THE DEI SHIFT
DIVERSITY. EQUITY. INCLUSION.
Advancing Medicine, One Story at a Time

Season 5 Episode 3
Pediatric-to-Adult Transitions of Care, Part 2: Intellectual and Developmental Disabilities

Transcript

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Learning Objectives:

1. Define Intellectual and Developmental Disabilities (IDD), and the specific example of Autism Spectrum Disorder (ASD). Describe how these are diagnosed.
2. Describe key issues that healthcare teams should keep in mind for patients with IDD, including ASD, as they transition from childhood to adolescence to adulthood.
    a. In the clinic
    b. In the ER/hospital
3. Give examples of advocacy efforts for healthcare for members of this community.
4. Strategize how one can create inclusive healthcare environments, spaces, and culture for people with IDD, including ASD.

[0:00-1:25] 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, a Medicine hospitalist and Pediatric primary care physician, here with my Co-Executive Producer of The DEI Shift…

Dr. Maggie Kozman: Dr. Maggie Kozman, a Medicine/Pediatric hospitalist. Today we're excited to bring you part two of our longitudinal series in Pediatric to Adult Transitions of Care, which we love to talk about as Med/Peds physicians.

Dr. Jaeel: Yes. In this episode, we'll be applying the concepts and strategies we discussed with Dr. Shirin Alonzo in part one – which is episode three of season four for those of you who want to go back and listen to that first – to a specific patient population, those with intellectual and developmental disabilities (IDD), including autism spectrum disorder (ASD). This patient group faces some incredibly difficult challenges as they transition from the pediatric healthcare model to the adult one. And adult practitioners don't always receive the type of training we need to receive these patients well from our pediatric colleagues.

Dr. Kozman: Yeah, there are just some things we don't even realize need to be accounted for in the care of these patients until we ourselves are going through the process as we'll hear, or we take the initiative to ask about the experience that these patients and their families are having as they transition to adult healthcare settings.

[1:25-2:35] Introducing Guests Dr. Susan Hingle and Dr. Mai Pham

Dr. Jaeel: Speaking with us about this topic are two wonderful guests, Dr. Susan Hingle and Dr. Mai Pham. Dr. Hingle is a primary care physician and medical educator who practices in Southern Illinois University,

Dr. Kozman: And Dr. Pham is a primary care physician in Washington D.C., and founder of the Institute for Exceptional Care, a nonprofit organization created to help people with disabilities get the care and support they need in order to thrive.

Dr. Jaeel: Thank you both so much for being here and sharing your clinical and personal experiences with the pediatric to adult transitions, with The DEI Shift and our listeners.

Dr. Mai Pham: It's wonderful to be here. Thanks for having us.

Dr. Susan Hingle: Yeah, I agree. Thank you so much for having us. I'm really excited to talk with both of you as well as with Dr. Pham. She has become one of my “sheroes.” I have this dream of a thriving world full of joy, connection, belonging, and potential. And I think conversations like this are really important steps towards fulfilling that dream.

Dr. Kozman: Thank you so much. We appreciate that and we're really excited to get into the conversation with you. We like to keep things casual here on our podcast, so we ask that you call us by our first names. And is it okay if we do the same for you?

Dr. Hingle: Absolutely. Yep. Yep. Sue's good for me.

Dr. Kozman: Great. Thank you so much.

[2:35-4:31] “A Step in Your Shoes” Segment

Dr. Jaeel: So before we get started, we like to ask each of our guests on The DEI Shift to share something for our listeners about themselves. This can be something like a hobby, a favorite food, a meaningful experience of yours, just so we can get to know you a little bit better and your background a little bit better, and to flex our cultural humility muscles. We call this segment, our Step in Your Shoes segment.

So Sue, would you like to get us started and share something with us in the audience today?

Dr. Hingle: Sure. So I can tell you that I am a diehard Chicago Cubs fan. I have been since I was seven years old. And being a Cubs fan has provided really valuable life lessons, like patience, persistence to celebrate progress, and that it's not all about winning. That it's fun to root for the underdog, and that when they do win, like the Cubs did in 2016, the joy is even that much more incredible.

Dr. Kozman: That's awesome. Thank you so much. I love the way that you put that, then your loyalty and Mai, what would you like to share?

Dr. Pham: I guess it's important to know about me that I'm a first generation immigrant. I was born in Vietnam and came to the States when I was not quite seven. Also important to know that I am the only daughter in a family of four. Which means, I guess collectively, that one, I've had to spend a lot of my life bridging between cultures, between generations, languages, but also I've had to learn how to be pretty scrappy and fight for the food at the table.

Dr. Kozman: Literally.

Dr. Pham: Literally.

Dr. Jaeel: Well, thank you so much for sharing.

Dr. Kozman: I'm sure that's translated into your clinical practice

Dr. Pham: On behalf of my patients. Yes. Yes.

[4:45-9:47] Experiences with the Patient Population

Dr. Kozman: So let's jump right into the discussion for today. Could each of you first start us off by sharing your own personal and work experiences with the patient population we're talking about?

Dr. Hingle: Yeah, I can start. I can start by telling you, I have an amazing son who has been diagnosed on the autism spectrum. He has not always been treated well in his life by a lot of people, especially our educational systems as well as many of his peers, and he is a big part of my “why” for this work. He is a big reason for why I want to work diligently to try to achieve that dream that I mentioned before about a world full of joy, connection, belonging, and potential. On the professional side, I have an outpatient general internal medicine practice, have been at the same place for 25 years, so have had many of my patients for a very long time. Very wonderfully diverse patient population. I have some patients with IDD, some patients with autism, some patients with other disabilities, some patients without any disabilities. But my goal is always to provide high quality, empathetic, patient-centered care.

You know, I was thinking, one example that I had related to what we're talking about today is I have this lovely young woman who has IDD. And we struggled at first. And after a couple of visits, I learned that she was afraid of white coats, that that is something that triggered her. And so now in her chart it says “Do not wear white coats”. And no one on the healthcare team wears a white coat when she comes in to visit. And our visits are so much easier now. And we've really been able to, to connect on a personal level, and it was something as simple as really trying to figure out that it was the white coat, that that was the issue.

Dr. Pham: Yeah, and I'm not as versed as a clinician as Sue in this area. How it happened for me was that I had been checking along doing my health policy work, but I was mothering at the same time. And our second child, Alexander, was diagnosed late, around age eight as autistic, and I had not received any training in it. No one around us seemed to feel like they needed to direct us to any specific resources, and he seemed to be thriving, and so we just kind of took it one year at a time, right up until he had his first crisis as a sophomore in high school. And in that mad scramble because, you know, as a mother, when you see your child at risk, you really hop to. And working our network, finding for the first time ever, resources that included have someone I call our family's autism coach to explain to us what was happening, to explain to Alexander what was happening, why his brain worked the way it did, and then to steer us to evidence-based clinicians who really could teach us and guide us and partner with us. That was revelatory. And so for me, it's been a vertical learning curve on that through my fingertips in a different way through, through that lived experience as a mom.

Dr. Jaeel: Thank you for sharing that experience and the passion that you both bring as parents first to your clinical practice, to the policy work that you do. And as clinicians, I think we have a little bit more access to resources than potentially some of our patients and our families. And to hear that even in this position of relative privilege, it's still really difficult to find the resources that we need helps to normalize that, I think, for the rest of us and our patients. On the clinical side, those of us who practice and see patients and are out of sorts and out of our depth, I think it helps to know that it is hard to be able to get those resources, so thank you for bringing that up.

Dr. Hingle: I think there's a couple things in what Mai was talking about that are really important to pull out because they're related to the work that the Institute for Exceptional Care is taking on. And one of them is equitable access to resources. And, I think, though incredibly challenging, my family was fortunate to be in a location where they had access to someone with that specialized training.

Dr. Pham: Absolutely.

Dr. Hingle: And this really should be something that is included in all training. Because in many places people don't have access to even psychiatrists, let alone psychiatrists really trained in how to navigate patients with autism.

[9:47-15:25] IDD and ASD Definitions

Dr. Jaeel: We've already started jumping into our discussion, but I just wanted to back up just a little bit and give our audience some definitions to work with. So, Sue, would you mind defining intellectual and developmental disabilities as well as autism spectrum disorder for our audience?

Dr. Hingle: Sure. And Mai can jump in because some of the work that IEC has done recently came up with its own definitions, which may differ a little bit. But when I think of IDD, I think about it as a disability or differing abilities in the way an individual kind of acquires knowledge and skills in how they process information, differing abilities in educational attainment, and the acquisition of skills needed to really function independently and socially. I wanted to point out that IDD is not low IQ, that two thirds of people who are diagnosed with IDD have average or above average IQ. And then autism spectrum disorder, there's a whole, and I know we can probably get into it, a whole set of criteria in the DSM. But it's a neurodevelopmental disorder that really impacts how individuals interact with other people, how they communicate, which is a key piece of it, how they learn and how they behave.

Dr. Pham: Yeah. The only things I would add to that are that from IEC, from the Institute for Exceptional Care's perspective, we focus in particular on the kinds of disabilities that appear at birth or in childhood because we think that that timing magnifies the impact that the disabilities have on people's ability to develop socially, emotionally, intellectually. And I guess I love the way that Sue described it as different abilities because that is the key there. We try to emphasize in the definition that we use, that everyone has something to contribute and even when it doesn't look like they do, they have value. They have their own kind of competence.

Dr. Kozman: Thank you so much for sharing those really helpful definitions and encouraging our listeners to keep those in mind throughout the rest of this episode, but also moving forward in each of our individual clinical practices.

Dr. Pham: What I would like to point out to your audience though is that these criteria are not mapped onto specific known pathophysiology. And I will tell you that as well-intentioned as they are, the criteria with check boxes that imply a binary answer, someone is autistic, someone is not, can cause a lot of grief in real people's lives.

So, for example, Alexander has a friend from summer camps that we go to as a family who has the exact same phenotype. The only difference really is that his friend is passionate about roller skating and physics, and Alexander is into math and origami and nature. Truly, that's the only difference. But his friend lives in a small town in Virginia and was diagnosed only with ADHD. He didn't get the services or the benefits. Alexander was in a big city and got the autism diagnosis. You can say, okay, that's user error. Someone didn't apply the diagnostic criteria the same. But then I'll tell you, let's look at within the same child, Alexander went through two rounds of testing. It was on the third round that he got the diagnosis. So he was not autistic the the night before. School psychologist sat down with us and then the next day he was. I'm pretty sure the kid's reality didn't change in between the two days. And so I think this is why it's important to note that NIH has been thinking through for some years now - they just have not found a way to operationalize this - that we need to exercise more humility about how we think about neurodevelopmental differences because we don't know the exact pathophysiology, and that the wide range of phenomena, not just IDD but also mental illness or communication differences, that all of these live on a spectrum, if you will.

Dr. Kozman: Yeah. I think it's so easy for us as clinicians, one being problem solvers. Identifiers and solvers. And two, being trained in a system that requires an ICD-10 code to be able to get any kind of resources mobilized or justify a clinic visit or a referral, or getting a social worker involved in your clinic. It really just trains our brains to think about, okay, do they meet X, Y, and Z criteria? And therefore I can, I can apply this label, which may help in positive ways, but also hurt and do some negative things. So it's really important and really valuable. I thank you guys so much for kind of pulling us back out of that mindset and reorienting us to view these individuals as whole people and then, view these diagnoses as a spectrum where different features may be more prominent in one person than another, but they're all still different abilities that affect the way that we should be approaching healthcare for our patients.

[15:31-29:27] Systemic Challenges and Potential Solutions for the Patients and their Families

Dr. Jaeel: We've started talking about this already, but as this patient population ages out of pediatric care, can we talk a little bit more about the specific challenges the patients and especially their families might be facing that might not be present or as difficult for patients without ASD or IDD.

Dr. Pham: Sure, I can start. Sue has a little more experience with this than I do because her son is a little bit older. But one of the things that happens when you become a young adult is that you drop out of the educational system. And as many challenges as we had with that system, it is much better resourced and more oriented to supporting this population than outside. So in the employment world, there is no analog of ADA, that requires schools to offer support and services and individualized education plans, et cetera. There is no such requirement in the working world despite the American with Disabilities Act, and so people - young adults, late adolescents and young adults suddenly find themselves without a ready place to plug into the world. Some of them may be college capable, some of them may be employable, but there is usually an improvisation that needs to happen at that stage. And then, while all that is going on, of course, clinically they have to transition from the pediatric to adult clinical world. And that poses several challenges.

One we've touched on: how little training general clinicians get. And I want to be clear here, God love the IDD specialists - would love to have more of them, there can never be enough of them. At 10 to 16 million people, this population is just too large to take a center-of-excellence approach to. So general clinicians, the vast majority of whom receive very little, if any, training in IDD, are simply not prepared to even try to be good transition partners with their pediatric counterparts. And so that is a challenge. And then you run into the insurance problems. So with the Affordable Care Act, there is a reprieve for those with parents who have insurance and they can stay on that commercial insurance. Or if they live in a state that has expanded Medicaid, they can and, and they can go under federal insurance exchange, but it does require multiple transitions and in many cases a PhD in Social Work to figure that out. Sue and I are very well educated, but neither of us have PhDs in Social Work either, and so you can imagine for less well-resourced families this is unbelievably stressful.

Dr. Hingle: Yeah, I think Mai was talking a lot about our systems and our systems are, I mean, I forget how that saying goes, “They're designed to get the results that they get,” but they're not designed to really be patient-centered. And for patients with IDD, a lot of things take longer. And so a 10-minute doctor's visit is not going to be successful. There's no way. I mean, it isn't even for people who *don't* have a diagnosis of IDD. And so that's one systems issue that I think is really important to pay attention to. And so for my patients who have one of these diagnoses, and even patients who don't have these diagnoses, who I have learned over time require more time, when I send them out to get their appointment, I will say, give them two appointment slots or give them three appointment slots. And so you have to be proactive and I have to explain to the patient, every time you call in for something urgent, make sure you tell them that Dr. Hingle said to give me two appointment slots, or three appointment slots. And then usually the reception desk will come back and say, I have so-and-so on the phone. They said they need two appointment slots, is that right? But I think that that's one systems issue that, you know, it generally doesn't work for anyone, but definitely doesn't work for patients who may have processing issues, anxiety issues, things like that.

I think another systems issue that comes into play here is when they're transitioning. So we have these laws that say when someone becomes 18, they're independent, they make their own decisions, and there's not that many 18-year-olds who really should be making independent decisions. This group, family support, family group, or other social support is really, really important. And I can tell you that there have been occasions where I haven't been asked to go back with my son. And usually if someone asks, he'll say, yeah, yeah, I'd like her to be there. But sometimes they don't even ask. I think the other thing is that, sometimes when they process information slow, an assumption is made that they're not intelligent. And again, I think that that has to do with kind of our hurried life that we live in America in general, but definitely within healthcare. So I think that that's something else, is really needing to slow down.

Thinking about when they become 18, they're independent. So like phone calls from the doctor's office, the dentist office, things like that. They'll go straight to my son now rather than through us. And he's not, he doesn't like talking on the phone, he just doesn't. And he is very, very straightforward. “Is this so and so?” “Yes, it is.” “We're calling to confirm your doctor's appointment on such and such.” “Yes.” And they're like, “Are you gonna be there?” “ Yes.”

But again, I think that that whole part of the system we need to take a look at and see are there ways to allow them independence yet? Build in the supports necessary for them to really be able to function highly within our healthcare systems.

Dr. Jaeel: Yeah, I'm really happy that we're talking about this from a larger systems level. I mean, one thing that I've noticed in terms of transitioning patients is as a system on the pediatric side, we're more, I think, sensitive to the kind of high level of burden of going to repeat appointments, multiple visits with not just clinicians, but with ancillary services, therapy, social work, all of that. And a lot of the times these patients are able to build it in kind of a one-stop, a couple of different clinical visits in one go versus on the adult side. And this is something that I had struggled with with some of my patients who are transitioning. It's separate appointments on separate days, trying to figure out different schedules. You can't just go into one clinic and go down the next door down, see your pulmonologist, see the social worker within the same visit. [The system] really makes these patients and families go through so many hoops just to be established and continue to get the follow-up that they need. I think that we talked about this over and over again in different ways that we need to get to know a lot of these patients as individuals and to understand specifically what each of them needs, what their families need. And I think building that into somehow our clinical workflow where we know, for example, when you do reminder phone calls for this particular patient, they need a second phone call to this other individual or this other family member. I love that you have a system already, Sue, for your patients that know to call for additional slot times. I think it's going to be up to us to kind of find creative ways within a rigid clinic structure to be able to individualize for these patients?

Dr. Pham: Yeah, so one thing that we have learned at IEC is that we don't always need to wait for the system to respond. We can prod it. So in one of our projects, it's called the Seamless Alliances of NASA and Suffolk on Long Island. We're working with a coalition there that includes community members and disability service organizations, but also the major health systems and hospitals there, as well as insurers, to solve the emergency department problem. So this challenge that people with IDD have with interfacing with healthcare is magnified many, many fold in the ED because it's a high stress situation for everyone involved. The resources are strapped. There's a lot of risk, right? There's clinical risk because of COVID or other factors going on, and it's a terrible environment in which to have misunderstandings. So what the coalition decided to do was several interventions, but the first ones most relevant for this topic we're talking about is something we call the Digital Snapshot. It will be an app on any personal device connected to a cloud-based registry, and it's not a health passport. It will have clinical information, but really the information that goes in it is decided by, driven by, that person and their family and their support people. Not by the clinical world, so it's not a mini EMR. It will have a face page that will tell you the absolute essentials: My Name, My Allergies, Whom to Contact. But then the very next page is Tips on How to Work with Me. Here's what I'm like when I'm at my best: Click this video; See, I'm happy and athletic. Here are my anxiety triggers. Here are ways to calm me down: I like listening to music. Click here for my tunes. And then the back pages will have all the clinical information. But we really think that this tool will become an amazingly powerful self-advocacy tool for people wherever they go. It doesn't have to be the ED, it can be, you know, with an ambulance team. It can be with their primary care practice. The other thing that we noticed about this tool as we were designing it is that, gosh, it would be great for the rest of us, too. So, I just want to point out that for my 84-year-old Vietnamese speaking mother, I would love this tool. And I think that that's one of the things as I was listening to Sue describe how she has adapted in her clinic is one of the strategic pillars and kind of guiding principles of IEC's work is people with IDD can lead because they are the tip of the spear. They are among the most vulnerable groups who can teach us, how can we design healthcare with universal design principles? How can we make healthcare easier for everyone? My God, it's so hard right now and we all just accept it. We're all, we have this learned passivity about it, when in reality we can say what we want and they are willing, you know, the IDD community is willing to put themselves out there to say, design it for us. And it's like the healthcare equivalent of curb cutouts. Right? Curb cutouts were designed for people in wheelchairs, but it turns out, lo and behold, they're also great for parents with strollers, the elderly walking with kids. Who knew? Who knew that having to step up was hard and not necessary? And so, having two clinic appointments, gosh, that would be better for someone who's having a mental health crisis too, not just someone with IDD.

Dr. Kozman: Thank you both so much for sharing all those amazing points that you made. I appreciate that you emphasized a lot of systems issues, but also some patient specific issues and ways that you as clinicians, and then also through the IEC, have adapted things to be very personalized, including the tool that you mentioned, Mai. I agree, I think it would be universally helpful for all of us, and I really love the part of it that talks about: "This is what I'm like when I am well," or "when I am happy and I feel good." I think that's something that we rely a lot on our patients' caregivers in the pediatric world to identify - "is this their normal or are they still not back to their baseline, their normal, happy selves?". And we rely on adult patients' children or their caseworkers to kind of help us identify an adult who isn't feeling well, but what their normal baseline is like. And to have that in a tool would be so valuable. And I appreciate that you also mentioned in a setting like the emergency room, right? Very triggering, traumatizing, and healthcare in general can be a very traumatizing experience for patients, whether they have IDD or not. And so I'm curious in different healthcare settings, settings like the emergency room, the clinic, a hospitalization, can both of you talk about how maybe those different clinical environments might have different challenges for patients with IDD, and ways that clinicians taking care of these patients in those settings need to be a little bit more aware and alert than we typically are with our neurotypical patients?

[29:27-34:28] Circumventing Healthcare Challenges in Different Environments

Dr. Hingle: I think we talked a little bit about the assumption of independence and I think particularly, I mean I guess it's in all settings, but knock on wood, my son has not required hospitalization, but I can imagine, he has a lot of sleep issues and obviously patients in hospitals don't sleep well anyways. Also has some anxiety and so I think things like visitor policies and not being allowed to have someone in the room after whatever the visiting hours are over, I think is a systems issue that hopefully there could be exceptions made to. You know, some places they don't make exceptions. Some places they do make exceptions. So that's one that I can think of, is sort of being able to have your supports around even if it's not fitting with the policy.

Dr. Pham: I think challenges with supporting different communication needs and preferences, challenges in accommodating sensory sensitivities, and as Sue says, having care partners or support folks there with the person. Challenges in getting clinical procedures done, whether that's phlebotomy or a radiology study, and challenges with medication as well. Of course you have to understand medication interactions. But the threshold at which you decide to sedate someone for a blood draw, for example, can be tricky. And what can you do to get there or to avoid that? I think one thing that many, many clinical practice sites don't understand, have never been trained in, don't have access to, are the kind of behavioralist approaches to help people acclimate to being in a clinical environment.

So, there are some who do it well around the country. I would point to the Lee Clinic in Kentucky as one example. They are a primary care group, but they serve primarily adults with IDD and they have become a really important node in the clinical community in that space because they help to coach both the patients and the support folks and their clinical peers in how to make these clinical interactions go more smoothly. So for example, if a patient has to go to the dentist, Lee Clinic will work with them to practice just sitting in the chair, and not freaking out, and then modulating the light levels, and the temperature, and maybe weighted blankets, to find the combination that works well for them. After several of these sessions, conditioning sessions, then they'll go and have the actual dental exam. So I think there are paths to solve many of these problems. It's just the training, the resources to make clinicians more confident. Because I do want to point out too that curb cutouts are not only good for the people who use them, they're also good for the people who are trying to help the people who use them. So the more universally designed our system is, the less burden it is on the people trying to support someone with IDD and I would say that's true of clinicians too. It's really rough on clinicians. To have a system around them that doesn't help them serve these patients, they feel terrible. They know they're not making the best decisions. They know something is not right, but they haven't been given the knowledge or the tools. And so when we approach our clinical partners, because everything IEC does is through community and clinical, community and healthcare coalitions, we say, “Listen, we're trying to help you solve your problem too.”

Dr. Jaeel: Thank you for framing it like that. 'cause it is hard to just kind of hear these are the best ways to do these things. And then you look at the reality of your clinical setting with things like time, resources, people, patient load, all that, and it's distressing to see how different and far apart those are. So, yeah, that's amazing that the resources that this clinic provides are both for the patients, the families, and for the clinical settings and the clinicians in them. So, so far we've talked about all these challenges for our patients and families, and we've started touching on some solutions, but I just wanted to delve deeper into that and ask about some successful initiatives you've seen work in various clinical settings.

[34:28-43:29] Successful Initiatives and Resources in Clinical Settings

Dr. Pham: So I mentioned the Lee Clinic as one example. I would also point to the Down Syndrome Clinic at Massachusetts General Hospital, which is obviously just focused on Down Syndrome, but has I think some really wonderful best practices when they use multidisciplinary teams and they not only provide clinical services, but they will actually produce a plan that's essentially an advocacy plan for their patients. And sometimes they will even send a social worker or another team member with that family to the school, or to the specialist's office, to advocate on their behalf. Just before COVID struck, they were actually working on an online tool because there's so much demand for services like that. They can never meet that demand, especially from out-of-state families. So they try to think, well, how can we at least partially meet this need? And they came up with an online tool that takes you through survey logic to answer questions about this person or this child. And then it spits out personalized checklists that you can take to your GI Doc, to your psychologist, to your PCP, to your school, et cetera. And that became something that a major insurance company was willing to pay for as a wellness benefit. And so that whole cycle of thinking about the whole person and family unit, thinking about what this child needs to thrive, which is a lot of things, way beyond the walls of the clinic, thinking about what is appropriate within the purview of the clinical team to help them to get to those goals and those resources. And then closing the loop on the other end by being available to their peers for curbside consults or whatever. That I think is an amazing model.

And then I would also point to a group called StationMD, which when I first learned about this group, I had to pause for a minute because I thought someone was telling me a joke. It's like, there's no way something like this exists. This is a group of urgent and emergent care clinicians at multiple levels who only focus on people with IDD. They provide completely virtual care, and what they do is they are the first line of defense in triage and assessment, and they have amazing results in reducing avoidable emergency department visits and hospitalizations because so much of why people in this population end up in the ED are because of preventable things. Misinterpretations of clinical presentations, misinterpretations of behavior, lack of knowledge on the first responders about how to de-escalate situations and, and, you know, lack of knowledge about how to connect them to community resources. So StationMD does all of that, and along the way they didn't realize that it would be a part of their job but they've now come to own it and embrace it: they coach the other service providers that they touch. And so through that way, it gradually filters out into the community, and clinicians ever so gradually accrue these experiences and become a little more confident over time. Not the ideal way to train the workforce, grant you, but I'm so grateful that they exist.

Dr. Hingle: So building on sort of the virtual piece, you know, there's some work going on in Missouri related to telehealth, and then they also have utilized the Project ECHO model, which is a model to train multiple clinicians to be able to provide care to this population. And they have done it for patients who have IDD diagnoses and autism spectrum diagnoses, and have really increased the number of clinicians who feel now more comfortable that they're able to meet these patients' needs.

Dr. Jaeel: That's great. I'm writing all these down so I can refer them later on.

Dr. Pham: And California has some great centers of excellence too. And we didn't mention academic medical centers, but there are quite a number of them that have exemplar programs that listeners can also tap into. I would point to Vanderbilt and Montefiore and University of North Carolina, UCLA, UC San Francisco - Clarissa Kripke there is a primary care doc who has spent her entire career focused on this population and teaching others on how to provide care in the home.

Dr. Jaeel: One resource that I found really helpful, and this really helps if you have an inpatient setting that also has a pediatric floor or a pediatric set of services, but a lot of hospitals have a Child Life Service, which is ancillary service that can really help for pediatric patients adjusting to being in a hospital and help their caregivers also kind of adjust to a lot of those changes and coping with what's going on in that acute care setting. And I've actually asked them to help out with some of my adult patients who are admitted. And they've been incredible to kind of bridge that gap between home and hospital, but also between families and the clinical care team.

Dr. Pham: Yeah. It's amazing how in medicine we forget, one, that children are people too, and, two, that adults also need help with life.

Dr. Hingle: I could see, Pooja, that whatever training those life specialists get really, again, that they could then help to train the people who are doing adult social work, and things along those lines.

Dr. Kozman: Yeah. Our Child Life Specialists are incredible and there is a Child Life Specialist certification, but there are people involved in the department even without the distinct certification who use the skills to be able to support our patients, whether they have IDD or they have a history of medical or physical or sexual trauma in their history that make it very difficult to be in the hospital. I'm thinking of a particular adult patient with a mental health issue that benefited from having coloring pages like they were child coloring pages. Unfortunately, didn't have adult books at the time, but she got them from either the Child Life Specialist or the Occupational Therapist, and was able to cope with being in the hospital for a very prolonged time, using a resource that traditionally is only accessible to our pediatric floor. And if you're in an adult hospital that doesn't have a pediatric resource, not always something that we think to do to support our patients, but it really improved her quality of life to just have something that occupied her artistically and helped her pass the time and express herself. And I would walk in and every couple days or so she'd have a new colored picture that one of the nurses had taped onto her wall for her to sort of look at throughout the day and make her hospitalization a little bit easier than it had been.

[42:10-46:00] Invitation to Join Initiatives for Change

Dr. Kozman: I want to highlight other resources, well, actually different avenues of resources too that we, yes as clinicians but just as people in general, including our non-clinician friends and family who may be listening, can utilize or just be aware of and spread awareness about patients with IDD and some of their needs. So even just looking at the IEC website, members of the IEC have been on PBS, have been on NPR. There is a film about autism spectrum disorder and just normalizing and humanizing patients, individuals, not even in the clinical context of patienthood, but personhood of individuals with ASD called “In a Different Key” that's been on PBS and recently came out for the public to see more of what the day-to-day is like for patients with IDD in various contexts. And for us as clinicians, kind of removing it out of the clinical sterilized setting and seeing what day-to-day life is like for the majority of us who may not have personal or family experience, can really just contextualize a lot more about some of the challenges and also the strengths of this community, the resilience factors, the things that we can support just in our day-to-day lives, whether we're at work or not. So I just encourage our listeners to take a look at some of those resources, and we'll link to them in our Show Notes as well.

Dr. Pham: I so appreciate that call out Maggie and I will also offer an invitation. It's not on our website yet. We have begun an initiative called the IDD Advocate Corps of which Sue is a member, and this is a very, we think, unusual kind of movement building exercise. It is a space where we are engaging health professionals of all kinds. They come from many different sectors, clinical, insurance, research, government, just to name a few, but we partner them with people with IDD, whom we call self-advocates. And the goal here is to actually leverage your professional standing and your professional relationships to make change from within healthcare. So this is a community that has been working hard to develop a mission and a set of shared goals, a set of shared values. Working on a charter and, and we hope to, um, do more formal recruitment and stand it up early next year. But if anyone listening to this podcast is interested, many of the health professionals in the group have a family member with IDD, but not all. Some of them just feel really passionate about not just supporting the IDD community, but also that there is opportunity here to make healthcare better for everyone. There's opportunity here to really operationalize what they mean when they say equity and inclusion and. An opportunity to leverage all of the influence they've accrued over their careers in the service of something bigger. So just putting that out there. If you're interested, just contact us through our website and we can connect you.

Dr. Jaeel: Thank you for letting us know that, and for that kind offer. And I just wanna commend the fact that you guys are getting all of these different professionals and individuals together to start working on these initiatives and talking. I think it takes us back to the very beginning, Sue, when you were talking about, you know, working on connection and belonging and potential, and I think this is just one really inspirational way to be able to do that. So thank you so much for both joining us for this rich discussion. As we start to wrap up, I just wanna ask if there's a takeaway message that each of you would like to leave us and our listeners with.

[46:00-48:45] Closing Remarks

Dr. Hingle: I can start there. I can just take us back to, I think what has probably been a thread throughout our conversation, which is kind of that whole concept of equity and co-liberation and really want to leave people with that mindset that you don't necessarily need to enter this work to be a helper, but because by doing this work to really provide high quality, empathetic, patient-centered care for a specific population, it is going to do that for everyone. And that is how we do get to that dream, that vision of a thriving world full of joy, connection, belonging, and potential for everyone.

Dr. Pham: I think what I would share is that you may be surprised or you will be surprised at how nourishing this kind of work is. We at IEC, what we do is we bridge between the disability community and healthcare, and when we bring people together, across those divides, they are nearly always surprised at how much they learn from one another and how nourishing it is, and it helps propel them onto the next thing in changemaking. I have learned so much from people with IDD in ways I never imagined and in ways I don't think they could have explained to me ahead of time. It's in the doing of the work and in making yourself vulnerable. Hearing feedback, learning what people really want and desire, and being creative about how to help them get that. And in the doing of that, your work feels more effective. You will feel more effective. And that's the takeaway I want to give you.

Dr. Kozman: Thank you both so much. I love that the emphasis on equity and collaboration and then that the activities we do or the work that we do towards those goals is nourishing. I feel nourished. I feel like I've learned a lot through this discussion from both of you, and really appreciate your time. That's all the time we have for today, but we'd like to invite our listeners to join the discussion online, share your stories and experiences with us. The experiences you have with transitions of care for patients with IDD, you can send those via email at our address, thedeishift@gmail.com, or on Instagram and Twitter at the handle @TheDEIShift. That's the D-E-I Shift. We'll also have a transcript and show notes like I mentioned for the episode with all the resources we've discussed today. So thank you again to both of you and thank you to our listeners for joining us. To our listeners, don't forget to claim your CME and MOC credits at acponline.org at the link that'll be in our social media posts and on our website.

See you next time. Thank you, Sue and Mai!

Dr. Pham: Thank you so much. It was a delight.

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