

Moving from Spending to Investment: A Research Agenda for Improving Health Care Financing for Children and Youth with Special Health Care Needs

June 22, 2022

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Hello, good morning and good afternoon. Welcome to Moving From Spending to Investment: A Research Agenda. Next slide. My name is Chris. I am a professor of pediatrics at the University of Colorado, children's hospital Colorado. I will be moderating today's discussion. We will be recording this webinar and it will be available on the website in the coming weeks. Next slide. Joining me today are three great friends in our efforts. Meg is a senior project director at the Center for innovation and social work and how that Boston University. Dennis is a pediatrician and associate professor at the University of Buffalo. He is division chief of General pediatrics at the University of Buffalo and an attending physician at a children's hospital. Jeff is a pediatrician and senior scholar at Academy health. Next slide. Keep in mind that we are offering live captioning for this webinar. You can access captions by selecting close captioning at the bottom of your zoom screen. Or, you can click the link in the chat to view the captions. If you are having any technical issues, please enter them into the question and answer box and we will try to assist you. Next slide. Please put questions in the question and answer box. We will hold the questions until the end of the presentation but we will have plenty of time for questions. We want this to be an engaging conversation and we encourage you to submit the questions. We will try to get as many as we can today. And if we can afterwards, those we do not have time to address today, we will send to the presenters and post them after the session. Next slide. This webinar is part of three webinars that we are doing on the national health system's research agenda for children and youth with special health care needs. I am the principal investigator of the network that has created the research agenda with our partners. We are nearing the end of our first five-year funding cycle as a cooperative agreement with the maternal and Child health Bureau. One of the major activities that we have done in our first five years is put together a national research agenda. This is with input from multiple stakeholders over a long time. The rationale for doing this is that children and youth with special health care needs are a highly prevalent population, roughly one and five children in the United States or perhaps even a bit more and the numbers are growing. However, health outcomes have not changed a whole lot in the last 10 to 20 years. This is despite very well articulated core outcomes that have been developed by the CYSHCN and the Child health Bureau. System standards have been published for standards of care for special health care needs are relevant. There has been substantial and growing research that has been done on this population. Outcomes have remained more or less the same. We put together this research agenda with the hope that it will both better integrate and prioritize priorities of families as well as other stakeholders and to focus the research effort that are being done by investigators across the United States to drive improvements in healthcare outcomes. Next slide. The development had basically three parts. We started with a consensus development process, the RAND/UCLA appropriateness method to set priorities and to level set those priorities across our different stakeholder groups. This was back in 2017 and 2018. The first paper was published in pediatrics in 2020. It was first authored by Dr. Ryan caller. As soon as the paper was published we realized that there was more detail needed to really flesh out the research agenda. We sought additional stakeholder input with

families including families from diverse backgrounds. This was as well as different clinician groups that had not participated in the first go around with the RAND process. We took all of the data and we put it together and we develop six broad areas of research and refined a set of research questions. The details of that are published in a supplement to academic pediatrics that was published in March of this year. You can see the first page of the first paper in that supplement on your slide. The supplement and all of the papers and at our open access so anyone can read them. We hope that the supplement papers will help to guide researchers, funders and other stakeholders in prioritizing research questions to look at. Financing is one of the six research areas. We will talk about that more specifically today. Next slide. I will turn it over to make it to talk about our first topic in the paper.

Thanks so much Chris, I appreciate it. It is a pleasure to be with you all here today. I wanted to spend just a few slides setting the stage for children and youth with special health care needs and healthcare financing in general. Before we start talking in more depth about the research agenda itself and the proposed project within it, I want to do this. While we are all concerned with children's health care coverage and benefits and cost share covering and reimbursement in general, by general CYSHCN are higher utilizer's of healthcare services than typically health the developing children are. Their associated costs are higher as a result. Financing for their care attracts more attraction among payers and the opportunities are greater. So, that is one of the rationale for why there is a focus on children and youth with special health care needs and healthcare financing. Children and youth with special health care needs often require healthcare and related services from a broad array of providers. This makes up a complex system of care. It is difficult for everyone to navigate. As a result, robust care coordination is required to ensure appropriate care, minimize redundancies and gaps and maximize return on investment. Payers are obviously not the only interested parties in healthcare financing for children and youth with special health care needs. Adequacy, affordability, and continuity of coverage are significant challenges for families raising children with special health care needs. This results in family financial hardship and medical debt. Providers spend significant time and effort on essential or under reimbursed care. Next slide. I noted on the last slide that children and youth with special health care needs are higher utilizer's of healthcare services and their costs are higher. The data presented here shows some specifics around those costs and highlights the need and opportunity we have for improving value in pediatric healthcare spending using children and youth with special health care needs as a population focus. Next slide. So the data presented here shows the lower income families raising children and youth with special health care needs report better quality healthcare coverage. Quality being defined here as adequate and continuous coverage. This is explained by access to public coverage, chiefly Medicaid and the children's health insurance program or chip. Ability for which is income sensitive and Medicaid offers a robust benefit package for children under the early periodic screening, diagnosis and treatment or EPSDT benefit. The last slide spoke to adequacy and continuity of coverage, increased affordability of coverage and benefits as also seen in Medicaid and chip as demonstrated by the data. In 2018, 41.3% of families raising children and youth with special health care needs reported having public coverage only and 15.8% reported having trouble paying medical bills for their child. In 2019, the percent of families raising children and youth with special health care needs reporting healthcare coverage went down to 36.6% and the percent reporting trouble paying medical bills went up to 18.2%. Conversely, reimbursement rates for providers tend to be better under private insurance. How can we think about improving value in healthcare financing for all from an equitable standpoint? This is taking in the perspectives of payers, providers, and families. Next slide. One way is an increasing emphasis nationally on alternative payment models or APM. A majority of APM's to date have been designed and

tested with adult patients. The aim is to increase value in healthcare financing by pairing reimbursement with increased quality. There is a continuum of payment models aimed at increasing value with increasing amounts of financial risk for providers along that continuum. This is a very simplified way of thinking about this. We could do a whole hour on APMs. For the purposes of our conversation today, we are going to focus on very very high level definitions. On the continuum of APMs, they start with a basis of pay for service. That is not a letter a PM. That is where we started. This means that providers get paid for what they do regardless of the outcome. Starting the APM continuum we have pay for performance. Providers get paid a little bit more for specific services that are shown to impact higher quality of care and or lower costs. For example, getting a little extra for getting a flu shot or competing a developmental screening are included. The next is bundled payments. This is a lump sum to cover an episode of care. This covers all of the care a patient receives in the course of a treatment for specific illness, condition, or a medical event. This is a very traditional episode of care associated with a bundled payment, it is like a joint replacement. Finally we have capitation. One amount for a patient's total care is included. There is the greatest level of provider risk associated with capitation. If the cost for a specific patient are larger than the amount of capitated payment a provider has received, they are. If the costs come in under their capitated amount, the provider gets to keep the extra. Next slide please. So let's think a little bit about value regarding special health care needs and the context of this. There have been studies using APMs for pediatric patients. They can show decreased costs or increase quality and or increased family satisfaction. But these studies have been conducted in specific clinical environments and with relatively small numbers of enrolled kids. There are questions about whether those findings, those successful findings are generalizable to larger populations of kids with special health care needs and whether they are generalizable to other kinds of settings. There is wide variation across pairs and states which makes standardization challenging. There are underdeveloped consensus measures of quality from a rate of viewpoints, providers, payers and families. There are questions about to whom value accrues and to whom it should accrue. I think my colleague Jeff is going to speak to this in a little bit more detail in just a moment. If we are defining value using the quadruple aim which is improving population health, reducing costs, enhancing the patient experience, and improving provider satisfaction, then looking at this multiplicity of perspective in defining value and then figuring out mechanisms to get to value is a very rich and robust area for further exploration. Next slide please. I am going to turn the floor over to my friend and colleague Dennis. Thank you very much.

Hello everybody. This is Dennis. Thank you for the introduction to the next set of slides. I'm going to be spending some time talking about the research studies that are proposed within the paper, in the supplement that we referred to earlier in academic pediatrics. We will start by referring back to the 2017-18, the RAND process and method that gave us the foundation for the priorities, the topics to focus under finance. Within a multiple stakeholder process, and iterative process that outlined in the paper that Chris referred to earlier, we started with three different areas of focus. The first meaning that a payment model, what a payment model might lead to improved quality of care for children with special health care needs. The second is what kind of return or investment do you have on a care coordination, to have care coordination whether it is a particular person or a program for care coordination, what type of return investment do you need? The third is what are the value outcomes for return that are meaningful for stakeholders? We then took a literature review to undertake some gaps in knowledge. What is in the research area? What we found was essentially what make mentioned which is wide variation in current scope and models of practice. There was underdeveloped quality and outcome measures. This means that it was difficult for us to be

able to look at you know, to be able to assess our cross financial return and investment. Also, there was no consensus on really looking at appropriate contracts and paradigms of care. This would allow us to evaluate a financial model of care. Are stakeholders then looked at a range of studies which really describe existing practices. Practices of alternative payment models, financial models that would allow us to give a better landscape of what is actually going on out there, that would be able to describe the range of outcomes, that would lead us to proposing next steps, assessing feasibility, and being able to move the field forward. Next slide please. The first study that we proposed is a descriptive study of alternative payment mechanisms beginning with 5-8 case studies and examining how accompanying payment models would be able to implement the outcomes. So, let's take an example. If you have a child, let's say with spina bifida who requires multispecialty care, care coordination, therapies, you know accruing services and cost both inside and outside the healthcare system, it is helpful to be able to describe why it different payment models, the impacts would have on this particular case. And, because of the range of payment models that are currently available, as Meg had described, that gives us the possibility of describing what those different payment models, what kind of impacts on a range of things such as benefits and coverage, co-pays, you know networks, the things that are available on different alternative payment models. The results of this would then provide recommendations for pilot projects that would enable us to try to narrow down different aspects of alternative payment models. There were some things that we mentioned in our paper including the impact of risk stratification's. For example, how do we identify different children and their special health care needs and their needs would be applicable underneath different payment models. The range of benefits that are covered, the different levels of co-pays, the contributions are included. The outcome of the study would provide recommendation for the pilot project. This includes experimental design and quality improvement that would allow us to move forward. In that sense, we are proposing a crosswalk of the findings and different alternative payment models to be able to come out of this particular proposal. Next slide. The next study that we are proposing is to really Mark closely examined the return investment for care coordination and youth with special health care needs. This one we are proposing is a quantitative study, being able to use different population data. And, it deals with different sources of payments and a range of outcomes. There are studies that look at care coordination for children and youth with special health care needs. What we are proposing is to look at this in more of an expansive way using a process called para-mapping to be able to broadly look at the range of care coordination activities. The activities that are covered would be touched by the act of care coordination. We would propose looking at care coordination as the independent variable, either assigning an individual and or utilizing a care coordination measurement tool to be able to look at the activities that care coordination are doing. And the outcome variables certainly will look at cost utilization, they will look at service needs, when we are talking about the expanse of care coordination, we also have to consider not just what is in the healthcare system for example, does care coordination result in reduced hospitalization? What is the impact of care coordination on services outside the healthcare system? What about therapies? What about the education system? Social services? You know, this is, this is a valuable research question with in integrated systems, with multiple services and also across different services, mentioning the education system where many of our children receive services. The mental health system, different healthcare systems, different social sectors, you know, there is a lot of areas where we can be looking. Next slide please. The third area we propose is to address the question of what are the values that are meaningful to a range of stakeholders. This is where we are looking at a qualitative study really defining what the value means. A number of the studies that we looked at in the literature review really looked at the issue of cost. This was to a healthcare system. As we know, that is not the

outcome necessarily that all stakeholders are looking at. Whether it is quality-of-life, employment, impacted family members, you know, impacts on other services outside the healthcare system, we are proposing a qualitative study. Really, it is using a variety of a group of stakeholders including parents and caregivers, providers, payers, educators, disability groups. And we proposed using a human centered design facilitated approach to really look at the components and the aspects of the journey in and across different systems. When we utilize the term human centered design, we are talking about an approach that looks at the journey and the experience of the child with special health care needs and the family and the, all of the providers that touch and care for the child. The purpose of this value outcome study is to really define what is right. You know, what is the value? What is right? It may not be currently captured in health system data. As we know, healthcare system data can be limited in being able to assess the outcomes that are meaningful to a variety of stakeholders particularly families. Let's go to the next slide. I will be turning it over to our friend and colleague Jeff.

Good morning or afternoon everyone. Thank you for joining us. I really appreciate the perspective of Dennis and Meg. My perspective is probably a little bit more from the population-based payer perspective. And, I wanted to just say that a lot, there is a lot of emphasis right now on value-based payment methods and lot of what these studies that Dennis proposed and the, a lot of work that is being done and articulated by the Center for Medicare and Medicaid services, it is around moving to value pay based models. Meg talked about the perspective of the continuum from pay for service to capitation. I wanted to spend a little time trying to put together some of these thoughts to say that if you are sitting at a payer organization, be it a managed care organization or state Medicaid program are probably the federal programs, there is a lot of things that have to line up to get a value-based payment method. For children with special health care needs, there are some unique challenges here that I just want to highlight as I go through this. These are the four components that really come about when you try to develop a population based on value-based payment systems. The first is to define the population either by complexity or by complexity. There is always a tension about whether we are doing an episode of care for a specific disease which is may be easier and may be very easy in adults where there is lot of morbidity and mortality around hypertension or diabetes. It is much more complicated for our population for those with special health care needs. We have to stratify the population for complexity. This is one significant challenge where there has been some great research on it. We have to figure out how we can use that to apply to payment methodologies. I want to just say here, also we should talk about social risks and relational risks as well in defining the population as we learn more and more about their impact on health outcomes. Dennis talked a lot about what kind of model for care coordination and how to figure out the investment and the model for care coordination. I think that that and the effort taken is really another important area. Multicenter studies could potentially give us lot of information about how care coordination is being implemented. Measuring quality is something that I would say, I would be frank, we have a lot of measures but how they are implemented in a value-based payment mechanism, that is really more nascent work. I think we have come to realize as we try to develop value-based payment models, we need to go to families and look at their experience of care. On the other end, we need to look at real outcomes that matter to families be at things like kindergarten readiness or family quality-of-life and in between those two is really the idea of looking at some of these utilization parameters that are important. Perhaps there are important for payers. These are quantified and certainly they are not important for every population. The link between the utilization outcomes and some of these outcomes for families, I think that is really important to study as we look at measures as well. Last as far as you know, last

but not least is looking at how these payment models are incrementally used. I do not know of anyone who has turned a switch on and off and said there is a payment model that is fully formed for some sort of a capitated full risk model that everyone is happy with. I think that there is really a continuum here. All of this is to translate into some incremental improvement, hopefully. And, I think that one of the challenges that we have is that since all of these pieces need to be in place, it is hard to figure out where and how to pilot it and how to get it going. I will say that I think states through the Medicaid programs have the potential to be laboratories and they already are. I will say that a lot of the work has not gone into children with special health care needs. Things that we can quantify are things like just understanding how many payment types are out there from different, different kinds of issues along the continuum. Understand how risk is shared so that we can bring in systems that cannot take on high risk but would be really interested if we could protect them from risk. Understand how MCO contracts work for these types of things. Next slide. Just a couple other thoughts from the payer perspective. I think we need to understand that insurers and Medicaid programs work with the data they have. The better data, the more data the better. But sometimes, you know sometimes, the amount for example, the amount that they pay, you would like to think it was exactly based on the work effort and the salaries and all that sort of stuff. It is often more of a negotiated thing. We need a sound construct for the model from the payer perspective so that they know what is being paid for. As I said earlier, we need measures of both outcomes and of processes of care. And, here some things you know, some processes like having a care plan are having contact with patients are often valued by payers. I think there needs to be, we could study and I think we should commit to looking at involvement and ownership across a broad swath of health and other sectors. This is so that from a payer perspective, I would say as well as from all of our perspective, if you come to understand the importance of having an involvement of children, youth, and families in the model and in the development of it and in the ownership of it, I think it goes a long way at the payer perspective as well. And then we need to be able to understand that this is incremental. We are making these steps incrementally and I think we have to just keep on going to make sure that we go further into risk stratification or further into better quality measures. I think if we own it together, it is more likely to happen. Last thing, last slide, I wanted to bring up the issue of using research dollars and to understand and challenge all of us to make sure our research dollars are used wisely. What I said before about ownership and the product goes also to ownership and the research. If we can co-create research with families and with Medicaid and other insurers, we have a much higher likelihood of understanding where and what we get, where and what we get researched. We can talk a lot about scaling up what we test so we make sure that a pilot is implementable across other systems and not just localized to a specific system. And, I think we really have to start thinking of some of the research as continuous quality improvement that we are trying to do at multiple sites on a national level. And, the last thing is making sure that we call on our colleagues that control more of the funding in healthcare to participate and to think about their responsibility for moving this from dissemination to implementation. It will be new to them but I think it is really where we need to go, probably as we start the research. With that, I'm going to turn this back over to Chris. Thank you again.

Thank you so much Jeff and thanks to Meg and Dennis for a great summary of the financing research agenda paper. A lot of good questions. I do not need to ask you to ask questions. There are already probably seven or eight great questions that will take some time. Thank you for that. I would again, try to direct you to the research agenda supplement. It is in the March issue of academic pediatrics that was put in the chat. Each paper including the financing papers summarize what is known briefly, gaps in knowledge. And it recommends some ideas

for research projects that could be done to help to answer some of these questions. As far as I know, none of the projects are actually underway nor are they funded or are ongoing. They are ideas that many people who do research could do potentially to help coordinate solving these questions. I will just ask one quick question and we will have a lot from the audience. For really any of you, we know so much about alternative payment models and how they might meet adult needs. What research involving alternative youth payment models should be done to distinguish models best suited to children and youth with special health care needs from those suited to adult models? Ideas?

This is Dennis. I am going to take it. I will take a first crack at the answer. One of the biggest things that distinguishes pediatrics, the pediatric field compared to the adult field is the emphasis on something that we call life force models. Life force, the life force model looks at the unfolding or the development of health and wellness. You know this is from childhood to adulthood. Understanding that specific interventions and things that are done, paid for and supported by services at specific times have large impacts down the road. This is particularly true for children and youth with special health care needs. The alternative payment models I think we need to be looking at pediatrics. They should be looking at those programs that support life force models in adults. You know, the model is to pay for rehabilitative services for example. And pediatrics, we talk about habilitative services. There are also other programs under alternative payment models that are looking to be supported in APM, that includes programs that promote two generational care, parenting practices, relational health practices. You know, I think those are areas where more research needs to be done particularly as it is related to children with special health care needs.

Great, thank you Dennis. Another question directed -- can you speak more about the findings in the paper that you cited that [Indiscernible].

I really hope that I did not misspeak and mention care coordination in that context. The point that the data shows us is that families of kids with public insurance, Medicaid or CHIP have greater adequacy of coverage. They have better benefits and they have more continuity of coverage. So, I think that if you are defining value based on continuity or quality, based on continuity and adequacy and thus are two measures that you find more typically in public insurance, there is also the aspect of affordability for families. There are very limited, either no cost-sharing or very very modest cost sharing allowed for Medicaid and CHIP for kids including those with special health care needs. Those three measures of quality are the point that I was trying to elevate for that data. It is not so much around care coordination. Care coordination is a challenge across the board regardless of payer, unfortunately. I think that is one of the reasons why return on investment and care coordination is an emphasized research topic. It is so ripe and rich and ready for improvements, thanks.

Thanks Meg. I will just kind of go in order. They are all good questions. One listener would be interested in hearing more about family centered outcomes that could be used with value-based payments. And Dennis, maybe I will ask this of you because you mentioned it when you were talking. How might we identify those outcomes? How might we use those outcomes? Do you have any thoughts on what they might be?

Yeah, I have plenty of thoughts. I think those are great questions. I may come back to the human centered design approach. This is because that is something that we mentioned in our paper in this presentation. And, there is also a related question in the chat about the different stakeholders that might be part of that process. The idea of a human centered design approach is to be able to look at the entire journey across different experiences and systems. And that is really very much centered on the person or the user or in particular, the family. So outcomes

that might be identified when you look at the journey would include things like you know, what are the things that are important to families. I think that is the interprocess that comes out. There is some literature that looks at things like missed school days, missed employment days, family finances, there is a number of social drivers of health that can be impacted. They can be identified within the family centered care approach in the literature. There are some other things that might include family stressors, you know, one of the things that comes up in the design approach is you know, to look at the emotions, the stress, you know, or the need for empathy as we designed the system and we support it through the research in finance. It is a really broad topic and I do not want to begin to say like the range of outcomes that may be identified. I want to present those as there are some things that are identified.

Great, thanks Dennis. I think it is very key to think about human centered design as a research technique to really use you know techniques like appreciative inquiry in following family abuse to get outcomes that are more relevant to their day to day experiences. Okay, another question, to Jeff this time. The methods that you proposed in your studies of Medicaid programs, are they meant to be standardized within a given state or across states?

I think there is a lot of opportunity to standardize across states Chris. I think, I think that I will just say that some MCO's operate across states. They might run different programs in different states. I think that if we could get some greater understanding of how one state uses a bundle of care and how that compares and what the outcomes are, I think that would be really helpful. I feel like with those four things I told you, I feel like it is a little bit of which one are we going to lockdown first. If we can lockdown the complexity of some understanding of the complexity of the kids and even some of the measures that Dennis was talking about, whether we start to look at utilization and some family centered outcomes, we can then see the impact of the payment models on that. If all of these parts are always moving, it is really hard. I think because the states are really the developers of these programs and I would say I think in a lot of cases they are really hungry to figure out how to develop these better, we have the opportunity to help them to participate in some of these research questions.

Great, thanks. Bright, here is a good one about transition age youth. One of the listeners asked about how research might address the changes families experience with moving between health plans during transition ages. This is in terms of outcomes and improving the process. I might take a stab first. I think maybe one thing is to decide on the outcomes we want to look at together with youth and families. And then, we can go from there. I do not think those are well defined yet.

This is Dennis. I will mention another thought on this. When we are talking about large data in integrated systems, being able to capture the individual like an individual going from the pediatric system to the adult healthcare system, that gives you an opportunity to be able to look at what happens around that age. You know, some of the literature there does raise questions about whether those you know, somebody who goes from the pediatric healthcare system to the adult healthcare system does drop out of regular continue as really medical home type care or a period of time. And looking at the costs involved within that you know, during that transition time and how long those individuals may stay out of the system is relevant. I think one of our challenges there is ensuring that we do ask these questions from an integrated standpoint. You know, I think one of our challenges with the national survey of children's health for example is that it is focused on children. When you look at adult

healthcare data sets, you are looking at adults. We really have got to look at data sets and research opportunities that allow us to get past that cut off you know, that may be somewhere between the ages of eight and 21.

Chris, I just want to say that I think there is a fundamental question here which is adequacy of insurance. This is for kids as they trenches in. It seems like we sometimes look at you know things like you know their providers or the network of providers and whether they are getting the services they need but so many kids and in so many states as they transition to adulthood, we really don't know enough I don't think about whether or not what there gaps in coverage are and how they are getting their coverage. And we don't think about what those challenges are.

Great. So here is a question sort of related to how to integrate the neighbors, the medical neighborhood participants and stakeholders into research. Specifically it deals with home care providers. How to integrate home care providers into the research model where you know, typically it just looks at payments for direct medical services back and forth? Any thoughts? It is a tough question.

This is Dennis. I'm going to chime in with an observation. It may not directly answer the question but in looking through the chat, there is a related number of comments and questions and I would just like to comment. It will touch on the home care. We are really proposing not just a kind of a broad look at what is available out there but we are also asking folks to really kind of rethink some of the fundamental methodologies that are being used. For example, if you looked exclusively at a healthcare system, you will get what is in the healthcare system. You know, there is one technique that we proposed. It is the use of [Indiscernible]. We have talked about care mapping to get an expansive look at the system that care coordinators would be touching really to use that is the foundation. There are other aspects such as like when you are looking at different sectors, you have to look at an integrative care model for an integrated system to be held to develop contracts, allowing us to look at cross sect her [Indiscernible]. This is about creating hybrid funding models. Those are the ways that when we are talking about hybrid financing, we know that there is both downstream impacts in other sectors as well as other impacts on health care financing. These are not easily answerable questions. But, getting the landscape and the variety and some of the really innovative models out, into the literature is really the foundation of what we came up with in this paper.

If I could follow up on that with just may be more of an editorial comment than anything else, I think that not only homecare but home community based services in general, if the view were taken that they are an integral part of the healthcare system, and also and integral part of improving value because when you think about the spending on home and community based services, it is really around the return on investment and keeping people out of more expensive institutional care. So if we thought about it that way and in a little bit more comprehensive, from a more comprehensive standpoint, it is part of the continuum of care. It is part of the continuum of the experience of being a person with a disability or a special healthcare need. If we thought about it in the context of quality of life and well-being, if we thought about it and all of those different contexts that inform the a, I think it might help get us a little further down the line then we might be otherwise. I have to also feel compelled to highlight the uncompensated care that families provide to children with special healthcare needs at home. That goes completely unrecognized by the system. They are the backbone upon which pretty much the whole thing operates. And, there is no sort of acknowledgment

of the value that they contribute to the system or any kind of financial compensation for a lot of the care that they provide. I think that you know, looking more holistically and looking more expansively on home and community-based services, long-term services and supports is the foundation for everything else above it, that could be a different way of thinking about things that could help improve value and help sort of fulfill the mission that we set out in the title of the paper which is Moving From Spending to Investment: A Research Age .

I would like to add if I can really quickly that I think one of the areas that would be really ripe for research and more fundamental is just how these you know, the home care you know, or the services, how they are communicated with the medical sites. I feel like you know, the care coordination that we talked about, it is so crucial to understand in those systems. Whether there is ongoing communication, whether there is ongoing dialogue, whether they just fire missiles across the wall at each other, I am sorry. [Laughter] but you know what I am saying. They just kind of you know, there is just things, reports sent back and forth but not any dialogue. That would be a really useful thing to look at that regarding value.

Great, thanks. All right. There is a suite of a couple of questions that I'm going to try to answer and post to the group together. There is a question about how engaged the patient centered outcomes research centered Institute is engaged as a funder for this work. And I think the answer to that is they are not currently engaged by the network that we are part of plans to engage funders in the upcoming year to five should we get refunded to identify funding needs and to establish more dialogues. This deals with the success we have had regarding funder and with the Packard foundation. Related to that, there is a great question that I will post to the group. If you had a magic wand, what would you recommend to funders, especially federal agencies to help realize the research agenda related to financing?

I will answer Allison's question and that I would love for there to be a unified effort around measurement. This would be between MCHB I mean, there is these kind of measures that we need, the population-based measures but we need these kind of measures that are specific to families and to utilization of services and to measures that require linking data between Medicaid and maybe vital records or other programs. I think that that is maybe more in the infrastructure. I think we would get further if we had some of that integration.

I second that. I want to add you know, if I had a magic wand, there would be more quality measures that are specifically targeted to things that are important to kids with special healthcare needs and their families and their providers as opposed to just these narrow clinical measures. And, as a result of those, improved quality measures, there would be greater accountability in the entire system for where the money is going, how it is being sent, and what return on investment is coming from it.

Another magic wand I would like is to be able to have data, as much as possible, to be able to share it among payers. There is a lot of data that is not being raised for research purposes. Some states and some payers and colleagues, they have better data than others. But, you know, investment to be able to create accessible, clean data, to be able to utilize these measurements that we have been talking about and across systems as well, as a way to be able to focus, to be able to for example get across the hip the divide or the landscape, you know, we talk about places that have the claimed databases, they are an excellent start. Being able to put really and truly integrated data systems, to be able to examine these outcomes is where my wand is.

Great, thank you. We have one --

I have one thing about the quarry. The queries re-upped financing included their ability to look at the value of programs and research that they do. This is new from the prior 10 years. I think there is an opportunity to engage their.

Great. We only have one minute. This is more food for thought. For two decades, we have heard all the reasons why telehealth was so difficult to implement. In two weeks of March 2020, everyone figured it out. Do we need a similar leap in alternative payment models? How would this go? We could talk for an hour on that. I think it is a really interesting question to start to and with. Okay.

You know, at the very bottom of my feet, it talks about return on investment. I would like to highlight another comment that Meg made earlier. We are talking about moving from spending to investment. You know, our children with special healthcare needs, you know, we need to invest and being able to try to put all of this on a cost savings that may or may not actually be there, we need to recognize the investment that we need to be putting into all kids and some kids need more resources and others. That does go into the area of outcomes and value and we talked about what is the you know, what is the thing that we can suspend. I think we have to be looking at investment and not you know what we are looking to cut out of the pie.

That is right, thanks Dennis. I think that is a great note to close on. So, thank you all. Thank you for your great questions. There are several more that we might be able to answer later on. Really really appreciate the dialogue. There was a lot of non-question dialogue to. That was really great. Appreciate that. This will be posted on the website. The articles in the supplement are posted as well. Please visit the Packard website for this and much more. Really appreciates the participation of all but especially of Dennis, Meg, and Jeff. Thanks again.

Thank you.