

A Family-Centered Research Agenda for Improving Health Care Transitions for Children with Special Health Care Needs

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Hello and welcome to a family centered research agenda for improving healthcare transitions for children with special health care needs. Next slide please. I'm Chris Stella, I'm a professor of pediatrics and section head of pediatrics at the University of Colorado and Children's Hospital Colorado. Am also principal investigator of children and youth with systems research network. I will be moderating today's discussion, we are recording this webinar and it will be available on the Lucile Packard website in the coming weeks. Next slide. Joining me today are three of the authors of this paper and experts in this field. Megie Okumura, professor of pediatrics internal medicine and policy at the University of California San Francisco. Ify Osunkwo put, professor of medicine and pediatrics at atrium health and she is also the director of the sickle cell disease enterprise at the Levine Cancer Institute in Mallory Cyr, program manager for children and youth with special health care needs at the Association of maternal and child health programs. Next slide please. Please ask questions, we want this webinar to be as interactive as possible. We will have plenty of time after the presentation for question and answers, we encourage you all to submit questions in the Q&A box and will try to get as many as we can today, although given the large number of participants, some will be deferred until later. We plan to collate the questions that can't be answered and answer them off-line after the webinar. Next slide please. Before we begin, I would like to thank the Lucile Packard Foundation for Children's Health and HRSA MCH B for their support of this webinar and the larger effort of developing our national health systems research network for children and youth with special healthcare needs through a cooperative agreement. This research agenda that we are going to talk about today and also in subsequent webinars was developed as a major part of our national five-year cooperative agreement, the reason for the network is the number as well as the proportion of children and youth with special healthcare needs is increasing in the amount of research is also increasing, however, health outcomes are not improving for this population and research is not always well coordinated. The needs of families are not always included in the research priorities, however, MCHB has developed core outcomes for youth with special healthcare needs and efforts between AMCHP and NASHP have developed system standards and those are very well articulated. Health systems research needs to be aligned with these outcomes in the efforts need to be coordinated. Next slide please pick the development of this national health systems research agenda was a major part of the first five-year funding of our research network. It began about three years ago with a multi-stakeholder process, called the RAND appropriateness method and this process and its outcomes were published in 2020 by Ryan Collier and others in pediatrics. After this effort, we realized we needed additional stakeholder input to include more families, more diverse families, and more diverse provider groups, so we undertook some qualitative work to get that information. We combined that with the results of the RAM process to identify six major areas for research with questions prioritized in each of these areas, transitions of care, caregiving at home and caregiving processes at home, principles of care, child healthcare processes, family health and financing. Seven papers within the six areas have been accepted as a supplement to academic pediatrics on this

will be published in early 2022. The first of these, transitions of care is available online. Next slide please. and today's webinar, we will focus on transitions. Dr. Megie Okumura is the first author of the paper and we will start our presentations today. So, take it away.

Thanks, everybody for coming today and I am excited on behalf of our authors to share the highlights of the paper and hopefully, you are able to access it relatively easily. Next slide please. so, I guess I am preaching to the choir for many of you on this webinar either with lived experience or working with patients. Just a basic background we know that transitions from pediatric to adult healthcare is a vulnerable time for adolescents and young adults with special healthcare needs. It is well documented that adolescents experience a lower continuity of care and higher morbidity. We have had many decades of research describing barriers by patients, providers, systems and policies in various domains. Next slide. Luckily, many of the academic societies and our subspecialty groups have advocated for improving this transition process. In addition, health systems have and working on trying to improve the process and quality of care delivery. Unfortunately, there is not clear evidence to optimal transition outcomes for everybody. We still continue to struggle without. Next slide please. so, as part of this writing group, we were charged with fixing or answering me stakeholder questions, which are what are the best models to accomplish youth adult transition planning? How might this translate to other transitions such as new providers, new settings, new schools, and how do gaps in insurance and community supports during early adulthood affect health outcomes and how can we reduce that? That was a little bit daunting to us. Next slide please. because fixing healthcare transitions is complicated. Barriers to healthcare transitions are complex, as you know through multiple stakeholders and domains in which healthcare transition crosses. We really require a multimodal approach with input from patients and families and again, many researchers on this call now there is no single magic bullet that addresses the transition healthcare process. As noted, there continues to be a significant research gap in order to address many of the access and domains that were asked of us and what we try to address in the paper. The tip of the iceberg, we need to understand better optimization and implementation in healthcare transition service models, how do we do it, how do we get it done? We need to define the adequacy of related activities and also recent focuses, the readiness of the development, the services and continuity of care and healthcare settings so we can continue to improve the quality of care that we would ideally have for everybody. Next slide. In order to address we needed overwriting research principles to advance the field and in particular for our writing group, first and foremost was to include patients and families and our colleagues, our next two speakers will be addressing this correctly because most studies don't engage, family or youth in the research process, especially in the beginning and the disconnect between family and its goals and provider goals serves as a source of continuing failure to improve healthcare transitions by aligning the goals of families, youth and providers it provides us opportunities to advance the field by defining appropriate process and outcome measures generating creative solutions. Next slide please. we also need to look beyond healthcare. Many interventions focus on clinic-based interventions but young adults and families don't live in clinics. Strategies that work with community engagement, schools, outside programs that fulfill the needs of youth will allow youth to a girl and develop in the healthcare management skills. Working with community programs that will facilitate additional barriers to healthcare and bring additional to the process. And bringing in rigor in the real world. What I mean by that is we need greater use of randomized controlled trials, it will help evaluate measurement and outcomes which are really greatly needed. That's not a bad thing. And if we can include the theoretically driven models and evaluations that allow us to greater generalize those findings across multiple healthcare systems. Is the implementation science strategies to see what really works is really

critical to change healthcare systems national. Next slide please. and finally, we need to address policy and funding and funding strategies are key to implementing the sustainable transition programs, as well as allowing for more longitudinal studies, again, many of our research has been data short-term, they end the age 21, so longer-term studies, clinical trials, that process is critical. Projects describing cost-effectiveness and strategic funding strategies really have not been widely performed, Geisinger had done some work in terms of cost-effectiveness and there is still how to effectively fund and measure in state and federal demonstration projects would help advance how to best fund incentives and programs to ensure high-quality healthcare transitions. Next slide. Final thoughts, what is really nice compared to doing this work 20 years ago was that funding agencies I now increasingly prioritizing healthcare transition research. National Institute of health, various funders have all started to increase funding and prioritize healthcare transition so it's a great time to focus on this research gap. The push towards robust development of transition managers and key outcomes are needed in terms of advancing this field and again, theory driven interventions that are disease agnostic and raise a test that are critical to changing the way we go about the healthcare transition process. Moving on to our next speaker. Ify Osunkwo, will go into some of the facets we covered.

I will interrupt real quick, so sorry, I wanted to point out that live captioning is now available for this webinar, so you can access the captions by selecting the closed captioning button at the bottom of your screen or there is a link in the chat you can click for webbed based view. Please enter any technical issues into the Q&A and we will take care of them.

Sorry to enter a. Spam

I think you very much and thank you for handing off. It is amazing that the work that was done with this paper dovetails nicely with the work we are doing in parallel at my site under AP 20 funding project. Transition is very complex and we took the approach that TRIAD is a critical component of how to achieve the good outcomes she mentioned that I really needed in this population. So, comprised of three different components. The patient with sickle cell disease or any chronic medical illness, the community, either advocacy groups and the medical community, including pediatrics and adults, but also the approach and what you need to address is complex and you need to use a TRIAD approach to do that as well. Social, cycle and medical issues and the size of the wheels are intentional. The patient is the most important member of the triad and the psychosocial issues trump the medical issues any day. Next slide. So, we did a community stakeholder assessment to find out what exactly did our patients, community members and healthcare providers need around our agenda for transition and five things, as emerging themes. They wanted care to be standardized and consistent and patient said we want an action plan for when we go to the emergency room and provider said we want to guideline if we see a patient with sickle cell disease, we know what to do every time, every patient. Patient education was a really important theme, needed additional resources, provided education across the different provider idols. Inpatient and ER, was a pretty important component that emerged. Community engagement and improving the patient provider relationship was also highlighted as important things to address and whatever we decide to do from a research perspective with transition. Next slide please. so, we were funded to do a study looking at transition and we chose as our research component looking at peer mentoring for transition but at the time, and 2016, there was really no standard for transition for sickle cell disease and we figured how could we do a study and I have standards? We decided to compare peer mentoring with no peer mentoring but offer all 14 sites a standardized process improvement model for during transition, using quality improvement. And we wanted to have change across medical settings in the community. The

guide presented in the picture is one of our coinvestigators who actually has sickle cell disease and we named the project after him, Trevor Thompson, because he was an advocate for transition and peer mentoring in the educational system. It really highlights why it is important to do this work and do it now because we are losing patience every day. So, our standardized intervention involves quality improvement, community engagement, and education around transition and what happens when you change care settings from pediatrics to adult care. We used a transitional model as our guide and we used to model of improvement as a QR package and we put together a product this of package for all 14 sites. We had urban and rural, academic and nonacademic, different settings, different types of providers and different levels of experience as community advocacy groups partnering with us. Next slide. We looked at each partner as an equal member of the research triangle, the doctor was not more important than the patient or the community agency but our SMART aims were as followed. Sickle cell disease is a complex disease in these patients die early, they have a lot of morbidity and mortality, three times higher mortality and young adults than younger ages and older ages. Was imperative we do something about that and our aim was to improve the health of these patients by implementing an evidence-based model across care. A timeline was 24 months and we had our model and our guidelines and the six core elements. Next slide please. She had mentioned the need for process measures and outcome measures and we chose two different measures. One for process called process measurement tool and one as a desired outcome up by the both patients and providers on the one at a plan for emergencies and our goal was to reach 75% compliance with every patient having an individualized treatment plan for when they got sick in the ER, in the hospital and the process measure was customized to our sickle-cell clinic leveraging work done to standardize a process of what we do for patients, every patient, every time across pediatrics into adult care. This is what the two look like and you can find the tool on the website. They will have a link in the chat box as well if you would like to see it. This was for sickle cell disease but the components are the same. You want a way to measure what you are doing in clinic in a very structured and organized way so you can compare apples to apples and not apples to oranges. Next slide. And this is our emergency care plan. It is familiar with the asthma action tool. We spent two years working with her patients, community members and providers to figure out what exactly should this look like and because they wanted, tell me what I should do at home when I'm stable. What should I do at home when I well and when I get sick? The green, yellow and red zone at home and when I go to the hospital, show the providers what to do for me when I am really sick, what I am getting better and what is my discharge plan? You have two different sides of this acute care and home management plan. What happens when you measure yourself against yourself? You think you are better than you really are and we had a teacher sites to measure themselves based on a structured tool. That process measurement tool. The panels above shows that everyone measure themselves better than they were. Some people scored a zero or 30 or 40%. After two years of monthly coaching and reiteration of this process, we were able to get our site to where they measure themselves equally according to what the standardized tool look like. Next slide. So, over two years, what happened? We did a. We were able to implement a structured process for how you take care of the pediatric patient ages 16 to 25, all the way into adult care and remain in adult care from the provider perspective leveraging with community members and an adviser on every team doing this work in the clinic. So, we noticed that about 92% of our pediatric clinics in 71% of our adult clinics were able to score 90% or higher on their process improving tool over the 24 months. This is impressive because some of our sites go to zero at the beginning of this process. And using quality improvement, we walked with them every month at our coaching calls how to do this work, step-by-step, with a lot of coaching and off-line calls to kind of help them figure out what works for their independent site. Every clinic was different. Their staffing

model is different. Their support levels were different, their level of technical expertise and exposure to QI methodology was different. If you look at the panel on the right, pediatric patients in adult patients were able to significantly improve their outcome in terms of getting their emergency care plan to the level we desired of the time. And even during Covid, we did not find a significant dip in process because this now came embedded and how they did work every day in the clinic whether staffing model. What did we learn? Transition is really important in a major concern for sickle cell disease and for all children with special health care needs. You can standardize a program for transition, and can and should be done and using QI makes it feasible. You do have to have a validated tool to measure programs compared to each other, so you don't have this perception of I'm doing better than I really am. We looked at 14 different sites across the Southeast in the Northeast and we saw significant process over two years and implementing the structured process. We believe that community partnerships were critical. Having the organization held accountable, having the patient's hold us accountable and it has to be a part of your process from the inception all the way through to the implementation. And we also found that there was one member of the team that was absolutely needed. A coordinator, navigator, care manager, whatever you want to call this person but nobody had to be the glue that was a liaison between the patient and the medical team and the community. Thank you very much, going to pass it over to our final speaker, Mallory Cyr. Take it away.

Great, thank you so much. Megie Okumura and Ify Osunkwo queued up some of the things I am going to talk about, and I kind of want to bring us home with where do we need to go from here in terms of research, in terms of the transition conversation, and share a little bit of my personal asked variance navigating healthcare on the adult side because although I am the quote unquote youth perspective, I've been navigating adult healthcare for about 15 years, which is as long as we have been having this transition conversation. So, I'm happy to be a part of this, I'm very excited for everybody that is joining us today, so thank you. So, the first thing I want to talk about is, how are we measuring transition? We have the national survey of children's health that we measure up to age 17 and when does transition really happen? 18, 26 after the ACA if we are looking at insurance? It all varies a great deal. And we also look at who is recording misinformation and one thing that I learned during my time during transition, if you talk about transition with a parent or caregiver, and then you have the same conversation with the young person who is transitioning, you are probably going to get very different information. As Megie Okumura said, patients don't live in a clinic, how are we capturing the bigger picture, you know, after that transition discussion is had with an adult provider? Do they go back? Did the young person feel respected? Did they feel valued? Did they feel listened to? And if that transition falls off the map, if it does not continue, are we capturing why? We've got to remember to look at the social determinants. Transportation is a huge issue. You know, changes in insurance, all kinds of things. Especially with covid, which I will talk a little bit about, you know, the transition landscape has changed. Madeley complex individuals don't even feel safe accessing healthcare in a lot of ways so we need to really broaden the discussion of how we are capturing not and really focus on the idea of patient satisfaction, not just at the apartment where the discussion occurred. There is also thinking about cultural components. What does transition look like, and how are we, and why are we, as, you know, professionals, medical professionals, you know, setting the standards and how much are we project being what we believe a successful transition looks like? Again, during COVID-19, I have seen a lot of young people, young adults with disabilities and medical complexities who are moving home. Who are changing their living situation or healthcare situation because they want to be aware there are natural supports are and this is a very scary time for anybody to be accessing healthcare. If you are looking at something big

like a healthcare transition but you have providers that understand your needs during this time and you know that you are going to get the quality of care you need, we need to reconsider what this looks like and how we are measuring success. Thinking about the idea of family within research, you know, we typically within MCH defined family leader or family as a parent of a kid with special health care needs, however, the idea and model of family is evolving and part of that is because our children with special health care needs are growing into adults who have families and families may not be a nuclear family with having children or, you know, what we sort of idealize in our own minds, but they are still a family and they need to be involved in these very important discussions and research opportunity. We need to start engaging different voices. Having these different voices at the table to share their experience. And one thing that I think we need to really shift away from as within transition, there is a lot of youth don't care, families are not engaged, youth don't manage their health, poor self-management and why a way to disengage people from being involved in the conversation. I have seen within the healthcare system, you know, so much blame and even with in public health, we need to start shifting the conversation to the systematic barriers and we talk about this a little bit in the article, but it is more than care coordination, care coordination is great, I have never had it, I know it can be great but we are out there managing, I always , as an adult, manage my own care. I am eligible for additional supports. My husband and I have made the conscious decision of we are each other's natural supports and families and young people can plan and prepare and do everything within their control, but if there is nothing welcoming them on the other side, it is all in vain. So, I will talk a little about my experience and how we can make that shift. Next slide. So, this is just the teeny tiny micro snippet of my transition experience. I have been, as I said, navigating this for a decade and a half. I moved to Boston to go to graduate school where I navigated a healthcare transition and then, my now husband and I made the decision to move to Colorado after I finished graduate school and what I think is really important is that transition is not stagnant. Transition does not end when you find your first adult provider. I should have the freedom to move to another state where apparently the healthcare is really great, because that is where my life is taking me. We had an incredible PCP in Boston who, I will say work for a safety net hospital, which is not typically aware medically complex individuals are referred. But that is a whole other research topic but we got the best quality of care I have ever experienced. So, was really difficult leaving her, but, you know, due to a lot of variables, we chose not to stay in Boston and we were moving to Colorado. I was like great, Colorado is the transition capital. We got the hook up, it's going to be a great. Here I am, a national healthcare transition expert, advocate, I've got all my ducks in a row, I have my Boston provider talking to transition champions in Colorado. I've got my affordable medical, I am God transition, let's make it happen. So, we are doing this and we are trying to coordinate everything and I got a text message from my collar to contact that said nobody is interested. So, what do you do with that? I'm planning, and preparing, I have my spreadsheets. Ask my husband, I am a planner of all things. But I was physically told, no provider in Colorado wanted me. What do you do with that? So, unfortunately, I got to Colorado because I had a job waiting and this was our plan and it took me ending up in the emergency room to get connected with primary care. We are told and judge, don't go to the ER, primary care, primary care, what if you can't get that? I was connected to a provider, whatever through the emergency room on that provider was, she had one star on yelp. I'm not one to go to yelp for providers but I was like maybe I should check it out after a few encounters. She wasn't assigning prescriptions for my life-sustaining medical treatment, she was just off the grid. So, that did not pan out. I switched, I don't even know all the transitions but basically, I have had five PCPs and six years and some of those were great and then my insurance changed. Some of them weren't great but they were resident so they cycled out and nobody thought that as a medically

complex individual maybe I shouldn't have a doctor that is going to leave in two years. Then, I had doctors that sort of believed me and having them as a PCP because I was nifty and I am sure they wanted me on their docket and they made judgments, you know, I walked into the room and they said, do you have this medical condition? You remind me of my other patient that has that. It was very clear she had not looked at my chart. She just saw, like she is nifty, but she was very combative and a time I tried to advocate. It was a very traumatic experience. And when I was in the hospital, for a very severe G.I. bacteria that I got, don't eat seafood in Colorado, guys. Don't recommend. I had no support. I was not listened to, I almost died. And a is very traumatic to even relive. But it showed me how broken our adult healthcare system is and I am not saying that there are not good adult providers out there because I know that there are. And very fortunate to now have one who listens to me, who respects me, we have a dialogue, a partnership. But I am terrified that if I had a crisis, I am not safely cared for in the adult system. And there is a whole universe of medically complex adults who have had a similar experience. I know young woman who is starting an initiative to address medical PTSD because that is very real. So, as we talk about transition, you know, part of that is understanding why a family may not want to do X, Y or Z or entertaining, you know, have the conversation. If somebody is saying, you know, I know that if you do X treatment, this outcome is going to happen. Listen to them. You know, we talked about on our practice call about how conversations had in the emergency room do not even translate once the patient gets admitted and that has been my experience where I was able to get what I needed in the ER and once I was admitted, I was told that I cannot manage my own care. I was flashing my central line in the bathroom because I was told I could not use what I needed to keep my medical device and they just couldn't get it. It was awful. I don't typically talk about this experience because of the transition conversation often stays in the pediatric landscape, but we need to start broadening the conversation involving adult providers and understanding why, why nobody wants us. I know we are not profitable. We are working right now on a system that is incredibly overburdened. People with disabilities act being evaluated like Covid has really made these inequities for medically complex individuals come to light. People with disabilities are writing their wishes on their arms because they are unable to have an advocate with them and we have total strangers deciding whether our quality of life is worth it. Those are the conversations that we need to have. And it is scary. That we need those adults who are experiencing the side of the system involved in the transition conversation. We are here, we are ready, we are doing the work. But if nobody wants us, what are we supposed to do? We need to infuse education around how to care for and work with, don't do things for, do things with us. We are coming to you sharing our lived experience, our expertise. I have had my disease for 36 years and I am being told by a med student that I can't have antibiotics because it might not work? How about we try it? You just started yesterday, yesterday. It is really, really difficult because we advocate and advocate and advocate until we break and that is the truth. Yeah. So, what that, I will turn it back to Chris. Thanks.

Mallery, thank you so much for this great story. How it applies to the real world. We have so many great questions that can help people like you if they are well answered. Thank you for your honesty. More is good. I am not being articulate, but thanks. We have so many good and deep questions that have been imposed. One that was already discussed a little bit in the chat that I will start with, which is, who is the most important member of the transition team? I think we know the answer to this, the pediatric doctor, the adult doctor, the patient, the transition coordinator or the parent or caregiver. In the chat there was consent sons it was C Andy with the parent and caregiver. I wanted to open it up a little bit to the three of you to discuss how that works and why that works or does not work.

I will go ahead and start. I think that sometimes in healthcare, we forget why we are in healthcare. We became doctors to take care of patients. Why would I be the most important person in that equation? It is the ultimate form of an ego trip to think the doctor or the healthcare system is the primary important person. I vote for it is the patient. I kind of lump patient and caregiver together because he really can't separate a patient from their caregiver. There is some separation for independence but that is the process and not every patient can achieve independence. I talk about interdependence. As a provider, I want my adults to become interdependent with her family members or caregivers and their healthcare team. From internally to the health system, the coordinator is the most important person to Courtney things between healthcare and the recipient of healthcare, the patient. So, that is my thoughts. Great, Maggie, and he I would agree, I'm in internist and I have a primary care practice that focuses on adult with special health care needs. My colleagues, when I think about patients and their families and caregivers, many of my older 90-year-olds are being cared for by their children, their spouses. That family centered care is critical. Regardless, it is not foreign to adult medicine, but it does get quickly superseded by the pressure. I saw a lot of comments about not finding providers. My own institution is close to all new patients and probably will be for the next several months because we have a loss, and exodus of primary care providers. It is hard. There is a shortage out there. You know, we are talking about a global system. There are so many things we could talk about and spend hours about and there is more defectiveness on the healthcare system's overall. It is affecting healthcare transitions because our system is not perfect. So, trying to strive for that, given the fact that we have developmental needs and transitioning issues that are specific to the transitioning world living in a microcosm of this larger spectrum that is U.S. healthcare.

I had another question teed up but I wanted to follow-up on your point you just made and pose this back to the group, there are not many providers who will see young adults with special health care needs. Is this a payment issue? Has something changed in the payment world? Is this another ability to assemble a team issue, what are the summary of causes? All of them you had mentioned. I have a risk-adjusted panel. So for the number of patients I have on my panel, it is formulaic. It lowers the number of patients I have. Technically, I should have 200 patients I have a small practice per half day. It went down to about 140, 150 because of risk adjustment. That allows us to spend more time for the case management. But with the pandemic, alluding to what Mallery is going to come on both sides. With a pandemic, there's a lot more have to deal with on a day-to-day basis. I probably spent more time outside the clinic with my patients than in the clinic for management. And that puts a lot of pressure is on primary care physicians. If you don't have the infrastructure, I'm in a large tour coordinator care medical center. I have a DME manager. I have a pharmacy, a farm tech. I have somebody who can take care of the G tubes and tricks in my adult primary care practice. Whereas if you are in a solo practice, especially rural areas, and California this is a big problem because unless you are in an academic center in an urban area, if you are in a small, the smaller practices, may be harder to do a lot of the care coordinating case management. My first patient visits are often, just to get to know, it's 43 minutes. For incentives for our VU productivity, it is really hard because you have to meet your IBU targets. So, there are multiple layers in terms of primary care delivery and even specialty care delivery.

I went to pick her back, the other is expertise in comfort., Pediatric hematologist on my Precht essays 18 years and older for sickle-cell disease. I have zero experience looking at heart attacks but I can do sickle-cell disease. We just haven't provided the medical school, to

understand the diseases that start and challenge and what happens is they get older. They are going to back away, they don't want to make a mistake. I think it is a combination of several different things. I'm learning how to read an EKG for an adult. Am learning about prostate cancer, diverticulitis but I am I pediatrician at heart. The style in the care coronation I is for my adult sickle-cell patients is really a pediatric philosophy, not the way the adult hematology function with their patients. Mallery, what are your thoughts about the barriers? You have seen a lot of this firsthand. I would love to hear what you think.

Yeah, thank you. You now, and what you said about providers not understanding these diseases, I think, is a huge issue, especially within the rare disease community. I am the oldest living person with my condition. I don't expect providers to understand and frankly, I don't want them to have preconceived notions. I always say, you know, my favorite words when I meeting a new provider is, I have never heard of that, but I am willing to learn with you and from you. We have a conversation. I think one of the biggest things is that, and this is a generalization, doctors don't like to not know things. They don't.

So true.

It is, and I think part of that is risk and liability, that always comes into play. But we need to shift that paradigm and not discussion of, you know, we all bring things to the table, right? As an adult, I have had this sort of weird shift about how I think about healthcare of I am going to a total stranger, to trust them with my life, who have about the same sort of technical experience as me but in a different way. And somehow, I am just supposed to go okay, whatever, like whatever you think. There is that power dynamic that is historical and patriarchal that we don't really talk about enough. But I think for me, you know, just having providers who are willing to learn and reeling to work with you for me has been the biggest thing and when people come in with preconceived notions or no, we are doing things this way because I am the doctor. And I have been told that, that is a great way to shut down that partnership. That's across the board, right? Regardless of the condition that a person comes in, every human being wants to be treated with respect, that humble inquiry. Because there are many diseases that people acquire that are rare that we don't know about and not can happen every year of somebody's life. So, we are talking about the greater scheme of how we improve care to everybody in a way, if we can make transition perfect, we would have the perfect healthcare system too. I think all physicians are striving, well, you know, we still have issues amount as a workforce issue that other colleagues can work on too.

Right, there are so many factors at play here. There training needs, comfort needs, culture change needs. Dr., as a smaller part of the package. There are some good things. Megie, you mention you can spend more time with a somewhat smaller number of patients now, on the other hand, the number of patients in the world or your area is growing, so that makes it hard in some ways and easy and others. Putting this together with a question from the chat, it is so frustrating for her parent's impatience when there are good tools and information and resources out there but no provider or provider team to coordinate and run all of that. So, what should we focus on first? This is a puzzle with so many pieces. What pointer do we start in?

I think the most efficient way is to start with what we have. If we have tools, use the tools. Let's teach you how to use the tools. That is how we did it. We have transition tools. They have been around for a while but nobody used them. Everybody said they were using them but they really were using them. So we started with the lowest hanging fruit, let's use what is

already available and then use the process to figure out what needs to be done. But the other thing is, engage your patients. You can't get anything done if you don't listen to the voice of the recipient. I may want to change ER admissions. The patient's want a care plan. So what do we do? NEG care plan. Because that is what is going to work. If we do admissions, you can't fix admissions with out using the care plan issue. Use what works and engage your patients.

Wow, fan that was great, we can say that about 12 times in a row not repeat ourselves. Thank you. Megie R Mallery, reflections on that? I agree, first capitalizing and maximizing on what we can do. I think some of the issues with capacity is a problem. This is where we talked about funding and policies, right? If you, so if Ify has a whole set up with the ED, she's got her care plan but she tries to call my clinic, it is closed. So, you can't do anything. And what do you do? Then you are stuck with the ED where Mallery had to go to. That is not a great place for getting your maintenance care dealt with. They will check, are you dying? Now, okay, bye. Call me when you are dying. That is really a terrible place to be. Especially to be effectively medically homeless. And that is dramatic and so, going back to the multimodal, when I think about transition, it's not a readiness, okay, we have maximized what we can do. We need additional help to bolster some of the system-level problems we have had. That could be training, capacity, right now capacity is a big problem, at least it looks like in Vermont and even in the San Francisco Bay area. People who are otherwise healthy can't find healthcare.

We need a system that is good enough to attract people as well. Yeah, great. Here is another question from the chat. Can you all talk, and Mallery, I would love to hear your perspective, your experience, about balancing standardization of care and having a plan in place for people with special healthcare needs to provide individual patient care and what have your experiences been like with that? That's a good question, I was actually just thinking like how to frame that because for me, you know, I come back to my experience in the hospital that was very negative and I know there is, again, I just cannot tween primary and specialty care being in the hospital but they're also sort of shouldn't be but there is. And I was physically asking, how can I change your policy? Like, this policy you have does not work for me. It is detrimental to my health. And I am, I was saying this as somebody who worked for our state Medicaid program. I literally wrote policy, so I was trying to it, I understand that you are working within certain constraints, however, what you are telling me is something that is very bad for my unique situation. And there was not like a process to accommodate that. So, for me, just being able to, you know, have some sort of like workaround or exception or, you know, instead of having it in my chart that Mallery needs to flush her line with heparin so she doesn't lose it, they put Mallery will not access her on medical device and have agreed to this, which is a blatant lie. Again, we are doing the blame thing and there is not collaboration. For me, every time I try to advocate, talk to a patient representative. Nobody ever brought that person to me. I, somehow, in my very ill state was supposed to obtain and advocate in this moment? So, I think there just needs to be about infrastructure for when these patients, and who don't fit in the checkbox. And not putting that on the patient because what happens on the adult side is that it is all you, you know? You need to do all the follow-up if you need your anyone appointment. You need to do all the work or they are hoping that he was sort of just phaseout and then they can take on more people. For me, was really wanting to know the process for these policy changes or how I could simply get a medical accommodation, I think.

Great, thank you. There are a couple of really good questions. I think I will pivot because we have time for about three more. I will pivot a little bit to workforce and education. We've got these system changes, we know reimbursement needs to be different. We know we need more people who care to take care of adolescents and young adults. How do, from those of you who may be participate in education, how do we get adult providers on board with embracing the concept of caring for medically complex young adults or young adults with medical complexity? How do we do that? Any in science, Ify, Megie R Mallery, from the other end?

We have been struggling with this for years. Sickle-cell is a pediatric condition and they usually die before their 21, now they live and how they are 70 or 80. Recent fellowship graduates have very little sickle-cell disease knowledge. Hospital medicine, ER, same issue. How do you position your argument or request to support their goal, their bottom line? What is in it for them? I took the approach that okay, asking you to be passionate and loving is not going to be the issue. The ER wants you in and out of the ER and four hours. Use this care plan. The adult hematologist wants a guide in terms of the easy-to-follow guidelines for whatever the treatment is, I give you that. Inpatient, how do I treat them so they don't stay 10 days? Follow the care plan. We have to figure out what was for each stakeholder and speak to that. Had a transactional way of doing medicine but that is how we got to where we are. As they see the benefits of the intervention you are putting in place the, they begin to let go, it's not that bad back it's not that scary. That I give them a number. If you don't know what to do, call, 24/7. It's a horrible way to live but it was important to get the ball moving. Editors complex. But you got to figure out, what is an for them? How do they save time, make my money, spend less, get you in and out of the ER, made the magic so they would be willing to do what you are saying? It's care but they have to get them to buy in and then they see the value.

I know we have one minute left but I think with in medical school, we need to infuse disability awareness, we need to talk about the rated embolism within healthcare and it needs to move from tokenism, not having one person with disabilities come in and talk for one class every few years Pickett needs to full integration where that is part of the curriculum and people know it is a thing before they get into the field and have somebody with medical complexities thrown at them Pickett needs to be infused in all of the training and curriculum.

It's a common support for a medical school residency and faculty practice, I surveyed all of our general medicine practice, many of them are very interested in young adults, and I think when we had a transition pilot, everyone was really happy to take it on. Especially when the subspecialist was able to get input. We can't make someone a sickle-cell specialist and I don't think you assume primary care will become a specialist in sickle-cell. You were collaborative with your colleagues anywhere working as a team Pickett the village. It's the medical village, we support everybody. Everyone has different expertise in a kind and respectful non-ablest way. This is going back to the humanism of medicine we need to work on. Not everyone in med school, maybe pathology was a good place to be, right? For some people.

Great. Well, thank you so much. I am very sorry we are at time. Not only are there a lot more questions but a lot of good ideas in the chat that we will collate and take to heart. This has been a really good working hour, honestly. So, thanks again. We will answer as many questions off-line as we can. Please continue to visit the Lucile Packard website which is updated very frequently. We would also like to talk about the next webinar in this series, which will be centered on the caregiving at home and the caregiving experience paper that

will likely take place around February. So, thanks again, and thank you to our panelists for just an incredible discussion.