions. When we talk about that, I really think it is important that we underscore we are talking about transition from hospital to home and, you know, adult oriented systems, and different care -- transitions of agency and insurance. A lot of things differ in the experience. Also, we talk a little bit about this, the health-related quality of life that exist for the child and the trust that is needed for better relationships between family, caregivers, and healthcare professionals. Also, as was previously mentioned, the social networking. Also the social network analysis. There is a whole pedagogy of research. We look at all of the things that are related to how health caregivers support each other, as well as within the system. I think, what is so important is thinking about the honoring the culture and ethnic diversity and that health equity has to be present, omnipresent. We have to think about the entire population with children and youth with special healthcare needs and think about race, ethnicity, geographic's, you know, thinking about urban areas and rurality. We have to remember that they are not defined by their healthcare conditions alone. So, thinking about, you know, those outcomes with that lens and ensuring the impact of the social determinants of health are drastic considering the research. You can go to the next slide. I say to you, as I close my comments, it is to think about our caregivers. We are thinking about this reframing. We talked a bit about the invisibility. So I would say to you, think about caregivers as visible. Think about them as part of the healthcare workforce. The experts in their child's care. Really, meaningful partnerships that make them holistic and really represents the life of the caregiver and their families. With that, I would like to turn it over to my colleague, Debbi. Thank you.

Hello, everyone. I am Debbi and I am here to kind of show you the real-time version of caregiving. Our son, Joshua, has complex medical needs. There have been times where we thought perhaps we were going to kind of have an easy road for a while as he became more

stable, but it is always up and down, with the complexity. It is a roller coaster of events and they do not seem to stop. Next slide, please? So, this is Josh. I want you to meet him. This is when he was at an infant. I know that he looks very antiquated -- that is what it looks like when Josh was there and he was in that first little stall as you came through the NICU door. That was reserved for the sickest babies. At the time, we had about -- he was probably the biggest baby at 3.5 pounds in the NICU. This is Josh now. Actually, the photo in the upper right-hand corner is Josh right now. The bottom one with Josh and myself, that was taken a little bit of time it. And then, the photo where he is at his physical therapy session was, of course, before the pandemic. We have an amazing physical therapist and has been with Joshua White since he was six months old, well over 20 years. They come to the house to see him. Those times, where he can go there, it shows how he really developed in his ability to kind of coordinate his body. There are no strings or anything attached. So, this is the sign on your left that we have as you come to our door. This was actually before the pandemic, but we wanted everyone to know why we have certain rules and conditions before you come into our home, because, well, something might seem mild and not relevant to most of us, but Josh, having exposure to a person with an illness, canned and up in the hospital or in the ICU. That is Joshua this past week. He has a new planetarium projector for his birthday, which is January 10th. He loves it and he just loves to stare at those colorful stars. As a matter of fact, so do I. I love to sit down in his room and we will listen to stories and watch the stars. Josh, you cannot see it but he has an iPad and he loves to watch the news, of all things. It is something that came about when my father, who passed away in 2018, would actually come to help us take care of Josh and he came every evening for five evenings in a row during the week, and he was Josh' person. Even though he is gone now, Josh still likes to do that and I think it gives him a sense of place and security and safety. So, that is Josh's room. So many of the things that we kind of take for granted, that we do, I do not know if you realize what has to go into it. There are times where you have all the meds memorized in your head. You still have to check, no longer -- it takes about 45 minutes in the morning to get ready with his meds. He has about eight pages of meds. He does get ready for that three times a day, Clarissa, with the tid. Next slide, please? This again is Josh's room. We post just -- we have so many different people coming into our home, looking after Josh one way or another. That is by his bed. We also have an air purifier over a bike the nurse's chair and we had to install one on our furnace to try to get rid of as many microbes as we can, to try to keep Josh well. Josh is on a ventilator. At least eight hours a day. Yesterday, he was just not really wanting to wake up and reminded me of that song, "today, I just do not want to do anything. I just want to stay in my bed." It does make it a little bit more difficult during these times because we are being rationed for the tubing that goes with the ventilators. We are being rationed, regarding gloves, for our staff, and we have to have someone watching Josh 24 hours a day. Our daily company is now only allowing three [Indiscernible] gloves per month. We have to purchase those on our own. There is Josh in his topic. We did have our home remodeled to have a walk in, but Josh -- he zips in from the ceiling. We dropped him down there and he has a special seat that we had our team, people at the hospital -- [Inaudible - static] it is wonderful for his muscles. Next slide, please. Those are Josh's meds. As you can see, there are a lot in the top drawer. There are his respiratory meds that you cannot see. My husband is the person who loves spreadsheets and Excel, so he is the actual spreadsheet that -- the physicians for each medication, when they were last ordered and when they have to be ordered again. He also has a spreadsheet, as you can see, the little clipboard on the left. He keeps track of the schedule for family members. We are kind of his PCAs. We have people we trust -- we do not want strangers coming in really. Josh does have orders for 24 hour nursing, but it is very difficult to get that right now. We do have nursing care as well. Everyone reports to my

husband for their availability once a month and he comes up with those schedules and we know who is doing the day shift and the afternoon shift and that night shift. Last night, the night before, my husband was doing the night shift and my son, my older son, was doing that night shifts. He has his own family and still does the evening shifts. I often do the day shifts. Nursing is really hard to come by these days, so you have to kind of make it as competitive as possible. That is the nursing area on your right, where we have a mini refrigerator and we keep Josh's things there. We also have a toaster and a coffeepot. It is almost marketing plans you have to have, to draw nurses to your home now. The bottom to the left is where Josh Cohen's elevator is, coming into our downstairs living room. It was very difficult, as you can see, where there is a platform coming down the stairs. Josh Cohen wheelchair weighs about 189 pounds. He weighs 100 pounds. Trying to maneuver the chair and Josh -- you cannot see it but there is a tiny foyer area, to get him on and off the chair is extremely difficult and takes a lot of strength and as we get older, we have to have some alternatives. Also, with the platform, it is probably broken down with probably 15 times over the past 15 years, and the last time, the power supply failed -- it was right when I was underneath it and it just came right down on my head. The middle picture is what is really important to me because that is entering into the nursing area. When we first saw this home, it was quite a long time ago, and we went down that hallway and we sought to the right, there was this huge storage area, and to the left, a nice, huge area for nursing staff and we thought, this is the house for us because it met Josh Colette needs. Previously, we were storing everything underneath the stairs in our tiny home and in the garage. Next slide, please?

So, like I said before, one time we went -- I don't know, if you month where Josh had no hospitalizations or surgeries and we probably had great nursing staffing. I was thinking we were on easy Street. So, I remember saying, because we got -- he got very ill and ended up in the NICU. I remember saying to one of my favorite physicians, I thought we were done. I thought we were done with the hard stuff. He said, Debbi, you will not ever be done. I could not see that far ahead, knowing as he grows and as we get older, there is always going to be difficult times. The photo to the right is just -- he had pancreatitis and -- I cannot even remember what else, but he ended up in the ICU, in the adult hospital. It was our first time transitioning to an adult medical system, where we did not know anyone. But I will say that our complex care clinic and the physicians in the ICU coordinated so amazingly that it really made the whole thing survivable for us. Because they were in constant communication with one another regarding Joshua, it helped a very difficult time -- it was not a great prognosis and it turned into something completely different. The photo in the middle is when Josh got home from the ICU, and all the time in the hospital, he did not open his eyes or wake up or react to us. As soon as we got him downstairs and we said, Josh, you have to go to the family room, we have to strip down your room and disinfect everything, Josh just -- we turned on the TV and he opened his eyes and started watching his news. It was an amazing experience, even though it was a difficult one. I mentioned the health of caregivers. I just showed that photo because -- full disclosure, I have chronic and acute anemia. I have to see my hematologist every three weeks and then every three months for possible infusions. Under what they might call the burden of caregiving, it is not really a burden but just a different life of caregiving. You have to also deal with aspects of regular life as well. Sometimes, I just feel like I am barely hanging on. Still, I have to manage all the aspects of Josh's care. So, self-care is the topic that comes up. I remember years ago, our pastor said to me, Debbi, I want you to concentrate on keeping up with your flute playing and with your writing and, at the time, things were so chaotic and difficult in our lives in every way with nursing staffing and Josh's illnesses and with so many surgeries, and my husband, at one point, was activated -- he

was in the Marine Corps for 33 years and he was deployed. He was going to Kuwait and Iraq cumulatively for three years, and at the time, they took our nursing away because that was before companies were allowing troops to keep their civilian benefits and I had to pay COBRA a couple thousand dollars a month just to keep one nurse and she was amazing for us but I had to ration the night she came. She would come two nights a week and I did 24 hours a day, it was -- self-care is an essential in this photo. I will tell you, I took -- I just escaped from the house and I ran off to the most expensive hotel and I stayed there for three days. So, it was amazing. Next slide, please. That never happens, by the way. That never happens. The other aspect of caregiving -- I do not know if everyone is aware of it. I mentioned earlier, for example, we get free boxes of gloves paid for by insurance. But I have to do is I have to subscribe to get other supplies. This is just an example. For the gloves, I might be paying about \$80 a month to get the extra gloves we need because we have several caregivers, including ourselves. We have -- we have bed baths, suctioning, all these things requiring gloves. There's no way two boxes will do it. We have to purchase these things that Carewell does. Those are also incontinence wipes. We only get a very limited number of pads. I do not know -- I think it is good to be aware of the expenses families take on just to get through having this kind of mini-hospital in your home and what you need to take care of your child. We have a waiver that reimburses us, but there is a lot of turnover in case management and our waiver plan and sometimes to get reimbursed for these things, it is like trying to find your way to the city of Oz and approaching the Wizard of Oz in the Emerald City, to convince them that you should be reimbursed. And then in the middle, that shows the competition, the dire need for homecare nursing. The agency here is advertising \$10,000 for a sign-on bonus to do night shifts and \$7500 for morning shifts. That is how scarce nursing is. We have safe spaces in our home. I look at social media and I look at people on Facebook, going on vacations, on Instagram, and their lives look so amazing and perfect and they -- it does kind of, like, hurt my heart if I start to feel sorry for myself, but I cannot really go to that place. What we do here is if anybody starts to say I really need a vacation, we just say, look out the window. We have to take the small blessings that we have. We have this outside area outside the window. Just look out the window and look at nature and, once in a while, you will see some bunnies or a deer or a coyote or something passed by. Then in the middle, to the right of that is a space where I am sitting now, where we made an extra spot for Josh, so that you can barely see it but there is a lift up there, a ceiling lift, so we can have Josh and our room when we have a number of nights or shifts that are not covered by nursing and we do not have to go way down to the lower part of the house, away from everyone. We can bring Josh upstairs and it gives us another space to change him, so he doesn't have to be taken away from the rest of the family to meet all his needs. I actually put that there when my husband was deployed, so I could make that through those several years. Then there is the lake. Then we have this -- it took me 20 years to get everyone out of that room, so I could have a room out of my -- just loves to go with me and watch his news. I can shut the door and pretend we have no medical needs and it is just us, hanging out together. That is one of our safe spaces. Next slide, please. We have a lot of people in our lives helped us make this journey. On the left, I want to say one of the things that started us off successfully was having a physician specialist who believed in us and when we were facing terrible biases, people would speak them out right in front of us, in front of him, and when I saw him go to bat for us and stick up for us and say, no, that is not right. You cannot make those assumptions about this family. It made me feel valued and made me feel like Josh was valued and we have had an extremely blessed relationship with Josh's physicians, some that have been with us since our oldest son - - you can see him smiling in the next picture -- when he was born. As we would watch them retire, I would just cry and I would just weep. I did not want to see them go, but what they

left us with was an amazing gift of advocacy and feeling worthwhile and even though Josh has disabilities and complex medical needs, just seeing him -- we saw him as a Josh and appreciated him for the contributions he makes and what he can do. That is myself and our two boys in the next photo. There is our older son. He has his own family and there is how her grandson, making cute faces. I started volunteering as soon as I left my job, which was a full-time job, so I could carry the insurance. My dad was a systems application developer at the time, so he was on contract. I carried the insurance but it was just too much of a burden. I did start volunteering as soon as I left my job as a -- I would say, if you want to see mom, at any time, you will have to sign up for a panel. That is Josh and myself on a panel together, participating as a team. We have a van for Josh that he loves to go for rides in and look out the window. It is also a safe space because he does not have to, right now, during the pandemic, he does not have to interact with others, but still gets a little bit of time out of the house. Even though there are resources to get lifts and accommodations, you have to purchase the van yourself. That is a lot. We are grateful for all we have gotten over the years. Josh started there with [Indiscernible]. They are retired right now but, anyway, we got to meet a lot of amazing people throughout this journey. It has been a blessing in many ways as well. Next slide, please? These are Josh's people. John, we wanted to get Josh -- we had to get Josh to a doctors appointment. It was about 17 below in Minnesota. Josh's van lift Froese open and our son, John, had to carry him out from the van into the house. We have amazing nurses that have been with us for seven years and the ladies up in the top photo, we call ourselves ordinary moms of extraordinary boys. We used it to meet at a restaurant when we could manage our schedules, but now we meet on Zoom every Monday. Our boys are all about the same age and we discuss their needs and they are really my people because they really understand. I think that is the last slide.

Thank you so much, Debbi. Strong encouragement to read through the chat, the many extremely positive and thoughtful notices of things sharing so generously. You're really bringing it home to all of us. I speak for many, that they would love to go and get their doctorate with you as their teacher. Thank you all to the panelists. Please answer any questions to the Q and a box. We will try to get through a couple questions in the last few minutes and stay on a little bit longer for folks who have the time. I will go ahead and ask the first question. So, I directed it towards Clarissa and Debbi. If you can weigh in, fleas.

Thinking about supporting family care and you were talking about the tendency focusing on folks that are new to the role of caregivers and perhaps a new diagnosis or new circumstance in the lives of the family. Can you talk through whether you think there are issues that are specific to folks in that new role? Those that have been caregiving for a long time, where what are the unique needs of caregivers who are really experienced and what research do you do to account for the spectrum? Clarissa?

Yeah, of course. The first thing that comes to mind is self-care. It never gets easy. It never gets automatic. Not to remember that the caregivers have needs, as well as the child with special health care needs and the other children in the family. I guess what I would say is my daughter's specialist, for a while, had an annual family day, where they would show new research and there was an element -- he did not even necessarily matter that much, what we were talking about. It helps me get out of a rut. You know, there are things that I learned to accept, that it was reminding me to not just necessarily go with that particular flow, and just get a fresh perspective on them. You know, routines can get very familiar. You know, you do not think about brushing your teeth every day or -- in a way, it is not necessarily healthy to

not make it too conscious, that you are doing what you are doing or -- there are times where you have to take a step back and say, you know, how can we make this better? Do we need to be doing all of this? Could we be doing less or whatever will help? Debbi? Debbi, you are muted.

Sorry, I remember when Josh had a milestone and the -- that was before he regressed again. We were happy about it. We did not know what we did not know. I remember, kind of, just rejoicing in that moment and one of the residents came to me and said you think you will take him home and everything will be fine? It is not. She began to let me know all the things that we could expect over the years if Josh survives. I remember just completely having a breakdown and having to call my parents to the hospital because it was too much for me to take in, what might happen later on. I could not take it in. I have since learned to take life 20 minutes at a time. I know you have heard me say that before. That is the advice I would give. Just be in the moment and handle the challenge and handle the joy and take it 20 minutes at a time. That is how you get through it. Not even a day at a time. 20 minutes, in our case.

Thank you.

You are directing that at me, right?

You got it.

One of the things I think is really great now -- some of the new legislation is families have access to health records and the care everywhere. I think one of the things that is helpful -- I think back to early on in my career. I am dating myself but we do not even have electronic health records. We had memory sticks and taking picture -- now, I do think that having families having access to medical records in real time, and across systems, and we are not relying on families completely [Indiscernible] -- I think helping families understand, you know, it is more than just saying, from the healthcare perspective, especially in her family, how do you access the portal? What does that mean? If you are traversing the systems, how do you let folks they are there? What do you do with that information? One thing I will say that they often do not talk about is sometimes getting access to the information without the context of a clinician can be very overwhelming. You are looking at labs and see everything out of range and that can be anxiety provoking. I would say, you know, the era of the electronic health record can be really great support to families, but in addition, when I think about the home health we talked about here and in the paper, it is a whole other arena in terms of the care integration that is needed across those systems. There was one about electronic health records. That is just one snapshot. When you think about the family at the epicenter and what is needed to go to the education system and the therapy system -- I think the care coordination part is really at the heart of it all. I would be interested in Debbi's and Clarissa's thoughts.

I would like to say a couple things about that. I love that you noticed there are so many aspects to the need for records. For example, our home healthcare agency does not have an electronic health care system. They pick up the flow sheets, which they also use as employee timecards. I actually had to write up a recommendation or a proposal on how they could implement an electronic system that would not be costly and use that with families. Right now, what we do is we keep a giant whiteboard and we keep all the vital information we have to keep track of on the whiteboard. There are ways for families that do not have access to

maybe use email to keep track of goals and so forth. They do an excellent job of that with our conference clinic. It is a lot to go through. We have case management through the case manager for the waiver. Also through our medical system. We have a lot of different outward organizations to coordinate and none of them are cohesive electronically.

Clarissa, I will point to the next question towards you to start. This came up a few times in your comments. When should self-care support for caregivers be introduced? Should folks wait to ask for support? Can you speak to that?

No. do not wait. It might not ever happen. I think probably the best way to handle that is in sort of a continuous fashion. Like, you know, Debbi would be grateful -- do not push. There might be times when you were thinking about self-care and it makes things more stressful. To continually bring it up -- our team has a social worker that comes in and asks us every single time, how are you doing? What is going on with you? There might be times where it is a parent, it might be appropriate to push a little harder, you know, like if a parent is visibly shaking or having trouble talking or something like that. Just to be aware of what a person is doing. I mean, you know, I'm already seeing a therapist. You know, I have my own ways of handling that. I identify the cases where people are not really doing what they need to be doing for themselves. I know what support they consider to be important, like whether it is church or a really strong extended family. There is a lot of variability in how people are doing that. Just because they are not doing it the way they should does not mean they do not have it covered.

I think self-care has been a difficult thing for me. I have a hard time saying no to anyone, including my extended family. Before the pandemic, because our house is accessible, I have a brother with MS. It is difficult for him to get from home to home. It is easier for us to keep Josh here. I ended up having all the big family patients at my house. I remember I was so worn down and not feeling well, so one of our physicians wrote a prescription or wrote an order saying we could not have Thanksgiving at our house because of Josh's condition. I let my family know that I could not participate. Just being aware of the individual, unique ways that families need help, it means you have to get to know them and realized them. I know it takes extra time to do that. There is not always that opportunity.

That is a perfect place for us to, unfortunately, bring this to a close. We could have a multiple day workshop on this topic. Seeing the chat, one of the most enjoyable thing for me is watching the different roles and professions and personal backgrounds that you shared with the rest of us. This is a great community. I want to thank all of the panelists and encourage everyone to visit. Thank you for Lucile Packard Foundation. To learn more about their work or children and youth with special healthcare needs and additional resources, Thank you. Thank you to my colleagues for this extraordinary discussion and thank you for joining us. We hope you found it informative and have a great day, everyone. Take care. [Event Concluded]