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Female Speaker: [00:00:01] Now I'd like to welcome Dr. Olunwa Chisora Ikpeazu to present on caring for the medically complex newborn following discharge. Dr. Ikpeazu is the medical director with Aetna Better Health of Florida's managed Medicaid and Florida Healthy Kids programs. Dr. Ikpeazu is a board-certified pediatrician and fellow of the American Academy of Pediatrics. Dr. Ikpeazu has over 20 years of experience as a clinician and healthcare executive.

[00:00:46] In her current role, she provides expertise and compassion, formulating effective transition of care plans for babies who are being discharged from NICU and guides the clinical team in coordinating care for a special needs' population. She also takes lead in Aetna's neonatal abstinence syndrome program for the health plan. Prior to joining Aetna, Dr. Ikpeazu served as the medical director for a Florida health plan that provided services to the children's medical service program which cares for children with complex special needs. Dr. Ikpeazu was an adjutant professor at the Vanderbilt University School of Medicine and Meharry Medical College. Please help me welcome Dr. Ikpeazu.

[Applause]: [00:01:43]

Dr. Ikpeazu: [00:01:51] Thank you all so very much. Can everyone hear me? Okay. Because my voice is a little bit shy. So, okay. We have a hotline for substance abuse. We have hotlines for gambling, but there's nothing for those of us who have to deal with day by day, sometimes minute by minute airway problems. We do need a more involved case management. This sentiment was expressed by the parent of a child who has medical complexity. Their frustration and their stress and some of the other more colorful sentiments I've heard over the years as a primary care pediatrician is the reason why, as a healthcare system, and as healthcare providers, we should really look for better ways to manage these children post-discharge.

- [00:02:52] Who is this child? Good question. These children have been called by different terminologies, different names. They have been called chronic complex children. They have been called medically complex children. The correct terminology now is children with medical complexities, CMC, is the correct terminology. They are a subset of the more known group of children called children with special healthcare needs. Children and youth with special healthcare needs. These children with medical complexity is a subset of those children. So, let's get to definitions. They are children who have multiple significant health problems involving multiple organ systems, resulting in functional limitations, high healthcare utilization, and technologically dependent.
- [00:03:54] And so, we'll take each, each of those definitions. By functional limitations, we mean that they're impacted by health, by the healthcare condition, such that they cannot participate in activities that are typical for children their age. Technological dependence means dependence on devices such as tracheostomy tubes, gastrostomy tubes, home ventilators, oxygen, total parental nutrition which is TPN. The common medically complex children have these common features. They typically have a high prevalence of neurologic and neurodevelopmental disorders. They may have underlying genetic disorders and they're commonly premature infants. And how did we get here? Good question.
- [00:04:51] When I was a medical student, about 30 years ago, children with severe neurological symptoms, problems, died from pneumonia. They died from aspiration. They died from sepsis. Children with very – severely premature children died from complications of necrotizing enterocolitis, they die from complications of respiratory distress syndrome. Children with genetic diseases such as trisomy 13, Patau syndrome, trisomy 18 Edward syndrome, the parents were counseled at birth that their children wouldn't make it past infancy. But I can tell you today, as a medical director, I have children that are two years old, three years old, five years old, who have these syndromes in my panel. I approve their 24-hour nursing care. So, these children are living longer. So, what has happened is there have been advances in the past 30 years in medical care, most of these conditions still don't have cures but they are maintained, so staying a chronic disease condition. So, which means the children live longer.
- [00:05:59] The unintended effect of improved treatment, of course, is that patients with complex diseases are growing in number and take up an increasing percentage of healthcare resources. Why

should we care? I'll tell you why. These children are at particular risk for healthcare inequities. They have poor healthcare outcomes obviously, and they have lifelong developmental challenges. Just as an example, a study, recent study showed that 40% of these children who were on Medicaid, the CMCs had not seen a primary care physician in a year. So, they had just gone from maybe one specialist to another to another to therapies and all that. So, the PCP who is supposed to have – take charge of the overall health of the child had not seen this child. So, they also at risk for – there's a lot of family and – family stress associated with this.

[00:07:06] So, if you have a two-parent family, they have a child who becomes a child with medical complexity, discharged from the NICU, they may have been living in a two-bedroom apartment. When they're coming back home with this child who's going to need a nurse in the house to help them with the child, they're going to have a home ventilator, they're going to have oxygen and different kinds of medical equipment. You better believe they're going to need more room, right. So, they were living there in a two-bedroom apartment with their two-year-old. They're going to have to get a third bedroom to take care of this child, have a room for the two-year-old, and maybe have their own room as well. So, that's an added financial burden on these people already, right. And so, coming out of the hospital as well. So, once you know you're going home with this kind of child that has all these medical issues, the tendency is that some of the parents reduce their workload.

[00:08:03] They work outside the home, they reduce – they take a part-time job instead of a full-time job, and sometimes they completely stop working so they can better care for their child. So, the result of that, the net result of that is a loss of income for this family that's already dealing with something as complex as having this child in the home. Of course, we'll look at cost of medications, skilled care, and medical supplies. For the Medicaid patients, not a big deal, but if you have a child like this, who has ten medications to fill a month, and you're on commercial insurance, like most of us are, you'd have to pay at least the copay of what, \$20 for each medication, or \$25, so you multiply that by ten. We're talking about \$250 just on medication refills alone every month. And then you'll have some other out of pocket expenses for equipment, for supplies, and things like that. So, it is a source of financial stress on these families.

[00:09:06] And again, just alluding to the family stress from the finances. You have also a sibling, a sibling, you think of a two-year-old, a

three-year-old who's waiting for his brother, his little brother to come back from the hospital. Well, little brother comes back, never talks, never speaks for one year, for two years, for three years. As a sibling, he never gets to play with his brother, the way the other kids in the neighborhood get to play with their brother. That, in itself, is stressful for a young child and it's very difficult to understand, and a lot of times, just because of the amount of care that these children with medical complexity need, the parents tend to pay, of course, more attention to the sicker child, and less to the other one. So, you have an element of neglect, an element of maybe loneliness on the part of the child, and they often – again, a study has looked at the siblings of the children with medical complexity and seen that there is emotional-behavioral problems sometimes with these kids, and that's understandable.

[00:10:10] Let's look at the numbers now, the impact on healthcare spending. Just to get a good idea of the impact these kids have, they constitute anywhere from – some studies have said 0.8 to 1% of, of the number of children in the United States. So, they constitute 1% of the population of children in the United States. It used to be 0.5 but with the growth, with the sustenance by more sophisticated medical equipment, the number now has increased to between 0.8 to 1% of the total number of children in the United States. But the impact of these children on the healthcare spending is 30%. So, by saying 1% of the population account for 30% of the total healthcare spending in the nation. That's a lot. That's a staggering number. We're talking about \$100 billion a year on these children. So, we look at again the readmission rates equals or exceeds that of elderly Medicare beneficiaries. Now, when something like this exceeds the Medicare beneficiaries, the CMS takes note of it.

[00:11:22] So, this group of patients are very, very important. Nationally, for Medicaid, those enrolled in Medicaid, 50% of Medicaid spending on children is on children with medical complexities. So, that again is a staggering number by itself. So, if you think of all the money spent on children who are Medicaid, 50% of that spending goes to 1% of the population. So, we really have to find a better way of managing the children so that we can at least reduce spending and have better healthcare for them. Other statistics there, 55% of children hospital – that's a typo, children hospital admissions is from the children with medical complexity. 85% of the cost of 30-day unplanned readmission in children hospitals as well is attributed to children with complex medical – with medical complexity. So, we're looking at challenges to providing care.

[00:12:23] So, we know that they have these needs. We know that we need to care for them so why are we not caring for them better than we're doing? So, we'll start from the providers. The providers, the primary care providers, for example, the pediatricians, they feel that they don't have the expertise to care for these children. They're very complex children. Some providers will say I've never seen this syndrome before, I don't know how to take care of this child. So, there is a certain feeling of inadequacy because again, because of how complex these children are that the providers don't want to really take care of it. There is a time aspect of it. If you've been to a pediatric clinic before, it's a very busy place to go to. You know, the, the otitis media, the upper respiratory tract infections, the coughing, the asthma, all that scheduled on maybe a 15-minute basis, right. You come in, you examine the patient, you take a quick history, you figure out is that an ear infection, you prescribe the antibiotics. In 15 minutes, you are done.

[00:13:27] Well, when a child with medical complexity shows up at your clinic, even if he has just an ear infection, he's not going to be done in 15 minutes. It takes just 15 minutes for mom to recite the medicines that he's had and all the specialists that he's seen in the past 30 days. So, it takes a lot of time and the way things are set up right now for the fee for service, there's no incentive for the providers to see these patients. So, they see them in 15 minutes, that's the allotted time, maybe 20 minutes, that's not enough time to take care of all their needs. So, time is a problem, that's why they're not seen. Financial challenges again, as we alluded before, the see – the fee for service method of payments is not very conducive for the, for the providers to, to continue to see these, these patients. There's more interesting ways to pay for and recompense them. So, things like value, value-based payment system are things that would help alleviate this and I'll talk about that a little bit further.

[00:14:33] For the family, we talked about the stress, clearly there is stress on the family when they have to manage and deal with these kids. There is limited health literacy and that's important to emphasize because sometimes if you're in healthcare, you think everybody understands what you understand, that's not the case. I talked about – yesterday about a mom, who was given instructions to feed the baby by the G tube, she knew how to do that, but she was going ahead and also giving something by mouth through the bottle. Well, the baby was aspirating because of that, that's not good, but she didn't understand the reason. It wasn't clear to her why the baby's airways have to be protected and not, not have the feeding go through the mouth

but go through the, the G tube for the, for the time being until the baby was able to protect his airways better.

[00:15:24] Finances, like we talked, just like I mentioned before, it's real for these parents. There's a drain on their finances. You hear things like I don't have transport, I don't have transportation to get to the doctor's office. I don't have transport money, I don't have gas money. So, there is a car, but there's no gas money, and you hear things like the case manager, somebody's trying to reach to them, the phones are turned off because of non-payment, right. They don't have money to keep up with the bills. Again, there is financial stress. They have stopped working or maybe cut down their hours and all of those things. So, that's some of the reasons why these children don't get the care that they need. The healthcare system, the healthcare system, we all know, is fragmented. What do I mean by that? There is all kinds of silos. So, you get something done at Broward General. So, you go there, you get a chest x-ray, and you're here today, you get sick, you go to the nearest, maybe you go to Jackson, they don't know what happened at Broward yesterday. They're going to start all over again, right. They start the x-rays, you know, you keep telling them I had this done yesterday. They say I don't have the results, sorry, you have to do it again.

[00:16:31] So, there's fragmentation. So, when you bring these children into a fragmented healthcare system, it cannot be a good thing for them. So, if they had a procedure done and somebody's trying to do that, it's not only unnecessary, it's a burden to the parents, it's a burden to the healthcare system. It's a burden to the child because you're putting him through something that he shouldn't be going through. So, the fragmented healthcare system is one of the reasons why they get poor care. The system doesn't talk to each other. Nobody knows what happened here, what happened here. We also have a lack of specialized therapies and specialists. So, again, because of how complex these children are, sometimes they have to go out of state, go out of town, to find the therapist that they need. The specialized – that, that one surgeon in the country who does that surgery for that condition, right? Sometimes, you have to go out of their home base which is a challenge.

[00:17:31] In my previous job, we all had a lot of requests for people to go to Boston Children's Hospital, Children's Hospital Philadelphia, and all those places out of state just to get that one person who is known to do this or do that, right. So, that's a challenge. Not everybody can get to that place. Not everybody needs to go there. So, it becomes a challenge if you're unable to go to Boston, go to Philadelphia, go to New York, wherever that care

may be, then you will not get the care you need, just because it's not available locally. So, a child, a typical child with medical complexity, as you can imagine, they do see a lot of specialists. They would see a neurologist, a neurosurgeon, ophthalmologist, pulmonologist, gastroenterologist, physiatrist, ENT specialist, of course, a primary care physician, geneticist, nutritionist, speech therapist, occupational therapist.

[00:18:30] This is a care map. So, all that we saw in the previous slide, this is just to put it – to illustrate how that works in real life. This chart was drawn by a woman whose child had a, who had a medically complex child. This is her blog and this is what her life looks like now. So, they have their family, they have for health, they have to see the dentist, they have to see the specialist, they have to see the pediatric, the pediatrician, they have to see all the pediatric specialists, the endocrinologist, the geneticist, the cardiologist, GI, ophthalmology, and ortho. Then you look up there, as the child gets older, he transitions into pre-school, times goes fast. So, they become three years old, four years old, five years old, they transition into pre-school or school, right. So, now you have to deal with therapies in school because he'll be getting his therapies in school such as ABA, PT, ST, OT. Hopefully, everybody knows what these means, right. Okay. So, so they're getting all that in school. You have to talk to the bus driver, right, because this child is in a wheelchair, needs somebody to help him, maybe going to school with a nurse, to help feed him, do all that good stuff.

[00:19:42] So, you're interacting with all those people, making sure the transportation and all that is coordinated to, to help the child. Then you look at the advocacy groups. So, if, if the child has a diagnosis that has an advocacy group, say Down Syndrome, whatever it is. So, the parents have to seek peer to peer, to be encouraged, to find out what remedies are out there, what therapies are out there. What are the latest and greatest things that can help their child? Then you look at legal and financial problems, issues that they have to deal with. Again, these parents know that dealing with a child who may never be self-sufficient, who may never be independent for the rest of their life, we all have children, right? You think when they're 18, when they're older, when they're 21 whatever, you know, you send them out, you kick them out. It's never – I have four, I know. So, it's never going to be the case with these children. Most likely, they're going to be dependent on you for the rest of your life. So, the, the, the good thing to do as a parent, you have to sit down and think about what happens if you get hit by a bus tomorrow, right. You have to have a care – a plan for them, legal, who is going to take care of them? Financial, where the

resources to take care of them for the rest of their life? So, they, they get involved with the, with the lawyers and all of that there. You can see that.

[00:21:06] And then you can see their family support, maybe people from their religious organizations, from churches, from mass, from whatever they, they go to and all that support is there as well. So, but having seen the challenges, and having seen how difficult it is, we really have to find out a way to navigate these challenges, right. There has to be a way. Where there's a will, there is a way, yeah. So, provider education is one of the things we do. So, provider education, which simply means that the providers, especially the pediatricians, there is a push now to during their post-graduate training, residency training, expose them to more of these children so they can learn about children with disability, so they can learn about children with atypical development, right. So, they can learn, learn about care plans, what that means. Psychosocial assessments, some of these doctors have never – they're not really conversant with this, they don't know how it works. So, that's the push to make sure they get exposure to that so they don't feel incompetent about taking care of these kids.

[00:22:16] We talked a little bit about payment reform. Again, going from a fee, from a fee for service model of payment to a value-based payment will be the best thing to, to take care of the reluctance that the, the providers have in spending time. The, the value-based payment looks at quality metrics. So, you have a panel of patients and you're paid to take care of your patients, right. You're given X amount of money to take care of your patient. So, the sicker ones, you pay more attention to. The ones that are not sick, you leave them alone, right. They come in every year for their yearly check-ups, then you have time to take care of people who are sicker. With the value-based, you are encouraged to do the right thing for the patient. Now, you're not looking at time, you're not looking at how many people come through your clinic. You're encouraged to be effective in what you do, effective which is doing the right thing and efficient, which is doing the thing right. So, you do the thing right so you don't have to do it again, right. So, efficiency and effectiveness is what the value-based payment model encourages providers to do.

[00:23:27] So, we also have access to specialty care. Like I said, we need more specialists in some areas. We don't have a lot of specialists, for example, in this area, I think it's ENT, pediatric ENT that's a little bit scarce. But however, if people have incentives to see the patients, they will see them. Some –

because we deal with Medicaid, some providers will say we don't see Medicaid. Well, if Medicaid starts paying better than the commercial, guess what? They'll open up their panels to see Medicaid patients, right. What gets incentivized, gets done, okay. So, for the families, what can we do to help them to navigate the barriers? We support the families, we bring them in, not as outsiders, as engaged partners. We discuss the children's conditions with them, and empathize with them, understand what they're going through.

[00:24:21] They're not regular parents who have a kid with asthma, that's not what they're dealing with. They're dealing with – like the, the parent I quoted earlier, sometimes day to day, sometimes minute by minute airway problems. Every day seems like your child may die that day. That's not an easy thing for a parent to do, so they need your empathy as a care provider at any level. So, bring them in, make sure they're equal and engaged partners in decision making. So, know the family now that if you want to schedule surgery for the child, they're just putting a random date in December or say at Thanksgiving time, right. You have to know if that's appropriate. It's not just the first opening for the, for the surgeon. You have to know the family to say will it be appropriate around Thanksgiving? For some families, the answer will be yes. Grandma will be in town, take care of my two-year-old, so I can attend the sick baby, that makes sense, right? Right. Some families the answer will be no. Grandma has a lot of drama, I don't want her when the baby is having surgery. This is real so you have to know the family enough, engage them to know what their preferences are, and then make those decisions, right.

[00:25:30] Because if you do it, it can, it can have again, a detrimental effect on them and their child. If you put him when grandma is there and they don't want grandma in that business, it's going to mess things up. Okay, so you, you know them, and engage them as partners in decision making. And then, you provide them with community resources. So, there's an organization out there that's giving respite care for parents, get them involved. They're giving housing for parents, get them involved. Whatever it is, provide those resources for them so they can take advantage of them, and link them to peer support groups. So, like I used Down Syndrome as, as an example, so there is a support group for parents with kids who have Down Syndrome, link them to it, so they can talk to other parents and they can provide support for each other. And for the healthcare system, again, value-based care. Value-based care, value-based care, you guys will get tired of hearing this. It's, it's the way to go. Now we are recognizing the healthcare system that there are

other determinants of health other than just what happens at the doctor's office, right.

[00:26:35] We're talking about social determinants of health, which luckily, somebody will be speaking to us about today. So, value-based care takes care of payment for non-fee – face to face services. So, if somebody's calling providers, coordinating care, spending time understanding the family, just like I said, there should be payment for that, not just when the family shows up at the clinic, right. So, if you're speaking to the mom on the phone, understanding her family dynamics, that's useful time. That's time that's impacting the care of the child, so those things should be compensated for. So, that's where the healthcare system should be looking at. And then care management. Do we have any care managers in the room? Just a show of hands. Care manager, care coordinator, very good. You are the right place at the right time. The healthcare system is fragmented and you guys are the glue that will get it all together. You guys are the ones talking to the parents. You guys are the ones talking to other providers, knowing exactly what's going on.

[00:27:35] So, the, the – I'll give you an example. The doctor might see an address on the patient's, patient record, right, that says 1990 South Date Boulevard. He says, oh, wow he lives in Miami, he knows that. You know it's a hotel, you know it's here. You know that patient lives in a hotel and it makes a difference because you know they can't pay the rent so they're now in a weekly motel and they're paying. So, their accommodation is not certain. The doctor just sees an address, the care manager knows exactly what's going on. So, shout out to you guys. The healthcare system is depending on you to get it together. So, let's talk a little bit about care management now. So, some definitions, coordination of care. This is a very long formal definition but I'll go through it. Patient and family-centered, assessment-driven, team-based activity that's designed to meet the needs of the children while enhancing the caregiving capabilities of families. Addressing interrelated medical, social, developmental, behavioral, educational, and financial needs, to achieve optimal healthcare and wellness.

[00:28:49] Then we have case management. Case management is just management and treatment of specific disease or condition such as diabetes, cancer, cerebral palsy. It's often focused on allocation of limited resources for a particular patient. So, case management is often disease-based. So, it's based on diagnosis. Then care management is a team-based, patient-centered system, system-level approach to populations, designed to assist patients and their support system in managing medical

and psychosocial issues more effectively. So, basically, care management is everything combined. It's care coordination and case management, and there's another concept which is called care integration. So, everything you do as the case manager, everything you do as the, as the care coordinator, leads to one thing. It leads to care integration. I'll give you an example of what care integration is. The definition is, is just care – delivering care to patients and families in a way that is seamless.

[00:30:00] So, they move through the healthcare system without any abrasions. They don't know that they're moving from one place to another. You make it smooth for them. So, I give you an example of what care integration is from my own personal experience. I had a flight booked from West Palm Beach to San Francisco that's going through Atlanta. The airline called me and said they delayed the flight. It was an evening flight, it was delayed. So, instead of leaving at five o'clock from West Palm, we left about eight o'clock. So, that meant that we missed our connecting flight to San Francisco. So, that meant that we couldn't get to San Francisco that day, we're going to have to spend the night in Atlanta and leave the first flight out of Atlanta. Care integration by this airline, I wish I could give them a shout out, I wish I can call the name but they haven't paid me, so I will not. But truly, they, they were perfect. So, because they delayed, because they caused the delay, they got us to Atlanta about eleven o'clock. They said go to the counter, they'll take care of you. Just tell them you were on the flight from West Palm that got delayed.

[00:31:12] That's exactly what we did. We stopped there. They gave us immediately, called our names, gave us vouchers so we could eat in the airport for free. We just handed in the vouchers and we ate, that was our dinner. And then after that, we walked – somebody walked us to a place to grab a bus, eleven o'clock at night, and then we took us to a hotel. They had our names already. We walked into the hotel, settled down for the night. The next morning, at five o'clock, the bus was there. We, we got ready, got into the bus, got to the airport, seamlessly, right. No sweat. So, if you contrast that to if, God forbid, I was stuck in Miami traffic like some of you did this morning, and missed my flight, it would be on me. The airline has no obligation to make all those arrangements, so what would happen? I would have to call immediately, knowing that I've arrived at Atlanta late, find a hotel, wherever, you know, any hotel that has an opening, within a 24-hour period, get into that hotel, book a room which I will pay for, unfortunately. And then get to the airport at

eleven o'clock at night, call a cab or an Uber or whatever to get me to the hotel.

[00:32:17] Now, I have a waiting period so maybe it will come at 12 midnight, get me to the hotel at one. I have to eat, so I have to pay, find something to eat and pay for it. And then in the morning, when I get up, I would have to call another taxi at five o'clock in the morning to get me to the airport so I can get the first flight out of Atlanta to San Francisco. That is abrasion. So, every point I feel the pain. I feel the pain calling a taxi, I feel the pain of making – booking for a hotel in 24 hours or less. So, that's abrasion. That's what we're trying to prevent for these children and this – and their families. It's the same thing that happens. I spend a night in Atlanta, one was smooth, one was not. So, care integration is all the efforts of care management and case management. They move through the healthcare system seamlessly, they don't feel the pain because you smooth out the rough edges for them.

[00:33:11] Okay. So, this is a typical care model that we have now. It's a little bit disjointed as you can see. We have a PCP, we have a referral coordinator, we have a health plan. PCP writes a referral, it goes to the pulmonologist, goes to the health referral coordinator who goes to the specialist, maybe therapies, maybe to the hospital health, and then to the family. So, it's a little bit disjointed but this is what we have now. And then this is what we like to see. You have a care coordinator. This is a team, not just one person. One person can't do this. So, you have a team of people there. This is usually out of the PCP's office. Sometimes, they might be in a tertiary care place like a children's hospital. It doesn't matter where it is, sometimes it's in an outside organization. But the important thing is you have a team of people who know everything about this child, right? They talk to the family, they educate the family, they talk to the specialist, they talk to the therapist. They are in contact with the hospital, they provide community resources. They reach out to them, they provide preventive and anticipatory care. Psychosocial needs, they help with that. They develop a joint plan of care. And also, they have the medical records and also, they talk to the PCP. So, this is what we want to see.

[00:34:32] We want to see everything pointing from one direction, so you call somebody, they can tell you about this family, they can tell you about this child, they can tell you what appointments he has, when he's going to have what done. So, we also want, in addition to just having all this contact, we want this group of people, this team to have strong competency in transition of care. That's another area where these children, we fail them,

when they're going from the hospital to home. Sometimes, the oxygen doesn't get ordered. Sometimes somebody forgets to tell the home nurse when they should be at the home. So, this team should have a strong component of transition to care. Again, when the child is transitioning from home to school, the team has to engage with school and to make sure that all those therapies we saw in the previous slide, the ABA, the OT, the ST can happen in school. If they cannot happen in school, where can they happen? Will they happen at home? All those things are necessary to make sure we have an effective care coordination and care planning team.

[00:35:37] In addition to that, also to be proactive, the role of the care team is to be proactive. Have a little plan for the parents, what happens when a hurricane is coming, where do you go? What happens when the G tube falls out? What happens when the child looks like he's not breathing anymore? So, there should be a written proactive thing. If somebody has pneumonia every end of the year when it gets cold, what do you do? Do you increase – you talk with the provider, pulmonologist, maybe they should do more frequent nebulization just to be proactive because whatever you do to keep that child out of the hospital is worth it, for the parent, for the child, for the healthcare system. So, effectiveness of care coordination just like I've said. It provides a positive impact of the health of the child and the family obviously. Increasing self-management through education and support. Again, when you embrace the parents, when you bring them in, they feel more confident in caring for their, for their child which is really a good thing.

[00:36:40] Families increasingly engaging in care and negotiating goals and priorities together, like the dates of surgery near Thanksgiving. Appropriate care resource allocation, while considering the issues such as social determinants of health, coordination between primary care, specialty care, and external organizations such as hospitals and managed care organizations. Reduction in, in hospitalization and, and emergency department utilization. A final word, CARE. It's opening for me here but it doesn't want to show you guys what I'm seeing but that's fine. So, you trust me when I tell you what I'm seeing on this screen. So, the CARE is an award, like I said, the children's hospital, the Children Hospital's Association, they came together, because these children – just the impact on the healthcare system like I said, 50%, 55% of the readmissions in children's hospitals are accounted by the children with medical complexity. They came together to see how they can modify the, the methods of pain meds. They can also improve care coordination and see what results they get.

- [00:37:53] They did get a lot of success stories, we're just trying to pull them up here so you guys can see. I'll, I'll just read it out. Children's Mercy in Kansas City, they used a state home in behavioral health platform in transforming care delivery for children with medical complexity, and what they did was they implemented – excuse me. They state per member, per month, to support service integration across providers. So, the Lucile Packard Children's Hospital in Stanford also – they, they did a local partnership with the local Medicaid managed care organization. They implemented a care management monthly service fee per child in the CMC case management program. So, they were paying for case management. Like I said, what gets incentivized, gets done. So, they had an aggressive case management program because they were paying. They had a special arrangement with the local Medicaid program and they were paying for that.
- [00:38:56] The UCLA Mattel Children's Hospital, using access and emergency plans to UCLA Mattel Children's hospital developed after-hours action plans to help families of children with medical complexity to avoid emergency department visits. These plans were then embedded in, in the patients' electronic healthcare records to ensure that any provider seeing the child would understand how to manage the child's care. This is nice. That's a way to deal with the fragmentation. St. Joseph's Hospitals, with a focus on creating comprehensive, comprehensive care plans for all children with medical complexity. St. Joseph's Children's Hospital implemented contingency plans and emergency protocols to reduce preventable emergency department visits when there was a change in the child's condition. So, as I was saying before, you have plans on what to do just in case something doesn't go right.
- [00:39:48] So, Wolfson's Children's Hospital, as a critical element of the care awards, Wolfson's, Wolfson's Children's Hospital in Jacksonville, Florida collaborated with the University of Florida UF department of pediatrics and community hospice and palliative care to implement a transition program for adults with medical complexity. As I said earlier, time goes fast, so these children needed transition of care plans, so when these children transitioned from home to school, from being children to being adults, you need a plan for them. So, that's what the Wolfson Children did in Jacksonville. And so, they – it focused on the care of the young adult transitioning from adult care and palliative care coordination. UF Wolfson applied change concepts to, to patients co-managed by their committee palliative care program, and they all got good results. Why, why

am I saying all this, and why are we talking about this? The Children's Hospital Association nationwide recognizes this group of children as very important, they're very impactful to the healthcare system. So, if 1% is driving 30% of care, and yet they have unmet needs. What happens if we can meet some of those needs and at the same time, reduce care. That's what this, that's why this topic is so important.

[00:41:06] Thank you so much. You guys have been an amazing audience.

[Applause]: [00:41:11]

Female Speaker: [00:41:11] Thank you so much. Do we have any questions from the audience?

Dr. Ikpeazu: [00:41:20] Questions, comments, thoughts?

Female Speaker: [00:41:31] Hi, I'm a lactation consultant with a WICK program and what we saw in the early slides, I'm sorry, I hear an echo. In the early slides, I saw how you integrated all the, all the specialties. Okay, I saw lactation consultant missing, and really, I think breastfeeding is a major component, especially for a lot of these moms with sick children, are outliers and they request pumps from us. So, I think that's a service, unfortunately, but I hope for the next one is going to be integrated.

Dr. Ikpeazu: [00:42:08] Oh, no. I agree with you. A four times breastfeeding mom, breastfeeding crazy person, I agree completely. Lactation consultants should have been there. But the, the slide is a slide, we didn't get that in there. Next time we'll get it in, but yes, lactation is a very important component, especially if we're talking about premature infants, they may have necrotizing enterocolitis. The best feeding for those children is breast milk.

Female Speaker: [00:42:37] And even if those babies are not breastfeeding yet but those mothers need to provide the breast milk.

Dr. Ikpeazu: [00:42:41] Yes.

Female Speaker: [00:42:43] So, most of those mothers or many of them are our clients and they request our services. So, we are very, I believe, a crucial component of the whole, of the entire process.

Dr. Ikpeazu: [00:42:56] That is correct because they cannot, like most people, breastfeed in the NICU, and this kid's transition to a NICU, so they have to pump.

Female Speaker: [00:43:04] Correct.

Dr. Ikpeazu: [00:43:04] And, and, and freeze.

Female Speaker: [00:43:06] Yes.

Dr. Ikpeazu: [00:43:08] And feed.

Female Speaker: [00:43:08] Yes.

Dr. Ikpeazu: [00:43:08] I know all of that. I was one of those moms carrying the little breast pumps to work. Yeah.

[00:43:16] Alright. So, I also wanted you guys to see this because I think it's just cute, the CARE award which means coordinating all resources effectively award. That's a nice and catchy acronym right there. So, that's what I was trying to show you. They learned a lot of lessons, they awarded it to a few children's hospitals. They had their preliminary findings, they had their success stories – can you just open this one for me? The success stories? I know they believed me, but let's just –

Male Speaker: [00:43:42] You want to show them.

Dr. Ikpeazu: [00:43:43] Yes, I want to show them, be proud. The children's hospital, Kansas City, and then the Lucile Packard Hospital, and you guys can always go online and take a look at this but it, it just shows the push towards managing these children better. I just wanted to show you that everybody is looking at these kids and trying the very best to manage their care well. Is there any other question before – anybody else? Comments? Hopes, dreams, aspirations?

Female Speaker: [00:44:15] Thank you so much.

[Applause]: [00:44:15]

Female Speaker: [00:44:28] Thank you. Thank you very much Dr. Ikpeazu for such an eye-opener and funny presentation. So, thank you so much. Now I know I'm actually standing in a very interesting position between you and lunch but they're giving me some signals. Do I need to say something? Wait for you? Tell me.

Male Speaker: [00:44:56] Thank you, Genie. Actually, we have a VIP guest. We've had great speakers and I wanted to take the opportunity. She says she's not shy so I'm going to put her on the spot. One of our proponents for many years, a big supporter is Senator Anitere

Flores. So, we have her legislative aide here, Tiffany Lorente, did I pronounce that, Lorente? Sorry, who is going to say a few words. So, please join me welcoming her. I'll tell you right now we have a legislative state-wide, one of our most critical programs that deals with all the stressors our mothers has is a nationally recognized, moving beyond depression program where we had licensed therapists go to these moms' homes in conjunction with their case manager, you know, to assist them. We've been recognized as one of the largest and most effective programs in the nation in Miami Dade County. We've been running it for three years. The contracts on funding has changed and now the first time, you know, I've shared with the elected officials. This is the first time in 18 and a half years, that I've been the CEO, that I've ever gone and asked for local funding.

[00:46:02] That's how important this program is. It cannot end. And I would like to have Tiffany come up here and just say a few words on behalf of the Senator, thank you.

[Applause]: [00:46:11]

Tiffany Lorente: [00:46:12] I am sorry I am the person between lunch, like wow. And I don't know all about VIP but thank you so much. My name is Tiffany Lorente, I work State Senator Anitere Flores and I have a couple of familiar faces in the crowd so that helps a little bit. Thank you so much for all of your efforts in, in protecting babies. Senator Flores is a 100% for the babies, in the belly, out of the belly, she's all about it. So, we're really excited to be here. It's truly a pleasure. Whatever you need, our offices are always open and he can vouch for that, Manny can vouch for that. He comes in unannounced and is, you know – it's awesome because he's like a cup of coffee. He's a walking cup of coffee, he just shows up and everything is all energetic for the rest of the day. We're so productive after Manny comes into the office. So, he's great and we – you know, we're really proud to, to be supporters and whatever, again whatever you need from us, we're here to help. So, thank you again for having me and enjoy your lunch.

[Applause]: [00:47:05]

[00:47:09] [End of tape]