Welcome to Conversations About Care: A Podcast for Pediatric Clinical Providers

Hi! This is Sandy Hassink and I'm the medical director for the Institute for Healthy Childhood Weight at the American Academy of Pediatrics. I recently sat down with my colleague Dr. Stephen Cook, Associate Professor of Pediatrics and Internal Medicine at Golisano Children's Hospital to discuss weight bias and stigma in children and adolescents.

Dr. Cook offers some clear steps for pediatricians to engage families on this topic of weight and obesity. Stay tuned to hear our conversation.

Sandy: Hello everyone! This is Dr. Sandra Hassink. I'm the medical director of the AAP Institute for Healthy childhood Weight and today I'm here with Dr. Steve Cook, associate professor of pediatrics and Internal Medicine at the Golisano Children's Hospital in Rochester, New York. Steve has a long-standing interest and practice in obesity medicine. Today we're here to talk about weight stigma and bias. So welcome Steve.

Dr. Cook: Thank you Sandy. I appreciate it!

Sandy: So Steve, I'm always interested in … I know weight bias and stigma, addressing weight bias and stigma has been a passion of yours and I'm always interested in … how did that come about? How did you get particularly focused on weight bias and stigma?

Dr. Cook: Well you know, I think it was a number of things. I mean working in the field, such as yourself, getting to meet so many people in pediatrics who are very interested in and enthusiastic in this and trying to, you know, help families both on a larger community policy side with things like daycare, school policy, strategies, and things like that. But also clinical because at some point obesity is a disease that needs a clinical intervention and we've seen so much of that really expand, and we've seen the evidence base expand.

I think it was probably after … the Affordable Care Act they identified that evidence-based interventions that were endorsed from US Preventative Services Task Force with a grade B or higher should be covered without copay. And most the things under preventative services are like screening or much more simple type of tools, but childhood obesity, BMI screening and treatment was identified in evidence base was expanded, looked at, and shown to be effective. And from meeting with so many other colleagues in pediatrics through the mid 2010's, '14 through '18, I'm thinking a number of us were either trying to set up weight management services, or expand them, or just keep them running. And as part of a survey with the Children's Hospital Association we looked at this and it was, you know, concerning because we had a really good response rate and a fair number of places had something, but the support and the finance part really wasn't great.

So we had this condition that was getting all kinds of attention on a media standpoint. A policy standpoint, but the clinical piece of it wasn't there. And as I looked at it and working with others this was like a systemic bias. It's a weight bias against a condition, and the two often I would talk to primary care doctors who are frustrated who said, "I can't help this family. They don't want to give in. They don't want to make change and it's not as simple as that." So just like we've advocated for kids in so many settings, this is a condition. And I'm not saying every child with high BMI really is in the same boat, but you know, for children with obesity, severe obesity for which a clinical intervention is needed. You know, we need to advocate for this at the Medicaid, the payor level, as well as looking at how it impacts the social life and emotional life of a child.

Sandy: So Steve you bring up so many good points because I think one of the more striking things about this disease of obesity, this medical condition, is the pervasiveness of weight bias and stigma down to actually within families, within schools, communities, in the health system, bias about providing resources for treatment. And so I think one of the striking things when … as this was all evolving was to look at the implicit bias within our own healthcare providers.

I remember looking at an implicit bias test that a bunch of providers took and just realizing that we were reflecting the cultural bias around obesity and began to think how important it was for us to first recognize that we adopted out own cultural view to be aware of that and to understand what that meant. And to address it with ourselves in both our clinical practice and in our advocacy for children with obesity and their families. So I think one of the things that I've been most interested in, at least as I've taught about this, was helping people find resources, such as The 0:05:02 Center, to look at their own implicit bias and begin there and just realize how pervasive this is and then understand that and the implications for … in all the places and spaces there in.

So I wanted to just ask you, as you deal with children, we'll just start right at the clinical level and you're meeting them maybe for the first time. How do you approach a family? Just to try to understand, are they and how are they being impacted by weight bias and stigma? How do you start that conversation?

Dr. Cook: Well you know Sandy, you brought up a great point about the implicit biased test and we actually had our research team that's running our intervention for one of our studies - these are behavioral coaches, had them go through the test and I wasn't surprised. Like all of us, we have some component of bias and a number of them were surprised that they have it. And a couple were actually trained in special ed and they were really surprised because they work with children with autism and other disabilities and felt they were really kind of in tune to understanding children and sensitive nature of children. And that's another reason I pointed out to them and others like we’ve done so much around teasing and bullying, and you know, identifying and not teasing, and bullying, and picking on children because of their race, their gender, their sexual orientation, their disability. But body shape and weight it's still free gain and it really has been. And so it's one of those things that just been there for such a long time so I try to really keep that in mind and talk to residents and families about it.

And so I try to use a couple things. People first language so if I do have to say obesity I say your child with obesity, your child has obesity, not your obese child. And I also ask them, "Is it okay if we talk about their weight?" And just starting a conversation with that. When I have a parent for a visit, that's what we get into. It's really important because there's a lot of disconnect there where a child may be well above the 95th percentile and as a scientist we think of, all right, this is like severe obesity and the parents are like, "Yes, he's a little overweight." I have to hold back and not correct them like, "Well no, mom. This is really kind of well above the obesity range." So it's checking yourself and trying to make sure that you can understand because at the end of the day it does … it's really important to understand what are the other important things in their lives, and obesity is such the condition that parents will … when you bring it up you want to discuss it, but if you don't start out right, they take this as an immediate assault to their parenting skills. Like you've failed this child because you know, their like 30 pounds overweight at the age of 9. That's not the case, you just try to ask what's going on and start the conversation. If we can build a little bit of confidence and reassurance even if it's something small, they can do that we know isn't going to move the calorie needle or the weight needle, but they can accomplish it, it's building that report. So I think it's really important to start out, you know, kind of slow and gentle in that sense to bring it into families. I try to make a point of you know, in some cases, this is a disease and it's not one phenotype. It's not just one disease. There are so many ways that this kind of evolves that we can't just chalk this up to weekend personal choice.

Sandy: So I think that I … so many things you said are so important. One is asking if you can talk about weight. I've had families come in and say, "We don't even use that word in our family." And I said, "Well what word can we use? What word can we use to talk about this?" If we can talk about this, what word would you like to use to talk about it?"

You know, you made me think of a case I had years ago when a mom had three sons and they were all … they all had obesity. We were in the midst of our visit and I don't know why I said this. I just happened to say to mom, "You know, I'll never judge you." And she burst into tears and she cried and she said, "You're the first person who's ever said that they wouldn't judge me. I have felt judged about this the whole lives of my children." So not that I think that that's the language we need to use, but I think we need to recognize how judged parents often feel, and they walk into our clinic with some trepidation about being judged. Yes.

Dr. Cook: Right. You know, it reminds me of a case of a mom and a dad I saw. Mom herself had severe obesity. Dad was really kind of thin. Dad had stepped out and this was like a 3- or 4-year-old girl who had a severe degree of obesity. I said, "Can we talk about weight, can we talk … she was like, okay." I said, "Just tell me kind of if this is okay to talk about," and she started getting upset. I said, "But let's slow down. What's going on?" And it jumped to ACES. This mom was in foster care and she remembers them locking cabinets so she couldn't get food. She remembers being yelled at from family members about eating and trying to sneak food. And now, both what she went through as a stress obviously impacted her weight and was also driving how she was not going to do that to her child. So it is such a complicated issue that we have to really peal back the layers of the onion and understand where we’re starting from.

Sandy: Yes. Steve, I think that's so important to recognize the multi-generational impact of weight bias and stigma itself, like so many other systemic biases. Many of our parents have had obesity, had an experience weight bias and stigma many times from their own childhood and are trying to either protect their kids from this or feel very judged about this. So I think we approach this with I think a lot of humility in having this conversation with our families.

What about the team, Steve? You know we all work in teams, we have our whole office staff, and all the people we interact with. Do you have anything you can share with us about how we talk to our teams about this?

Dr. Cook: Yes, it is extremely important and having been fortunate to work with you know getting trained by faculty who did practice based research and being shown how to do that and walk-through meeting with practices. This is maybe one issue that when we go into offices it is kind of an interesting and awkward discussion at times. Whether it's my practice at the hospital where I work in our primary care setting, or other primary care settings staff will come up to you after and say, "I always wanted to ask you a question about this." They never come up and ask you about that when you're doing a vaccine study or something, but it is really important for both reasons because obesity is a common condition and so a number of staff will have it. Or they'll be concerned their child has it as well as how they just kind of casually make comments. I remember seeing a toddler coming down the hall, obviously looked very large for his weight and his age, and the nurses are like, "Look at that big boy there." And it's like jeeze, you know, out loud at the nurse's station. People walk around like, yeah it's a cute kid. He's coming down the hall. Did you need that … did you need to make that statement?" And how that may or may not be perceived, and regardless of that person's weight status too. So it's also … you know it is a complex issue.

As you said, looking at the work out of Yale and that group where they've identified where weight bias comes in, it's all levels. It's dieticians, it's doctors, it's staff, it's surgeons. I can remember a few interesting comments made on my surgery rotations with the attendees. But you know, it's everywhere.

One of the key pieces that we brought up when we wrote this policy statement years ago was that it's not just in the clinical side. It's … it affects education at the earliest level. How teachers perceive, you know, children in elementary school. How people applying for graduate school and colleges are affected by the weight bias and perceptions.

Sandy: So Steve, you mentioned the policy statement and I know you were instrumental in writing the AAP's policy statement on weight bias and stigma. Do you have any thoughts about what might be new since the publication of that policy or where we might want to continue to and maybe turn our focus?

Dr. Cook: Yes. So it's definitely … the timing is unique because the policy statement is five years old now. So we actually have to review. We had a review call last week with Steven 0:13:16, with Wendy, and Rebecca Pool, and the team at the AAP. We've looked at it and it's a balance because there were certain things that we thought would be important to talk about in the statement, but then you have the pandemic layered on top of it. And what have we seen? We've seen obesity is such a big risk factor for sever COVID disease in adults as well as in kids. Seeing data where one of the more common chronic conditions identified in kids is obesity. You know, so how that plays into this. We don't know that we have enough given … you know related to the pandemic specifically to go into the policy statement for revision, but we think it's going to be really key as we roll it out. And trying to think of, okay, when this goes out, if we get this renewal of it out within the next year, it's going to point out those talking points of saying, "Okay, this is s0:13:16ill something that's very significant." I mean, I can tell you, again anecdotally from some families how kids who didn't like going to school, were teased and bullied for a variety of reasons didn't mind doing remote school. Some of which I asked families, and yes, being teased about their weight was one of them. You know, but there were others too. So that's one side of it.

The other sides were seeing just increasing rates of obesity because of the pandemic. There was stress, the response that happens with that. So many things complicating it. So it's definitely a time where I think revising the statement on how we identify and address it with personal behaviors and habits in role modeling and language. But then also we have to think of it from a bigger systems standpoint.

Sandy: And thinking of the bigger system, Steve, you know early on we talked about the whole systems response to obesity in kind of a biased way unlike other diseases. Can you tell us a little about what you've seen and maybe some things we could think about doing about that kind of bias?

Dr. Cook: Yes. Absolutely! So one of the big reasons, you know because you were such a help to me when I did this. I actually took a sabbatical leave about seven years ago I think it was, at the request of my chair to look at the idea of how we could create a clinical service for obesity for our pediatrics department. I worked with you and got connected with the AAP, the Children's Hospital Associations where we did a large survey of children's hospitals across the country asking about this. And actually worked with the State Department of Health as they were looking at could obesity be part of some Medicaid changes; they were going to look at making and where that would fit. This is also a time where it's supposed to be covered under the Affordable Care Act.

A number of us were thinking the opportunity was going to arise and I did a business plan with some graduate students at our university on how you put together a one year, three-year, five year prospective and looking at what population size we would see, and how many visits. And everything, which was hard and different, but really important. And then just seeing the thought of okay, as we finish this up, New York was going through a Medicaid redesign plan and looking at maybe revamping entirely how it was going to be paying for healthcare through Medicaid. They were told by a high-level finance person, "Well, if Medicaid drops free for service, we can't start a new clinical service like this. It's not started." So it got decided by a dollar and cents statement right up front. I was disappointed because it was like, all right, I understand. The university, or the center doesn't want to make a step going forward with it for that reason right now. But what's going to happen? And seeing how this has played out and played out in other places … I'm seeing colleagues who run very good programs who are being told to close it down cause it's losing money. And I'm in general pediatrics. You know, we're 75-80 percent of our kids are on Medicaid managed care. Please show me what divisions or departments are making big money besides the NICU.

So, you know, to me this isn't a matter of this is going to break the bank; this is the right thing to do. Now are we treating all kids with BMI of above 96 percentiles? No, but we need to offer something. And it is really concerning because then if feels like it becomes the battle or issue of my disease is more important than your disease. That should not be the case.

Obviously, we have endocrinologists and some specialists who take care of children with cystic fibrosis and type I diabetes and things like that, but if I look at severe obesity, based on our data in our region, three percent of kids are in the severe obesity range. That's more than some of those subspecialties and we don't have any formal type of evaluation, or service, or treatment available. We have small things, you know, someone gets a grant to work with the YMCA or after school program, but nothing that's meant to be really kind of comprehensive treatment.

And so I've been fortunate that my research also started to … the interventional research, really started to take off at the time that this clinical care model was put together because we talked with … and you were there with the academy, we talked with some insurance companies. It was interesting how private insurance thought of it one way, and Medicaid thought of it another way, and then large employers thought of it very differently because they saw it as a family-based treatment which was actually kind of encouraging because they saw the value of it to their employees. So it's been a challenge, but that's one of the things that I think is why we really need to look at addressing this not just on kids being teased and bullied. Obviously, that's important, but not allowing some type of treatment intervention that is available … there's an evidence base for. And it's being stopped on multiple fronts that feel systemic.

Sandy: You know, such good points, and I think that this is … obesity is really a call for advocacy to all pediatricians on all these different levels wherever we interact with patients, and families, and hospital systems, and insurers, and employers. I think understanding our own maybe implicit bias, our own desire to see equity in treatment for all the children with obesity in clinical programs I think can fuel some of our advocacy efforts here.

The other thing I've been so struck with is obesity, I often think is like the canary and the coalmine. It's a reflection of some of the society, socio ecological issues like food, access to healthy fresh food, access to physical activity, stress, now even COVID. That's really pervasive and really fueling this epidemic. And weight bias and stigma and parents feeling the blame … their own sort of maybe some guilt or some blame, really combines to make it even harder for families to work against these socioecological forces that are operating because when you feel guilty or you feel that maybe it's your fault, it's hard to have energy to do the hard work that obesity treatment takes.

So I think it's all interconnected. This fabric of interconnected forces at work here. And really in many ways a call to pediatricians to really be aware of the avenues in which we can all do advocacy wherever we are for these children.

So Steve, we're coming to the close of our conversation. Any last thoughts you'd like to share with our colleagues out there?

Dr. Cook: You know, I think it's really important that like we do all the times, we become the voice for children, but really looking at how care is having to evolve. We need to be the voice for the family and I think we've always got that as the foundation of patient-centered medical homes. So we understand it. So looking at, for example, the intervention I'm involved with is a family-based intervention with parent and child. We see the parents having weight loss as part of this intervention and the child weight corresponding with it. Now this is not an intervention for everyone, but it is an intervention. It's also one that we see in sense a two for one, and so advocating for the training that's needed, to get hospitals, to get health systems, to create, put the investment in, to set up obesity treatment services, clinical services. Because we do the advocacy very well and we do the advocacy very close to it whether it's promoting physical activity, afterschool programs, nutrition, food insecurity. Addressing those issues are all going to help so we're kind of doing that a lot in peds but we really need to advocate on the system side to say okay, let's put some dollars into this. I mean, how many other conditions have we started to address related to children since that time; in the past eight or nine years that are important as well but we have not addressed this. It's obviously more common it seems like and just as stressing.

So I think pushing on the clinical side; on the institution side to support this as well as advocating like we do with the payors.

Sandy: Yes, and I would just add that I think the COVID pandemic has 0:21:45 both the deficiencies in our ability to take care of these kids and fueled increasing obesity rates. So we have a perfect storm, but also an opportunity here to really highlight what's been happening and the vulnerability that really obesity confers on children for not only COVID but other chronic diseases.

So Steve we've been talking a lot about weight bias and I just wondered if we could spend a few minutes talking and thinking about the affects of weight bias physically, mentally, and emotionally on the child. Can you talk about that for a minute or two?

Dr. Cook: Sure. It's a very complicated issue and I think as you and I know, and other, that obesity really shouldn't be tagged as one phenotype. It's not one disease and so whether a child gets there because of mom smoking during pregnancy and that led to extra fat accumulation and a child having a higher amount of weight or being on a medication that drives up appetite because of mental health problems. Or, because of a stressful chaotic home environment and going between having food available and not having food available. And the body going through those physiologic shifts and stress response leading to increased cravings in eating, increased fat storage and accumulation. All these are part of those different phenotypes. Not that we're going to categorize someone saying you have a food reward type of obesity. I mean, we may have all been through something like that, but I think we have to look at the many factors that can lead to it. It's easy to point to … and we think we can point to like a genetic type or syndromic type of obesity, but we know those are really, really rare. But it's far more common to see how the stress, and the stress responses, and the coping mechanisms that emerge play into excess weight gain. And to the fact that that's a biologic set point that is then the body fights to defend that. To hold the weight at that point. And so you have more biologic process; food satiety ques, hunger ques that start driving to keep weight in that range. So it's not as simple as, well if they just put down the cookies and stop playing video games it would be that simple. It's not that simple.

Sandy: And what's always striking to me is weight bias and stigma itself is a stressful occurrent for a child. So being teased about your weight as a child by either your peers or your parents or you see it reflected in social media causes a significant amount of stress. We know that depression and anxiety are associated with a weight bias and teasing. And we know that the physiologic stress response that you talked about just a minute ago gets triggered by weight bias and stigmas and teasing itself. So in some ways the kids are in this look of being teased, and a stressor, and more stressors, and weight, and more teasing, and more stressors, and we find that they get into this loop. So weight bias and stigma is not just … like somebody said, it's not just words. It has an actual physiologic affect, emotional affect on the child. So I think we have to bear that in mind because just like any other factor that affects physical, mental, and emotional health, weight bias and stigma is one of those factors. And so we need to address it in ourselves, in our implicit bias and address it in the system and address it in how we approach our patients. All important considerations.

Thank you, Steve! I really appreciated the time you took today to be with us and all your comments. Thank you very much!

Dr. Cook: Thank you, Sandy! And I think like we should learn from a pandemic, never let a good crisis go to waste. And so maybe this is a time when we can embrace and make some of those changes. Telemedicine may be a great one that I think we've discovered that hopefully will help us along the path here. So thank you so much for having me.

Sandy: You're welcome.

Thank you for listening to my conversation today with Dr. Cook about weight bias and stigma. Also, be sure to check out some of these relevant resources including the AAP Policy Statement on weight bias and stigma, Conversation About Care bonus episodes, Interim Guidance on Obesity and COVID-19, Conversations About Care episode 4: Weight 0:26:20, and The Change Talk app on motivational interviewing.

Thank you all for listening.

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