October 8, 2025 Action Committee Transcript

- **ToniAnn Marchione:** Welcome everyone…we'll give it a few more minutes but this is a pretty impressive group right here. We'll give a few more minutes for others to join.

- **Jessica Sturgeon Pope**: Well, I will say that I really appreciated the discussion and the questions and everything that did come out of that last meeting, and I'm glad that people had some good takeaways.

- **ToniAnn Marchione**: Absolutely, and I'm just so glad I have the transcript, because I can read it over and over again. There's just so much to learn from, you know, what you said and what really is the situation.

- **Jessica Sturgeon Pope**: Yeah.

- **ToniAnn Marchione:** Hi, Eileen!

- **Eileen O'Shea**: Hi, everyone!

- **Jessica Sturgeon Pope**: Hello.

- **ToniAnn Marchione**: Eileen, can you and I meet separately, just to go over some of the, so we can start a process of how we're going to work this… nursing center of excellence, whole thing.

- **Eileen O'Shea:** Yes.

- **ToniAnn Marchione**: Okay. Hi, Elle.

- **Elle Rothermich**: Hello! Good afternoon, everyone.

- **ToniAnn Marchione**: Good afternoon.

- **Barbara Cass**: And ToniAnn, before we get started, can I also ask a question, or perhaps…maybe you and I need to meet, because as I mentioned on a previous meeting or call. We are in the throes of looking at our hospice regs.

- **ToniAnn Marchione**: Yes.

- **Barbara Cass**: And, while I do not want to imply that they're going to be done next week or the week after, we are moving along. And I don't want to lose this window where we could make some recommendations, to… to our regulation review team, which I'm on the team. But we have a window here, and I want to take advantage of that window.

- **ToniAnn Marchione**: Yeah, and it probably would be perfect timing, so, yeah, if we could… and maybe if we even…I know we have an agenda here, but we put the agenda together, and then I read the transcripts from the advisory meeting, and I just have so many ideas in my head right now of…You know, things we really should be considering, and thinking about, and the regulations are probably a good thing to, you know, talk about, you know, I don't know if there are any regulations that we would have to consider, like, for pediatric… like, when I think about regulations, as opposed to…bill addendums, or, you know, things like that. I'm just going to go ahead and get started, because we're already at 1:05, so… Along that line, I was just, for those of you who didn't hear, I may have said it before you came on, I was able to really read the transcript for Jessica's presentation to the advisory committee last week. And I, you know, I will say, and I'm going to pump up Jessica's head here again, because it's, like, it has changed the way I think about pediatric hospice. After speaking to her and understanding how she is doing it where she is. It came to me last night. Do we have what we need, and we're just not using it? So, when we have barriers, and we think about barriers, right? So, we know staffing is a barrier. Okay, so we want to work on how do we get nurses to rotate through hospice, pediatric hospice, you know. and kind of try and grow the pool of nurses, APRNs. Social workers, which, you know, that's a little bit easier. We know that's a barrier, but when we say, we have a barrier to providers and, you know, families themselves, because they don't really understand the benefits of hospice, and no one wants to give up, right? No one wants to give up their private nurses that… and, like, the more I listen to Jessica, I'm like, wait a minute, guys. what are we doing wrong here? We, as providers, number one, and I was going back and forth with, you know, what Dr. Moss was saying, and then, you know, what Jessica was saying, and we need to understand better, and we're doing it now at regional, thanks to Jessica's meeting with us personally here, where we're saying, okay, this is a concurrent care. Item, and should continue to be billed as concurrent care. This is a hospice item, and this is something that we would cover. But then also, and… and Jessica, keep me honest here - If I'm a provider, and I'm saying to myself, well, I don't, you know, I can't, you know, the trajectory of an illness, or to say that someone is terminally ill and is going to, you know, die in 6 months. But we have to think of it through a different lens. That's IF there were no interventions being done. That was if we don't have concurrent care where these children can have curative interventions along the way.as a provider, I would think, I would say, well, if we took all of that away. This child will probably die in 6 months, and that's what you're certifying them to. So, while we're trying to break down these barriers of how do we get people to understand, you know, that it's not giving up, that yes, they have to sign on to hospice, but it's a totally different way that we would have to present it. And… and still be able to, and…I see Regina's on, and maybe this is something that, you know, Regina and Jasmine could help us with. Are we really seeing that things that belong under concurrent care, and to be continued to be paid for under concurrent care not being paid for? Like, I think we've thrown a problem out there that we don't really even know if it exists. So, any… I mean, any thoughts on that? Because I've turned the cart a whole other way, and I don't know if, you know, I'm being crazy, or…I don't know. So… so what are your thoughts? And Barb, I'm going to ask you first.

- **Barbara Cass:** So, I think that's a question we may want Tracy [Wodatch] to help support, with, are there. And again, I'm not a billing expert, so that's why I love Regina and Jasmine, and we love to say DPH. We're not the financial people. Right. But are there CPT codes or diagnostic codes that are not being paid for that are related to concurrent care, and identifying, is it, to your point. We need to identify the problem. To act on the problem. But if this is just anecdotal information, we need to hear from the payers.

- **ToniAnn Marchione**: Exactly. And there's an article, jess, I did get this from you, right? The State of Pediatric Concurrent Hospice Care in the United States PDF. I don't know if we sent that to everybody, but I can scan it in myself, or just send it from you, but you might be at your fingertips. If you could send that eventually to everybody to understand. The article is The State of Pediatric Concurrent Hospice Care in the United States. And the article is really saying, we don't understand concurrent care. In this country, and we're not using the benefits of concurrent care when it comes to pediatric hospice. So… I think a really good education on, you know, concurrent care might help us, because We're not from what I'm reading, and from what I'm hearing, just because someone signs on to hospice we don't have to say, well, this… yes, this child will die in 6 months. It's if we took away all the interventions, if we took away all the curative things that we're doing for this child, that's how you have to look at it, and then say, yes, I certify them. you know, we have… we have babies on for a year, two years, because they can have all these curative things, and I think it's a big push of education, I think it's a big, I think concurrent care has probably been an answer to some of the things we've been calling barriers, and we just don't know how to use it. Melissa?

- **Melissa Witthoft**: Yeah, is this an issue of the fact that most of the time. We bundle pediatrics with adults, and so, therefore, with adults, there's more or less an assumption of the outcome, whereas with pediatrics, we should segment them differently to address a lot of the curative or the concurrent care measures that might prevent or delay death.

- **ToniAnn Marchione**: Yeah, Jess, how do you feel about that?

- **Jessica Sturgeon Pope**: Yeah, I think that's such a common occurrence that really happens across multiple states. It's certainly not unique to Connecticut in any way, but I think there is this inherent grouping that does happen with the adult side, because it's typically the adult practitioners that are providing support for pediatric patients, at least initially, when programs are being built and taken off, and everybody in the infrastructure of a hospice is coming from an adult lens, right? We have compliance officers that have been in adult-based compliance. We have CEOs that have been in adult hospice, and so I think it's very natural and very normal to have that lens going into it. And it's not to say that there aren't similarities in pediatrics, because we are still being good stewards of the hospice regulation. We do still want to make sure that what we are doing is in compliance with eligibility standards and things of that nature, but there is a different lens under concurrent care, and all that is is just opening the door of access, and thinking about every pediatric patient as being an open access patient. But at some point…to be boundaries and barriers put in place. Otherwise, we could consider thousands and thousands of children that could potentially be eligible for this support. But it really is, I think, even just speaking back to the point about the payers and understanding directly from the payers what their perspective is. Understanding where they also draw the line. Because there might be mutual benefit in having kids enrolled in a concurrent hospice care program, but certainly we don't want to open the door for every single person. And then I think that speaks to that palliative program need that I know has been brought up as well, and just delineating those services.

- **ToniAnn Marchione**: Right. absolutely, and I completely agree with that. Like, last night, I'm just coming from the lens of all the barriers that we've been talking about for the last year. Well, they'll lose this, or well, they can't have that, or well. The physician doesn't want to certify them terminally ill, or, you know, blah blah blah, and we have concurrent care. I mean, that's how it is.

- **Barbara Cass**: ToniAnn, do providers understand the real boots-on-the-ground providers? Do they have as good an understanding of… so, Eileen, thank you. We need to… we need to start there, with that.

- **ToniAnn Marchione**: You know what? I have…

- **Barbara Cass**: Oh, if they won't order it.

- **ToniAnn Marchione:** I have to say, I have one provider who refers to us that gets it. One that'll call and say, okay, you know, this kid is blah blah blah blah blah, but because of concurrent care, I'll certify one.

- **Barbara Cass**: And what's your universe, ToniAnn?

- **ToniAnn Marchione:** The number of providers I deal with? Probably about 15.

- **Barbara Cass:** So, that's a really low margin.

- **ToniAnn Marchione**: And forget, I'm not even… I'm 15 specialists, like pediatric oncologists. I'm not talking about the regular, you know, pediatrician out there that all of a sudden.

- **Barbara Cass**: Yes.

- **ToniAnn Marchione**: You know, hit with something with a kid, and they're like, oh god, this is, you know…You know, forget about that. So, the idea is. ToniAnn Marchione: how do we educate, right? How do we educate the providers and the general community? You know, to… we had, we had a press conference here, I think it was last week, with Senator Kushner, because Senator Kushner pushed for us to get money to expand our pediatric program. And it was successful, we, you know, we're in the budget. We got a grant to expand pediatric hospice at Regional Hospice. And where I… one of the reporters that was here was from, Hearst Media. And she said, you know, what do you… what is the biggest thing you hope that comes out of, like, this press conference and the exposure that you're getting about pediatric hospice? And I said. The biggest thing I hope for right now is that pediatric hospice comes out of the closet. Because we just don't… we don't get it. And I've been so, like, so ready to point my fingers at, okay, it's, it's, you know, it's Medicaid. No, it's not Medicaid, it's this. No, it's, you know, it's so hard. It's… I feel like they kind of have given us a path. And we just don't understand it. So, go ahead, Eileen.

- **Eileen O'Shea:** ToniAnn, and remember the… and Barbara, you will as well, there was a national survey, put out by NHPCO last summer. Jess, you know. I asked for that data for Connecticut, and it's incomplete, but one of the things that did spill out was concurrent care is confusing, and that there's not a good understanding amongst our providers. Specifically, because I filed that to say, that could be a future educational point, and how would that get disseminated, and, you know, you could be a whole campaign around that, how to access, and so on. So I can get that data. To share with everyone. It came out of, it was just made… public just… Last month, maybe?

- **Jessica Sturgeon Pope:** Yeah.

- **ToniAnn Marchione:** Wow.

- **Jessica Sturgeon Pope:** We published the last survey, I think 2020 was when the first survey came out. Very similar. Very similar feedback. And I think that's a big goal of all of the different agencies that are operating on a national platform is to try to increase that awareness, but it really does come down to the community connection and being able to foster those relationships and provide the education from those sources that are actually Meeting and seeing these… these kids and these families to help have those conversations, but…speaking to your point, if they also don't know what's available and what's out there. In a time when things are also very uncertain from a healthcare perspective, that it's going to…promote ongoing uncertainty, and so it really is that, detailed. person-centered approach, really, for lack of a better word, being able to really individually identify those potential referral areas and have those conversations.

- **ToniAnn Marchione**: Yeah, and, you know, it's funny, because I think part of the confusion, and, you know, we get this a lot, and we've started to now push back on a little bit. Like, we'll get a referral, and they'll say, well, you know, we want to keep it on the back burner right now, because they're really not ready for hospice, and I don't know if they ever will be, because then they're going to lose their private care, nursing. And now I go, wait, wait, are you sure that, like, are they really going to lose their private care nursing? I mean, and, you know, and now, now, do you know how many we've said over the past year? Oh, yeah, we get it. they're going to lose their prize, so we won't put them on, you know? And it's… no, it's like the whole different world, and I think…I think the couple of providers we've had that have said to me, oh, you know, yeah, they can't have both, they can't be on hospice and have private nursing, and I'm like, oh, okay. And it's like, no way. Look at Jessica's face, it's like, no, yes, they can. So…the idea… I think we need to make, like, a couple of pillars, Melissa. You know, like, you were thinking about what are… what are the goals that… that we can get to, and I think one thing is, is how do we…Or what kind of, Proposal or recommendation do we make that is an educational thing towards all providers about concurrent care? Like, what would that look like? And… and how do we do it? And how do we do it with the help of, you know, like, the state? And…So one thing would be about that, educating about concurrent care, which is huge. We already know one of the pillars is getting more providers, you know, nursing and things like that, so that's already a pillar. And what I'd like to, talk about with Barb, because you brought up a good point, is what do we do about regulations? And your hand is up, so why don't you shoot for that, Barb?

- **Barbara Cass:** So, can I do my first thought first?

- **ToniAnn Marchione**: Yes.

- **Barbara Cass**: So…We know, I think, and someone correct me if I'm wrong, but there's an assumption that many of these children are Husky beneficiaries. Right. And… I can only speak from my experience, but we have had wonderful partnerships with DSS. Working on enhancing… enhancing information education for Medicaid beneficiaries. So, and this may be something Regina may have to take back. But is there work that we can do with Husky providers, not on your first and your second pillar? How do we educate them? And, Regina, I don't know if there's already, I just don't… DSS does lots of education through their, rate letters, all kinds of vehicles that they have, so is there an opportunity there for both, education and maybe enhancing the workforce? And I know providers would say the Medicaid, the Husky benefit is not that great, But in many cases. that they will continue to do the work because they… providers see the value and the necessity of the work. So there's… there's an opportunity maybe there, but now the regulation piece, we… we are… our window for hospice is open. And we are still brainstorming here about how do we incorporate pediatric hospice into our hospice regs. Currently, and you will know this, Tony Ann, that We have one license, and it's a home healthcare agency license, and then there's a service classification of hospice. So not all home healthcare agencies are hospice providers. We have upwards of 25 of them. But we want to… our hope is that we will separate The home health care, that will be one license, and then we'll have a hospice license. So, two separate regulations to keep things clearer and cleaner. Right. And in those hospice regulations, we've started the conversation. And Elle, thank you for your report, because I did read it. I saw some of the challenges and recommendations And I have brought them to the group for consideration. So that was the first step that I took in what can we do in our hospice regulations that customize pediatric hospice, because I, as a nurse for 40 years, I will say this, and I've said it in our palliative care report, Tony and that Karen and I are working on, that kids are not adults, and they're two separate medicines. So, we want to be clear about that in hospice as well. They won't be as expansive, but we want to give some note and mention and carve out to pediatric hospice because It is special. Not because we want it to be special, it is special. So that's what I would say.

- **ToniAnn Marchione**: Yeah. And…

- **Barbara Cass**: We're open to any thoughts. Have to have a smaller group. you know, the theme of the hospice regulations, I want to be fair and reasonable, will not be pediatric hospice. We'll have mentioned making this because I'm a pediatric…nurse. Pain management. There may be different considerations… or no, I think a good example is families. The approach to families is very different, because you have children, peers, siblings. It is just…very different. The concept of family is a little bit different than with an adult who is in receiving hospice care. So, any thoughts that people have about that, I would love to hear it. And not that it's TikTok, the end of the month, these have a bow, and they're going to the commissioner's office, but as all of you can appreciate, developing regulations, it's a labor-intensive process. And it has to be… we want it to be thoughtful and address high-level needs, and I… I see this as a high-level need.

- **ToniAnn Marchione**: Absolutely, absolutely. So I see two hands up. Regina, you want to go?

- **Regina Owusu**: Yes, sure. So, unfortunately, as the questions were coming up, I was still trying to log in, and my, laptop was coming in and out. I did hear a little bits and pieces about concurrent care and, Husky providers. Unfortunately, I don't have the answer, because it doesn't come from my unit. However, I can pass it along and get response, but Tonya, if it were… if you would so kindly as to email me the question that you want, you know, answered directly, around that, I will, push it along and then, you know, respond and send it back to the group.

- **ToniAnn Marchione**: Absolutely. Thank you so much for that.

- **Regina Owusu:** Yeah.

- **ToniAnn Marchione:** Okay, Jess.

- **Jessica Sturgeon Pope**: Sorry, the unmute button wasn't working. I think really…there… I think there's just such a rabbit hole that can be gone down in regulation, as there often is, with pediatrics, but even just speaking to your point about families, you know, there…There's a lot to be said about having the standards really be raised for children to meet where the adults are at. But I do think there are those very specific instances, even thinking about families, and the fact that many of these kids go to school still, right? They're… they could be in school, they could be going to all their follow-up appointments. Following that regulation of a nursing visit once every 15 days is difficult, you know, for a pediatric nurse to potentially be able to do, because there is so many different things that they're operating on, because the hospice care team is not the primary medical care team at that point. But I think even with communication, I think… I think there are so many different aspects where there could be more well-defined areas. And… but again, it would be quite a rabbit hole to go down. I like your idea of having a separate work group to really, dive into those different things. But I think it's incredible thinking, and just that acknowledgement of how different pediatrics is. And I just really wanted to also say my own appreciation for that.

- **ToniAnn Marchione**: Yeah, I completely agree, and I think it would be good if we could… and…you know, like you say, Barb, we know it's not going to be all about pediatrics, but even just to get some things on the table that could be really a game changer, I think, you know, it would be great for us to be able to do that, so maybe we can throw something together separately and work on that. However, I also think it's a, you know, part of the work we're doing here. But to be able to just focus on that, I think we… if we can meet separately, that would be great.

- **Barbara Cass**: We know of, and I won't belabor the regulation piece, but do we know of any states That do address pediatric hospice in… because we do a state-to-state review, and here's where I would say we…shamelessly borrow, sometimes, the concept. If it's nice and we like it, we will, drop it into our regs. So if there's any states that you think that we should be looking at, we will absolutely do that.

- **Jessica Sturgeon Pope**: Yeah, I think there probably are several states that have, some of those things outlined, and it would be worth looking into, and I can also just speak to individual experience of setting up those MOUs with specific Medicaid programs, and having, That memoriam of understanding of where the scope is, and so it could be a combination of both of those things, where there might be something that's built within the state regulation, but also something that could be more individualized. At least from my experience.

- **ToniAnn Marchione**: Right. Great. Eileen, and then I see Elle has her hand up also.

- **Eileen O'Shea:** Ellie, you haven't gotten an opportunity to speak yet, so if you want to go first…

- **Elle Rothermich**: Please, please go ahead.

- **Eileen O'Shea**: Jess, and this is circling back to the definition and the need for education on concurrent care. For a point of clarification for my own learning, are we saying that with hospice and concurrent care, that, This would be an opportunity to level resources for families, such as, nursing. And, Additional…funding. So, how would Concurrent Care and the Katie Beckett waiver blend together. So, I know this is a problem in our state, the Katie Beckett waiver. We have, I think it's 320… Regina, I think, sent this information earlier, 325 children receiving it, and that many on the waitlist. I've heard from parents is that the waitlist is anywhere from 4 to 6 years.

- **ToniAnn Marchione**: And some of our kids are…

- **Eileen O'Shea**: Not able to receive the benefit because They die before they are able to access.

- **ToniAnn Marchione:** You know, and that's a good point, and I don't know how to answer that, and maybe Jessica will, or maybe Regina, because I really don't understand Katie Beckett. I don't… you know, when I think about pediatric hospice concurrent care, okay, so what is Katie Beckett giving us, and I… and, you know, I know it's something, I just don't know what, so I don't know if anybody can speak to the Katie Beckett waiver and let… and educate us more on that.

- **Regina Owusu**: Yeah, so that is one… one question I have written down that I will get some more answers on that. Because I know the Katie Beckett waiver is, you know, providing care for Pediatrics in the community, you know, and, and, from what I seen, previously, it's pretty much it… it translates care from, the facilities into the community, and as far as to, you know, what type of services, whether it's for concurrent care or not, I don't think the initial response that I sent really delved into that. So, this is one question that I have. you know, that I will research further on and bring it, to the group as to how… how does the concurrent care and the Katie Beckett, waiver work together, basically.

- **Eileen O'Shea:** Thank you.

- **ToniAnn Marchione**: Thank you, Regina, and I see Elle is shaking her head up there, like, she's… she's chomping at the bit, so go, go for it.

- **Elle Rothermich**: Oh, no, I just… hopefully I can finally be a little bit useful. So, I see, not a lot, but, in some of my work with Yale's Medical Legal Partnerships, so we provide legal services to, patients of Yale New Haven Hospital and their families, so…I, in that capacity, only work with adults, but every once in a while, we get an adult who has a minor child with special healthcare needs. And so, I've seen some children, who are on the waitlist for Katie Beckett. And that actually just, it delves into a question, my colleagues and I have been working on and really trying to think through, which I think we've talked a little bit about, different folks have talked a little about today, which is just, what is the scope, when we're talking about concurrent care, what exactly is the patient population we're talking about? So I think if we think about… there are certain children who technically have a life-living illness, and we think about a child with type 1 diabetes, if, you know, if they do not receive insulin, they unfortunately will pass away quite quickly, but once they receive insulin. then they're okay, and then we're really no longer talking about a child who is at risk of passing away. And so that doesn't really… I think what Jess was saying, that doesn't really seem like a child who would be a good candidate for concurrent care. And so then where do we draw that line? And then also, a supplement question to that, which I think gets into the Katie Beckett issue, is if you have children who, need more intensive care. than, say, a child who has type 1 diabetes that's well-controlled with just with regular insulin, there's no issues there. If we have children who would be candidates for institutional care, but they can be but they can be treated at home, but then they're okay. We're not really thinking about them passing away soon as they get those interventions. Is that a kind of child… a child that we'd expect to see served by more of a palliative service that was directly integrated into their primary care? So those are the kind of questions that we're wrestling with, and I think I can, just from the silly lawyer reg perspective, is that it can be really helpful to just have a very distinct definition of patient populations for these regs, even if it's it's distinct, but even if there's a little bit of overlap, we're just saying, like, maybe there will be some folks that match up in both, but something also to consider, especially if there's any sort of it's… there are some children, Katie Beckett, who may need to transition to hospice or concurrent care, so just trying to figure out where that web is, and then I think that would be… we have some thoughts, but we're not, obviously, on-the-ground clinicians, so just wanted to throw that out there, just…distinct patient populations for Katie Beckett versus concurrent care, hospice versus some sort of, like. Palliative pain management, where we're not really talking about a child with a life-loving illness if they're just getting that discrete intervention.

- **ToniAnn Marchione**: Jessica?

- **Jessica Sturgeon Pope:** I love that you brought up that point, because it's definitely a… I'm not going to say a point of contention, but it's certainly something that comes up frequently when you… when you think about appropriateness for hospice, and you think about concurrent care. And this really goes back to the analogy I drew in that conversation about, it's like, we were given all of these doors to access things, but there was no, like, door handle attached. And so, it…I think we really go back to the core of what hospice is, and that is really navigating and providing dignity and comfort at end of life. And the recognition with children is really just that we want to be able to offer that, because whatever illness they're going through, there is that heightened potential for death. When we think about the example used with diabetes, that is a… and I'm not going to say easily managed, because I definitely don't want to diminish how absolutely intensive that is on your daily life, but we have a good roadmap for how to manage diabetes. We have fairly, again, saying this sensitively, fairly accessible ways to manage this. And while managed, that child can lead pretty much a typically normal life, right? What we see on the other side of that, of potentially a genetic illness, of which there really is no cure, it really is only management of symptoms. We might have, evidence that indicates what that prognosis might look like, which gives us a little bit more credibility to offering that hospice eligibility, because if it's a 2-year prognosis for trying to think of an example. Tay-Sachs, let's say, is an 8-year prognosis, and they are 7. That's a pretty good indication, and if they're having other symptoms, that maybe there could be something that happens in the next 6 months. When we're looking at, the current state of the illness, if somebody is having difficulty managing their diabetes, for example, let's say that their insulin is no longer effective, they're looking at having to change doses, they've been in the hospital 8 times. that makes us start to question, is this illness now progressing towards a potential friend of life? And all of that, to sum up, really comes down to the medical provider making that making that justification and that eligibility. And that really falls on the medical director, the physician, the referring physician. That falls back on them and their license, their understanding of the disease trajectory. But I…think that's what makes it so hard from a regulatory perspective, is because every child is going to be so different. There's a reason why ACCA didn't put anything in there specific about eligibility for concurrent care, because there is no one-size-fits-all with a lot of these families, and I think it really comes down to the understanding on both the part of the managing hospice and of that payer source to delineate where that line is between something like a palliative following versus that hospice. And I think the other side of this, too, is it's important to have the Katie Beckett waivers, and to have the… the palliative model of care accessible because it allows there to be a stair-step method into a hospice plan of care. It's accessible from an emotional standpoint for most families. Typically, it'll provide more access to be able to give a better picture, so it gives us a better observance as medical providers to be able to be in the home. The issue with palliative care programs is it really does come down to funding and the financial sustainability, and that will then inform what the financial sustainability looks like on the hospice model as well. I don't know if that helped provide any other I guess…

- **ToniAnn Marchione:** Yeah, so exactly what you said is, like, what I'm… what I'm thinking about, right? So, it's… there's nothing cut and dry. So, it's like, you almost want to have, like, a state advisory committee that these people can go to and kind of figure things out when they can't figure it out on their own. But, I mean, that… everything that you said just makes a hundred… 100% sense, like… And my… when you… when we say. the only thing I keep going back to is when we say the, Katie Beckett and then the concurrent care. Who applies for Katie Beckett? Like, what makes…someone eligible for Katie Beckett, and what is it that they're getting? That's where I'm kind of stuck. So, if anybody knows that, I'd love to know more. No takers?

- **Elle Rothermich**: I can… I could do a little bit, at least from what I've seen from my practice, which is… which is on the legal side. But so, Katie Beckett, it started, a while ago, it's actually… it was a national program, and it was meant to address this issue of families who do not have financial resources that would make them ineligible for Medicaid, but have a child with really complex health needs that would generally be taken care of in an institutional setting. costing tons of money, but someone… a child who could actually be taken care of at home and integrated into the family. So, what it offers, and that's one of the major point to the waiver is that it allows families who would not normally qualify for Medicaid to get.

- **ToniAnn Marchione:** Got it.

- **Elle Rothermich**: Medicaid for these extraordinarily high expenditures that are expected to continue for a long period of time because the child has complex health needs that are chronic. So what at least I've seen, and what we've kind of seen a little bit in our research, and some of my other colleagues, again. or we're seeing with folks they've worked with, is that it's a very personalized program, that is… it's very similar to, the kind of the palliative, goal of just… of comfort care, and making sure that the child is well taken care of in the home, but you also have the component of… it's also… there's coverage for whatever the child needs to, stay alive and stay as healthy as possible. So I think that's why this seems like there's a lot of overlap with concurrent care, but you do get children in the Katie Beckett bucket, who, once they have those interventions, even if they have very serious healthcare needs, if those healthcare needs are well managed, we're not necessarily looking at a life-limiting illness per se, just they're very medically fragile. And so, as we've been discussing, so then you do get that kind of step, potentially, over… or the transition over to hospice and concurrent care, if it looks like the disease has progressed, or it looks like that it's no longer well controlled, as Jessica was saying. I hope that aligns with other people's experiences on the medical side.

- **Jessica Sturgeon Pope**: Well, to speak to your point, and correct… please correct me if I'm wrong, but I think a lot of the development of that waiver and similar waivers was also prior to us seeing a wider or maybe a broader net being cast through other insurance providers for concurrent care. So, when concurrent care was rolled out, of course, that really was Medicaid, right? It took us a long time to get TRICARE on board. And then from there, we're now starting to see that, buy-in of insurance… like, commercial insurances, and now we're seeing more managed care plans, as you all know. And so we… I think we're going to continue to see that happen, where there's just a broader range of coverage. And a lot of those families that were ineligible for Medicaid, the only way they could have access to something like concurrent Care was through another waiver to be with now. But now, since we have, like, Blue Cross is so incredibly concurrent care-friendly. That is an example of a payer that maybe would not have provided that when it was first rolled out, but is now willing to say, we'll cover 80% of your hospice coverage, and we're happy to Maintain that open door access for any of your other therapies as well.

- **ToniAnn Marchione**: Okay, now I… now I get it, and I want to go to you, Melissa, but I also want to tell you that I think another pillar that we have to have is…that bucket of payers, right? Private payers, you know, what we're seeing with, Medicaid and TRICARE, and, you know, that has to be one whole bucket that we kind of, that we kind of attack, and there was something else, Jess, you said, that I wanted to throw in there. Palliative care being sustainable, right? I mean, we have a palliative… an adult palliative care program here that we do in the assisted livings that we get $24 a visit for. That is a full-time APRN that is seeing those patients, that is helping manage those patients, that's getting $24 a visit. So Palliative care, you know, when we're looking at it from our lens in this task force, is something that we need to be able to say, look, we're happy to put them on palliative care, right? And we're happy to follow them, but we can't do it for $24 a visit. I mean. It's not sustainable. So with that, Melissa, I know you've been waiting.

- **Melissa Witthoft:** … just my comments, and I think this ties into a lot of what everybody's saying is. I think we need to keep in mind that we're coming up with a new design, right, for a program, and we need to take into consideration all these different elements, like the payer sources, the regulations, all these things will play a role in terms of how we design this, but we shouldn't allow ourselves to be dis… and I'm using this word loosely, distracted by the rabbit holes, by the details, but in fact. come up with, you know, maybe some straw models, some examples of, you know, a child with X condition, you know, and then go down, you know, what are the payer sources, what type of resources would they have available? What type of support will they need? And kind of have a design model that takes a bunch of different considerations, you know, some examples. Because you can, anytime you look at a situation, a lot of, you know, for example, Katie Beckett. It probably came up at a time when we didn't have a big fix, so Katie Beckett filled a hole. It plugged a hole for something that was much needed in the communities, but now we're talking about it. It's an element of what we want to have as part of our overall program. But it isn't the solution, per se. It's one of the ways we have to consider what we're going to do and how we're going to do it. So I think if we think kind of very top, top level. what should be this design, and then figure out how to make it work from there. You kind of have the end in mind when you're designing something.

- **ToniAnn Marchione:** Yes. Thank you for that, because that's, you know… I love how sometimes you just bring the thing to… you know, Melissa and I meet, like, after these meetings, and she sits and she shows me, like, slides of what we spoke about, and I'm like. Yeah, okay, you got… you, like, brought it all together, like, that was…

- **Melissa Witthoft:** In order to get these transcripts done, I have to listen to the… read everything, and then go through the entire hour or so that we've talked, so… Right. I'm a little more rehearsed ToniAnn, I think, so…

- **ToniAnn Marchione:** Yeah, no, that, that… I think… and yes, I agree, and I think that, so what I'm hearing, and do we all agree that if we have, different examples that we could… one other thing that I wanted to say, I'm sorry. when I think about pillars, and we've discussed this already, but I don't want to lose track of it at some point, is cost versus cost savings. Right? So, the cost savings that we could see with increased you know, palliative or a pediatric hospice, the savings on the hospital, the hospital sides and the, you know, the less readmissions and emergency room visits and, you know, things like that. So, I want to just keep that, in mind, too. And, yes, so, I think that's a good point. That just went right out of my head, that you said, so hold on. See, I get too excited, and then I lose, Oh, going down the rabbit holes, and then also talking about, examples of, so kind of making it… it's not a one-size-fits-all, right? And these are… these are some of the things we see in a pediatric patient, that they're coming for hospice, or Katie Beckett, or whatever, and… and here is their process through the system. Is that what we're… is that what we're kind of talking about?

- **Melissa Witthoft**: I think that's one way to explain it. I don't know if everybody's on board with how we do that, but I think that's one way to show, you know, what the need is, and how we address each and every patient's situation.

- **Regina Owusu**: So, if I can, if I can, come in here, real quick…Based on information I sent to the group sometime in, September. I guess we were asked to look into how many children were on the Katie Beckett program, and, you know, whether or not, you know, they were terminally or critically ill. Now, from what I got back for those questions. It stated that there was no data indicating whether the children on the program were terminally or critically ill. However, The, it says, and I'm looking at my notes here that I sent to the group, But it says that the children on the waiver are terminally ill, but are not terminally ill, but most aligned with being critically ill. And then, what we drew from the conclusion that even though there was a waitlist for that program. The children on the Katie Becker waiver will also benefit from palliative care services. So, I know that question has already been answered, that the children on the waiver can benefit from palliative care services. However, I know the question now being raised is whether or not Concurrent care is also… I mean, how that differs from Katie Beckett. So, that's the question I have, and I will research that and send it back to the group. I don't know if that helps.

- **ToniAnn Marchione**: Absolutely, I think, yes. Absolutely. And there was one, because I was just trying to go through the, the emails that you did send, and one was on the, the DRG. And I'm just reading through that again, which is, you know, hospital bills, Medicaid program services, the claims are assigned to a DRG group. Okay. Which is, you know, that's very helpful. This ensures hospitals are fairly compensated for the service provided by the department. All right, and I can… I'm going to send that back out to everybody, too. the payment methodology that can be found on the… on the website. So, yeah, as we're… and we're… we have, like, 7 more minutes to go here, but, Is there anybody who thinks… we have a couple of, you know, we'll see what Melissa comes up with our notes and kind of, what our next steps are, but for me, I hear we maybe do a little… a separate meeting with Barbara about regulations. Eileen, I'd love to touch base with you about the whole, you know, the nursing and everything, but then what we… what came out of this meeting, and the pillars that we're looking at, and going forward, and you wonder if at some point…and this may not be appropriate, I don't know, but do we pull in payers? Like, do we meet with payers and understand what it is so that we can discuss it? Yes? Okay, perfect.

- **Barbara Cass:** And, though.

- **Regina Owusu**: ToniAnn?

- **Barbara Cass**: Oh, sorry, Regina, just want to make one quick point, that when we start to look at cost savings. I know you had mentioned that we look at cost savings to providers, healthcare facilities, but I think we also want to really underscore, and again, acknowledging, notably, a large proportion of these children are Husky benefits. We want to be able to identify the cost savings to the state, and to the potential cost savings to the Husky program. Sorry, Regina, thank you for letting me do that.

- **Regina Owusu:** No, no problem. I just wanted clarification. So, when, when you say we're meeting with the payers, who are we looking at, ToniAnn? So, I… I would know if…

- **ToniAnn Marchione**: …Like, the private payers that are, you know, in most of the areas of Connecticut, like, you know, that either do or don't provide a hospice benefit. I, like, we had a newborn on with, I think it was either trisomy 23 or 18, I can't remember what, and the father, she was covered under and I can't remember what the insurance was, and they were not going to cut… they were… they… they, like, were… they didn't have a hospice benefit. So, that's what I mean by, like, the private payers, and understanding…You know, where they're coming from, from a concurrent care or hospice perspective.

- **Regina Owusu**: Okay. Okay, and do you still want me to pursue… I know, I know, Barbara, you had thrown out a question as to how we educate Husky providers on concurrent care. Do you guys want me to still pursue?

- **ToniAnn Marchione:** That would be amazing.

- **Regina Owusu:** Okay. Alright, thank you.

- **ToniAnn Marchione**: Look, thank you. Okay, are we missing…Jess, did you want to say something?

- **Jessica Sturgeon Pope**: I wanted just to say that I really appreciate the pillar approach, and that I think it makes sense to help break up some of those bigger topics into those areas, and I definitely think and I believe it was one of the pillars you mentioned, but I think a big part of most of this discussion really comes around the idea of hospice eligibility, and what defines hospice eligibility for a pediatric patient. And I think there are certainly ways that we can focus that, but I know that it's also one of those rabbit holes that we were talking about. go down very easily, but I do think that there's certainly opportunities there to define language in an accessible way that's also going to be flexible for the unique needs that come up in pediatric patients.

- **ToniAnn Marchione:** 100% in agreement. And I… and I have to say, well, this is, and like, you know, these conversations, and even… even the rabbit hole conversations, I, like, appreciate this call so much.

- **ToniAnn Marchione**: Because it's… and the more I'm learning… like, you think you kind of know, you know, okay, I think I know pediatric hospice, but, like, I'm learning something new every day, and I think… I think it's… I think we're in a really good place, and…And going to have an ability to really move this… move the needle forward here. Elle, I see you have your hand up.

- **Elle Rothermich**: It's just super quick, on Katie Beckett and concurrent care. I will double check this, because I haven't seen… I'm not involved in the case management, for any of the children who are attached to the… my clients, but, generally, Katie Beckett is a way for people to get Medicaid coverage who wouldn't otherwise qualify. So my understanding is that if you are under Katie Beckett, you have access… that child would have access to all the regular Medicaid benefits, including the hospice benefits. So that might be the way that Katie Beckett and Hospice Connect just.

- **ToniAnn Marchione:** Okay. Perfect.

- **Melissa Witthoft:** So, we've talked about having some speakers on our calls, our action team calls, and also advisory calls.is it possible to get Katie Beckett, those folks, the right people to have for our small team? Or…I'm just thinking ahead, do we need to pick their brains or have them do a briefing for us on our next call?

- **ToniAnn Marchione**: I think it might… maybe it would be good for our team, you know, and Barb, I don't know, did Dr. Moss talk to you about…You, next time, talking to the Advisory Council?

- **Barbara Cass**: She hasn't mentioned it yet, but I'm always… it's about MOLST, right?

- **Melissa Witthoft:** Yes.

- **ToniAnn Marchione**: I'm always happy to talk about MOLST. Okay, so you're probably… If she does it 5 minutes ahead of time, I can tee it up.

- **Barbara Cass:** Perfect, okay. No pressure there.

- **ToniAnn Marchione**: Yeah, I… so I do think, yeah, so the… the KD, that would be good, because we want to understand it as much as possible, right? So I think it would be good for this, for this group. To hear, you know, more on that. And…You know, and I'm… and I'm trying to toss in my head, Barb, like, the… the…I guess the saving… the savings to the state, per se. Where could we, like, could we ever get to the point where it's somewhat, like. I want to think about that more, because that would be… how do we save the state money through, you know, through this?

- **Barbara Cass:** I think, and I'm not an expert on this, but this is my high-level thought. All of these… all of these pillars are interconnected, and if we're providing children good concurrent care. During their hospice care, the overarching goal is you're going to mitigate risk for future hospitalizations.

- **ToniAnn Marchione**: Right.

- **Barbara Cass**: I think, but again, I'm not the expert.

- **Jessica Sturgeon Pope**: I think we were…looking at hospital data to look at length of stay and admission, because we also know that when if they are admitted, their length of stay tends to be shorter, since they have a resource in the community that's already in place for that continuity, for med management, for education, so they're not needing as much support at an inpatient level. But I think even if we look at things like vent management, and knowing that a child may be on a vent, but because they're with a hospice program and they're able to have more in-depth conversations about goals of care and advanced care directives, it may limit That family may choose to limit intervention or to discontinue intervention, as well for…quality, and just understanding what that looks like for their child. And in turn, not to be crass, but that does also save money on that state-based policy as well, since they're not paying the daily rate for the event.

- **ToniAnn Marchione**: Absolutely, and you know what? That was, like, that was my bad. I was separating even the Medicaid from how do we save the state money, so that it all comes together, so yes.

- **Regina Owusu**: Nope.

- **Melissa Witthoft**: I think it would be related… because probably most people on this team have actual dollars and cents associated with care support, whether it's the technical equipment or the hospitalization, things like that, to show if, on concurrent care we do this, or if no concurrent care, then hospitalization. So, I mean, I think it's a pretty dramatic comparison of - if we support them properly, the cost is much lower. If we don't, then the cost dramatically increases because of more, extreme interventions that are required.

- **Regina Owusu:** So, quick question, Melissa. Are you going to follow up on getting somebody from Katie Beckett to join, us on the next meeting, or how are you.

- **Melissa Witthoft**: I just threw that out there. I wasn't even sure if that was something we were interested in, and by the way, Regina, I don't know anybody at Katie Beckett.

- **Regina Owusu:** Okay, okay, so I can look into that, too.

- **ToniAnn Marchione:** Perfect. Okay.

- **ToniAnn Marchione:** Thank you all so much. I know I kept you a minute over, but this is… this is just great stuff. I will get in touch with everybody that we're going to meet with separately, and then, I think we… I think it would be nice to put together a nice one, especially for the regulations. And then, Eileen, I'll also be reaching out to you. Okay, thank you all so much, have a good day.

- **Eileen O'Shea:** Thanks, everyone!