Season 4 Episode 3
Pediatric-to-Adult Transitions of Care
Transcript

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Learning Objectives:

1. Define Healthcare Transitions.
2. Describe two barriers that patients and families face in transitioning to an adult-centered model of care.
3. Describe two barriers that healthcare professionals face in comprehensive transition.
4. Identify specific challenges that patients with complex medical needs face during the transition process.

Co-hosts' Notice: Physician and provider are terms used interchangeably by many in the medical community. The DEI Shift podcast team endorses and supports the use of physician in place of provider where applicable as outlined in ACP policy.

[0:00-1:22] Introduction

Dr. Pooja Jaeel: Welcome to The DEI Shift, a podcast focusing on shifting the way we think and talk about diversity, equity, and inclusion in the medical field. I'm Dr. Pooja Jaeel, an Internal Medicine and Pediatrics practicing physician and one of the co-executive producers of the DEI Shift. And my co-host today is…

Dr. Maggie Kozman: Dr. Maggie Kozman, also an Internal Medicine and Pediatrics physician who's a hospitalist and a senior producer of The DEI Shift podcast. Today, we're especially

excited as Med-Peds physicians who trained together in residency to bring you an episode on pediatric to adult transitions of care. This is a topic that we each separately gave a lecture on to our medicine or meds-peds colleagues during our fourth and final year of residency, because it's such a key topic for Med-Peds physicians. But also because we realized that there was a curricular gap in this area, especially when it came to training adult physicians how to prepare for receiving youth transitioning from pediatric care to their adult practice.

Dr. Jaeel: Yup. And transitions between pediatric and adult healthcare can be one of the most trying, disorienting, and health destabilizing things a young person and their caregivers experience. And while there are some tried and true strategies of how to transient well, they're not really widely known or implemented for a variety of reasons.

[1:22-2:31] Introducing Guest Dr. Shirin Alonzo

Dr. Jaeel: Speaking with us today about this topic is Dr. Shirin Alonzo. Dr. Alonzo is a Med-Peds trained physician with a unique neurodevelopmental specialty who currently wears multiple hats and delivers primary care for people of all ages in multiple settings. She has a focus on special needs and complex care pediatric conditions. She has a Master's in Public Health with a focus on family and community health. When she isn't practicing medicine, she enjoys surfing, oil painting, playing basketball, and spending time with her fur babies Buffi and Snowie.

Dr. Shirin Alonzo: Thank you guys so much for having me. I'm very excited and it's an honor to be here and share my passion with you and all of our listeners.

Dr. Kozman: Thank you so much for being here. We're so excited to learn from you and talk about this topic with you. Would it be okay with you if we all refer to one another using our first names during this conversation?

Dr. Alonzo: Yes, that would be fine. Just so you know, pronouncing my name is Shirin, or "Sherin," if that's more comfortable for you, I know it's a hard one to pronounce.

Dr. Kozman: Perfect, thank you so much!

[2:31-5:01] "A Step in Your Shoes" Segment

Dr. Kozman: Well, before we dive into pediatric-to-adult transitions, Shirin, we like to ask each of our guests on The DEI Shift to share something with our listeners about themselves. And this can be something like a hobby, a favorite food, a meaningful experience that helps us get to know you and your background a little bit better and flex our cultural humility muscles. And we call this our "Step in Your Shoes" segment. So, what would you like to share with us today?

Dr. Alonzo: Yeah, that's a really wonderful question. And I'm glad you guys are incorporating that into our segment today. Um, so I grew up culturally both with Persian culture and Latino culture. So I am half Iranian and half Venezuelan. And right now is actually Persian New Year time so it's something very special to millions of people around the world and it aligns with the spring solstice. So for us, it's a new year, so happy new year and it lasts a couple of weeks. Uh, similar to different cultures, we do a different kind of activity each day or have a different food each day. So the night before new year's, we'll usually have fish and rice with certain herbs and that's to mean, you know, rebirth and a new meaning. So, there's a lot of meaning and

metaphors and symbolism within the new year. So that's something we're doing right now. And a part of the new year is visiting our elders so anyone older that you. You kind of take turns and go a round and you receive something which is usually like money and either like a some kind of ancient book, whether it's a religious book, or a poem book, um you'll get money from it as a good faith and a good luck for the upcoming year. So that's something that we're celebrating right now. So, for everybody it's a new season or a new year.

Dr. Jaeel: That's so beautiful, thanks for sharing. How do you say, "happy new year"?

Dr. Alonzo: There are a couple of different ways, but the easiest would be "sala nomo bora."

[5:01-11:05] Transitions of Care Definitions

Dr. Jaeel: Alright, so let's dive into our discussion today because there is a lot to cover, uh, Shirin, we'd like to start off with some definitions. So, can you please tell us how transitions of care is defined? What is it defined as, and just more details about the special needs and complex patients that you work with?

Dr. Alonzo: Yeah, there's a lot of different definitions out there. So we'll focus on a couple just to streamline the conversation today. When we talk about transitions of care, that can be applied to a lot of different things, but our focus today is really the transition of care from the pediatric health care system to the adult health care system.

The Society of Adolescent Medicine, they define transition for adolescents with medically fragile conditions as a purposeful, planned movement from child-centered to adult-oriented healthcare systems with the optimal goal of providing healthcare that is uninterrupted, coordinated, developmentally appropriate, psychologically sound and comprehensive.

Each of these keywords is actually critical, but the other thing that's really confusing is how do we define these patients, right? How do we define "difficult"? What is a patient with a special need? What is a patient with a complex care issue? You know, how do we choose and who defines it and what is meant by it? So, for example, the Federal Maternal and Child Health Bureau, they actually have a specific term for this population and they're called CYSHN, so Child and Youth with Special Healthcare Needs. And they're defined essentially by, it's a very kind of general definition, so these children are at increased risk or already have a chronic physical, developmental, behavioral, or emotional condition.

And they also have to require health and health-related services of a typical amount beyond what general children without these conditions need. So that's also another very broad definition, right? And then if we look at well, how do people in medicine define medically fragile? Like when we want to give them home health services or give services in the clinic, what is a medically fragile person, right? Well, we think of it in practice as you know, a non-ambulatory patient that has a medical condition that warrants 24-hour nursing care. So it's somebody that you can't do things on their own, but not just can't move right. They need help having certain expertise and experience whether from a home health nurse or physician, etc. That's kind of the agreed upon definition of medically fragile.

So I know our podcast today is going to be about how we do that for these complicated pediatric patients, right? Because that's the definition of a transition of care. That's the goal of a transition

of care. Is this even possible? If it's possible, what needs to be done and what's happening today?

Dr. Kozman: Absolutely. Yeah, I mean you bring up such great points and that definition itself, each one of those adjectives or descriptors before, the end result of equitable care, is an opportunity for inequity, right? And for difficulty in transition and important medical information to fall through the cracks during a transition period. And all of these things that we're talking about are applicable to all patients transitioning from pediatric to adult care models, but more exponentially difficult for patients who have complex care issues, special needs, or fall into any one of those definitions that you described for us.

[11:05-20:05] Challenges Regarding Transitions of Care for Medically Fragile Populations

Dr. Kozman: So, now that we are more familiar with some of those terms and the process and the patient populations you addressed, can you tell us why this process can be so challenging, especially for medically fragile patients?

Dr. Alonzo: Yes, there are a lot of answers to the why, but I'm going to really focus on four different things.

So, the first thing that I already alluded to is that there's really no single definition. And if we don't have a single definition, then we're going to have a lot harder time defining what the goals are, defining how change is made, because we always need metrics, which are based on definitions in order to assess if we are making change. Right? So typically data and evidence is what drives decisions and data and evidence is collected based on definitions and metrics. So if we don't have a specific definition that we can all agree upon, then how are we going to make change when we cannot even show how important it is to make change for this population? So the simplest thing is why is this complex is we can't even agree on definitions that make sense clinically and financially. And so really the number one issue is, well, let's try to figure out a definition that works well, it encompasses many things, but that is specific enough where goals can be achieved and attained and measurable. There are a few clinics for medically fragile children who transitioned to adulthood, um, in this country. And you can Google this, each clinic uses a different definition, different qualification eligibility to be in that clinic. So, for example, you know, one of the clinics that I work at, our patients typically need to have at least one technology dependence and two to three minimum of two to three different chronic diseases affecting different systems. But there's other clinics and other lifespan clinics that we do also have in our town for specific chronic illnesses, like cerebral palsy, which is a lifespan, but you need to have cerebral palsy and a few other factors to be in this clinic. And then we also do have clinics specifically for Down syndrome, for example. So if we're going to create or develop a clinic, we can't use the broad federal definition, right. So then the idea becomes us as providers, if we're going to create a structure for them, what definition do you use? So that's a really complicated answer to your question, but the first part of it is the definition; it's really critical. You have to define what the patient population is, so that you can decide the next steps.

Dr. Jaeel: Can I ask a quick follow-up question: In your experience with these different definitions and different clinics, doing different things, is it that the definition expanded per clinic based on like patient advocacy or is it kind of predetermined by the clinic before they start, and that's the patient population that they admit, like, how does that even come about and does it ever change?

Dr. Alonzo: Yeah. And that's an awesome question. You know, there's so much being done in this country. But it's so fragmented. The clinic that I work in specifically that is for complex care, special needs has stringent definitions because it's run by a pediatrician. Now, when I became a part of the team, I'm an internist and a pediatrician. So I actually focus on the adolescents and accept patients that are much older in their mid twenties and those are my patients, right? So a lot of it is actually about morphing into a clinic that meets patients needs, but really it is provider-driven in terms of the expertise, comfort level, especially for this patient population.

Oh, I'm going to say the other, um, reasons for this being so complex is the patients, right? The patients are so complex. These patients require a lot of different, not just medical needs in terms of clinical needs, but also social needs, financial needs. So they really use a lot of public, um, assistance and public resources as well as the private, if they have them. And so these patients are complicated. They could live at home with their biological parents, but as you know, a lot of these patients also end up in the foster system because they are at higher risk for abuse. And so they may be in the foster system or they may live in group homes, they may be adopted. I mean, their social situation is so much more complex than a you know what, you know, a non medically fragile, complex care child. And these patients didn't have a lot more needs, right? So these patients usually are in wheelchairs or they have a G-tube or feeding pump, you know, the more severe will have a trach, you know, with the machine they need, you know, the parents and families initially need a lot of nursing care to help them.

But, you know, what's so fantastic about this patient population is these parents of these patients end up becoming like mini doctors. It is, they really know how to take care of their child so much better than anybody else can. And anytime the parent tells me no, you know, Dr. Alonzo's something is wrong. I say, I believe you, because you know the process, you know what you're doing. You've been doing this for 20 years. Right? And that's really another big difference. These, the parents have to coordinate multiple specialties for these patients. They have to coordinate multiple DME orders, so durable medical equipment orders. How do we get a case manager? Do I qualify for SDG&E medical allowance? And the thing is, as physicians, we think we don't need to know this stuff because in medical school, the focus is pathology, physiology need to be a good doctor. Well, that part of being a complex care physician is the easy part, right. So for me, managing the G-tube, modifying the feeds, you know, thinking of preventative medicine, that part's the easy part and it takes me minimal time. The part that's hard is everything else that doctors aren't trained for, that a lot of doctors don't have an interest in, I guess they think, oh god paperwork, paperwork, which is great. But the thing is you don't have to do it all. Okay. You just need to know what needs to be done.

I just need to make sure I understand it, that if we all have together, so that even makes this patient population more complex. And finally I'll touch on because I know we don't have a lot of time and I told you I can talk about this, like for hours.

Dr. Jaeel: Yeah, seriously.

Dr. Alonzo: The last part is that this is a really complicated financial situation, okay. So specifically for this patient population, it's even more complicated than usual because they're going to qualify for a lot of different things because they do have disabilities.

So, you know, the healthcare resources that these patients qualify for are significantly different when they're a child versus when they're an adult. And remember, this is just by date of birth, okay. They're not using development or everything else that even goes in their definition as the cutoff for financial reasons, right. Insurance companies and the programs decide that, okay. So that's where we have a gap in clinical and financial goals, okay. Now these age definitions based on date of birth may have made sense 50 years ago, but they do not make sense today. So why are we not shifting the way we think about this patient population and why are we creating this gap that just continues to expand? You know, our technology, we have so much advancement in medicine. Medically fragile children are living much longer. And all of us, I know, have had experience with this patient population because there's just so many more patients that have medically fragile conditions. So why is the system not adjusting, right? And that goes back to the other reason this is so complex is because of how medical institutions are reimbursed by financial institutions. That's the biggest thing, okay?

So in, for example, in California, we actually have over 40% of our children are Medi-Cal eligible and that's going to be based on poverty level income, or it's going to be based on certain disabilities. There are criteria, but think about it, about half of our kids in our state alone, which is heavily populated, are eligible for Medi-Cal, okay. So we have an opportunity there, right? So if our kids qualify for Medi-Cal, well okay, great. So until what age, right? So in California, these patients on certain Medi-Cal programs, it can be a lifespan [program], but the specific Medi-Cal program for these patients, it falls under an umbrella called CCS or California Children's Services. And currently that age cutoff is 21. So if any of you have ever had a patient that is with CCS, which the majority of these patients are, okay. Before they turn 21, it is a nightmare. We have to figure out what insurance are you going to have after 21? What are you going to qualify for? What adult providers is going to be okay treating you because my clinic doesn't accept this other insurance or, okay, what about these diapers? Where are they going to come? Like, why are we, why are we chaos?

Dr. Jaeel: And it's funny because the definition you talked about before, I mean, the terms were like purposeful and planned. So, we have to, this definition seems very ideal for the chaos that runs on the ground.

Dr. Kozman: It is not true to experience, that's for sure. We're chuckling as you're talking, Shirin, because both of us have, and still, continually are dealing with this, like you.

Dr. Jaeel: Oh, my gosh.

Dr. Alonzo: That's just the tip. You know, I'm just giving you a little sprinkle because those are some of the reasons why this is so complex.

Dr. Kozman: Yeah.

[20:05-21:28] Six Core Elements of Health Care Transition

Dr. Jaeel: It's so many. And I mean, I guess the next natural question is, okay, where do we start? Like, how do we even start parsing this process? And I think one of the things that, uh, at least we were taught when we were covering this topic in residency and some of the brief curricular notes about this is the six core elements of transition. So it's a model that's been

highlighted in the 2018 clinical report on healthcare transitions that was co-sponsored by the ACP, the AFP, and the AAP, so the organizations for internal medicine, family medicine, and pediatrics, respectively.

So for those who haven't seen this model before, it's an approach that identifies some of the basic components of a successful transition and then proposes a series of steps to actually implement that transition. So my question to you is, in your experience, is this actually happening on the ground? How feasible is it, and are there any practices that are using the whole thing from start to finish?

Dr. Alonzo: Well, I think, um, you and all our listeners probably know the answer to that question by now. Yeah. You know, what's so great is over the last 10 years, the whole, the first step is always awareness and that's kind of where we're at in, I think, our country in dealing with transition, right. We're not quite there at the implementation phase.

I have my own opinions on why and a big part of that has led to financial structure, right. There is no reimbursement based on like how well do you transition and there's no measure for that, right? So, well, where on the metrics does complex care transition fall? Nowhere. So why are we, why is anybody incentivized to implement ideas? They're not, right? Nobody in this field of healthcare business, right, does things without being properly financially reimbursed, no matter how good their heart is, right. But policy comes from data, definitions, measures, et cetera. That takes years, right.

[21:28-25:26] Improving Transitions of Care on an Individual Level

Dr. Alonzo: So what can you do today? That was your question, right? What can we do now? Well, we'll save future change for later. So for now, what can we do now in this chaos, right? So there's a lot of things you can do personally on the individual level that will affect systemic change later.

So the first thing you can do as a med student, as a trainee, even as a physician today, no matter what your field is, in adult medicine or pediatrics, because you do have patients that are medically fragile even if you're in a sub-specialty, you really need to assess your current healthcare system, especially your current primary care healthcare system because these patients need a medical home. They need a primary care doctor that understands their needs, has time for them, and is able to coordinate their care. So understanding, what is your system right now? Do we have what this person, this patient needs, right? So no matter what level of training you are, if you can figure out what health insurance right now, in today's day, does my patient qualify for? What makes them eligible? Is it their condition? Is it their age? Is it their financial structure? You might not think this matters as a physician, but it does. It's the crux of understanding the healthcare system and how to advocate for your patient.

And me as a Med-Peds physician, I look at myself not as a doctor. I look at myself as an advocate with medical expertise. And how do you become an advocate? By understanding your current system, figuring out the gaps, and offering reasonable solutions to make change happen. But then, after you've assessed for yourself, and I do this everyday. It comes with time, right. It comes with experience.

And honestly, I learned so much from my patients and their parents. They've figured out resources and I always ask them, they tell me, “Öh, I figured out this program for respite care,” which is essentially giving caregivers a break, right. And I say, what program is it, do you like it? Can you please share with me? I learned from my parents and I write all these down. I said, is it okay if I share with other parents? That's what I learned. And I've learned this through years.

So then, what's the next step? I teach this information to others. I teach it to my parents and patients. I teach it to my colleagues. I teach it even to my nurses and my medical assistants because it's important that we all are advocates, not just physicians, right. And that we all learn as much as we can.

The next thing I would really recommend is collect the information and network with other people that care about the same thing you do. Like right now, you have three Med-Peds doctors here, right? I just talked to my Med-Peds colleague and friend from medical school who's doing transitions in LA. Find the people that care about the same thing you do and exchange and collect information. Figure out in your region who are the sub-specialists that care for medically fragile children, right. Who are the pulmonologists on the adult side that can manage care for cerebral palsy kids that are 70 pounds? Who's comfortable doing that? Have a conversation. You just need a little list. You need 10 doctors in your county that are willing, able, and have the expertise, right. Okay, well that's, I love it and I love the one-on-one, but you know, we could go a step further. What if we created a website or a database of sub-specialty doctors and nurses and providers? And by the way, I'm copyrighting this idea.

Dr. Jaeel: It was like, I'll hop on that! It's so useful.

Dr. Alonzo: You either have a website or an app that connects the pediatric world to the adult world, specifically for medically fragile populations, which of course we would have to define. So how hard would that be in 2022? Not that hard, right? So, I mean, this is something we could do.

[25:26-28:24] Inspiring Trainees to Care For Medically Complex/Fragile Populations
Dr. Alonzo: The other thing that's really important is really to inspire, right? People get afraid of taking care of medically complex, medically fragile people, because they don't have the training in medical school. They don't have the experience. They don't have, you know, they haven't trained with a doctor, you know, like me, right. I will talk to you about this forever. I'll make this exciting for you. You're going to love it for the rest of your life. The difference you're going to make, especially if you want to be a primary care doctor, right? So, that's really the crux of this.

You need to, we need to inspire our trainees to care about this population. Just like we have to require geriatric training, right? Because our elderly population is a big population. You have to. It is mandated that in your training, you need geriatrics, right? You have to have a certain proportion of patients that you care for be over the age of 65. Well, why is that? Let's go back to finances. Because residencies are funded by the government. The government tells you, "You need to know how to take care of people over 65." Great. So, why don't we convince the government? You need to fund us for this transitional population. Change the age of when we're cutting them off from things and we need to mandate that everybody in this country has one month of complex care training. Why can't we do that? We can.

The question is who is going to light the fire, right? Who's going to like, what is it, light the match to start the fire, right? But those are some things honestly, that you can do now. Um, whatever level of training you're in, but hopefully that answers your question. I'm happy to always talk to you guys, or any of our listeners about this topic, um, and work on, you know, solutions like for today and for the future.

Dr. Kozman: Absolutely. I mean, I love so many of the things you just said, and my Med-Peds heart is really happy right now, but obviously we're in a little Med-Peds bubble here. But I mean, our colleagues in family medicine, in internal medicine, in pediatrics, in many other specialties within physicianhood, but also I've relied very heavily on our nurse practitioners, physician assistants, um, physical and occupational therapists, social workers, nursing staff, so many different people within all of the different healthcare fields. Many of whom have more expertise and experience in these types of services for our patients than, as you mentioned, we as physicians get trained in.

And having this very multidisciplinary and collaborative approach, I think, has been, um, in my experience, very, very powerful to help get patients the things that they need mobilized for them and their caregivers. So I love that you talked about how we really need to tap into our networks and tap into those who also care about this. So, I really love the passion towards collaborating on these issues and all of the ideas that you said. I will support your copyright.

[28:24-31:20] Learning About the Healthcare System and Health Insurance

Dr. Alonzo: Yeah. I mean, that's kinda how my brain functions, but I do want to make it really clear. I know it can be really scary to learn about insurance stuff, but you don't have to be an expert. You can do this as a med student. When I was a fellow, I messaged personally, directly, the CMOs of four different hospitals and I said, "Hi, I'm a neurodevelopmental fellow. This is what I want to do with my life. What do you think? Is there anything we could change in our current system? Are you willing to talk to me about it?" And every single one responded.

So I really just want to say, don't be intimidated. Don't be afraid. Don't feel like you have to be an expert or have 10 different degrees to understand the healthcare system. You learn it by experience, but even more, you learn it by connection and communication and being honest and just saying, I don't know much. Those connections will last you a lifetime, so as the structure changes, you will see that that will allow for better things to happen.

Dr. Jaeel: I love that idea. Just, I mean, jump in, like start somewhere. That's super inspiring. Yeah, because I, I'm one of those, I will be very honest. The financial aspects of the healthcare system intimidate me a lot and I rely very heavily on, like Maggie mentioned, our interdisciplinary team of case managers and social workers and they teach me so much.

I think taking that extra step and actually reaching out to them directly and trying to advocate for my patients, I've never done that, but I am super inspired now.

Dr. Kozman: Yeah, absolutely.

Dr. Alonzo: I mean, the more you know, the better advocate you're going to be. Case managers and social workers, yes, they know a lot more than a regular physician. But when you're a complex care physician or physician for anything and you figure it out yourself, I guarantee you, you're going to have so much knowledge and be able to make so many different connections.

Just do it for fun. At nighttime, Google things. Just go Google, look at links, read about stuff. You will become the best advocate for your patient and just knowing and honestly just Googling.

Dr. Kozman: Yeah, the, the insurance chart, which I'm sure has its own iteration in every Med-Peds residency and family medicine residency, probably. Maybe others that I'm just not aware. The chart where you list the different insurances available to patients in your state or your country, um, by age is overwhelming and daunting. But the, just the, even your experience of having reached out to those leaders in these organizations to say, “Look, can we collaborate?”, as opposed to us kind of always working in opposition, I think that's really inspirational.

And for them, you know, for our listeners in other states and other countries, um, Shirin already alluded to, you know, the different things, um, that are available for insurance for our patients in California. But Medi-Cal is MedicAid in California. Medicare is for those 65 and older. CCS is California Children's Services, which is specific, also government-funded, insurance for children who are medically fragile with a specific definition.

And so, maybe you're working in another state or another nation. We know we have a lot of, um, international listeners as well, and maybe your system does this better. And we would love to hear from you about ways that you do transitions of care between pediatric and adult healthcare mentalities and models in your nation, uh, and we'd love to learn more from you.

[31:20-32:18] Change Starts with You

Dr. Alonzo: Yeah, I think that's a great, um, a great call to action, Maggie, for sure. And I really want to end with, with really saying that change starts with us. It starts with you. It doesn't start with a massive system or a massive corporation. It literally starts with you and your patient.

That's how change happens. Advocacy comes from parental groups for all of these patients, right? The parents lead a lot of change, so you can connect with your parent and be their, be their, you know, champion, right? They need a physician on their side.

Change is only going to happen with parents and doctors working together with the system. We're within the system, but we are not leading the systems. We are following the system years behind and that's what leads to our chaos. So let's join forces, right? Change starts with you and us.

Dr. Jaeel: That's amazing.

[32:18-33:24] Closing

Dr. Kozman: Yeah. Perfect way to bring our conversation to a close. Of course, we have, there's so much more we would love to keep talking to you about, Shirin, and learning from you. But thank you so much for starting off our discussion today with this episode.

Dr. Jaeel: We'd like to invite our listeners to join this discussion online and share your stories, your experiences with transitioning from pediatric to adult care. You can send us your stories over email at thedeishift@gmail.com or on social media with the handle @thedeishift. That's the "D-E-I shift".

Dr. Kozman: We'll also have a transcript of this conversation along with show notes that include the resources discussed today. Thank you, Shirin, so much again, and thank you to our listeners for tuning into this episode. And, we look forward to bringing you more content on transitions in the future.

Dr. Alonzo: Thank you guys. And happy Persian New Year and happy new beginnings, right!

Dr. Kozman: Yes!

Dr. Alonzo: Thank you guys.

Dr. Kozman: Awesome. Thank you so much.

[33:24-34:36] Outro

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