

Pediatric to Adult Healthcare Transition - Pediatric Grand Rounds-20260918_073015-Meeting Recording

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● **Calderon, Delia** started transcription



Kamat, Deepak M 0:07

Good morning and welcome to Pediatric Grand Rounds. Just a quick reminder, please complete the evaluations at the end of the Grand Rounds. It helps me provide feedback to our speakers. Also, the CME code is in the chat and we'll keep repeating it so we'll have access to it.

It's my great, great pleasure to introduce this morning's grand round speaker, Dr. Azara Singh, who is an assistant professor of pediatric neurology at the University of Wisconsin-Madison and leads the department's pediatric neurology transition program, which was launched earlier this year. She completed her medical education at Christian Medical College in Vellore, India, which is one of the best medical schools in India. And after that, she moved to USA to do her categorical pediatric neurology residency at the Children's Hospital in Michigan. That's where I had opportunity to work with her for.



Azara Singh 0:59

Yes.



Kamat, Deepak M 1:07

two or three years. Following that, she worked in Charleston, West Virginia, as the only pediatric neurologist in her hospital and one of the handful pediatric neurologists in the state before moving on to her current position in Madison, Wisconsin. Dr. Singh's clinical interests include healthcare transitions from pediatric to adult medical services, neuro-palliative care, and medical education. She is an associate editor and the director of the Residence and Fellows Board at the Journal of Child Neurology. Dr. Singh, thank you very much for accepting our invitation.

The floor is yours.

AS **Azara Singh** 1:49

Thank you so much for inviting me, Dr. Kamath. And I enjoyed getting to catch up with you a little bit. So thank you so much for the invitation. I'm very excited, you know, to talk further about this very, very important, you know, this process. that is being codified and, you know, is being...

There are frameworks that are coming up that are being used in different practice types, you know, across the board. So I'm very excited to talk a little bit about that today. And so by the end of this presentation, you should be able to compare the differences between pediatric and adult models of medical care.

You should be able to discuss why intentional transitions are important for care across the lifespan. And you should be able to list the six core elements of healthcare transitions.

So to kick us off, I'd like to introduce Audrey Vernick. Audrey is the mother of Bennett, who's a 22-year-old young man who underwent A hemispherectomy in infancy for the treatment of intractable spasms. Bennett and Audrey are navigating his journey to adult medicine.

JF **Jane Fried** 3:01

Sent here.

AS **Azara Singh** 3:12

And Audrey is also the Director of Patient and Family Advocacy at the Pediatric Epilepsy Surgery Alliance, where she in turn helps other families navigate life with a child with neurological diseases and helps prepare them for transition. So let's hear from Audrey.

And let's pause here and we'll hear back from Audrey again at different points throughout this talk. But I like to start with this because I think she really frames so many of the problems and so many of the barriers and concerns that families who have to deal with this transition face on a daily basis.

And as we go through this, we'll examine a lot of them, and then we'll look at potential solutions that exist and what new directions might arise in the future.

And so let's start by defining what a transitions of care in the pediatric to adult setting are. So it really is the planned movement. So the three big things here are that it's a planned movement of young people with chronic physical and medical

conditions.

from a child-centered healthcare system to an adult-oriented healthcare system. And a lot of the tensions that arise during this process of transition, a lot of the barriers to transition arise also from the fundamental differences between these systems how patients have to navigate these changes. So if there's one thing that you take away from this talk today, it's that the transition to adult health care is not one single event. It's not about the handoff. It's a process that starts well, well before.

they actually transition and well before the time for the handoff actually takes place.

So the process of healthcare transition is a very vulnerable one for patients, and particularly patients with complex medical needs who are often called youth with special healthcare needs or YSHCN. So that's an acronym that you might see in this presentation and in the wild. So it's associated with complications such as increased medication non-compliance, increased risk of emergency room visits, increased risks of non-elective hospital admissions, and all of these can contribute to delays in care and progression of their underlying disease. So why should a neurologist care about transition?

Neurological conditions are disproportionately highly represented in young people with special health care needs, and they're a leading cause of disability and functional impairment in all adults. So many of these patients are medically fragile, and they have extensive ongoing care coordination needs.

And this makes disruptions in care particularly dangerous. So these challenges are also compounded by the underlying diagnosis. And because of these, many of our patients have ongoing longer-term care needs, greater care coordination needs, associated cognitive and behavioral comorbidities, and then difficulty accessing social supports and scaffolding as they move from pediatrics to adult care.

And then additionally, with the advent of novel and targeted therapies, many patients with life-limiting neurological diseases are now surviving into adulthood. So care transitions that were previously being treated as optional are now becoming more of an inevitability.

So this is a little timeline of the roadmap to how we came to this point in and this understanding of healthcare transitions from pediatric to adult care. So in it started in 2002 when

the AB consensus statement on healthcare transitions for young adults with special healthcare needs was published. And this introduced what later went on to be

codified. It introduced the underpinnings of what would later become the six core elements of healthcare transitions.

So then in 2011, the AP, the American Academy of Family Physicians and the American and the ACP published a clinical report on healthcare transitions. This was a consensus statement. And they introduced the six core elements of healthcare transitions.

which was then codified into what we now know as GOT transitions. And we'll look at some of those resources a little bit later on in the presentation.

From A neurological perspective, in 2014, now once Got Transitions was codified, the Neurology Transition Consensus Panel was convened by the Child Neurology Foundation. And then in 2016, they published A consensus statement, really drawing on and, you know, with Got Transitions as its foundation.

but specifically with recommendations for transitioning adolescents and young adults to adult neurology care. And so this was convened by the Child Neurology Foundation and then endorsed by the American Academy of Neurology and the Child Neurology Society. So some of the big professional organizations in the neurological space.

And now we come to 2018 where the 2016 National Survey of Children's Health was published. And they found that 17% of young people with special health care needs and 14% of people without special health care needs

receive transition planning support from their medical provider. So there is just like significant gap between what our best practices say we should be doing and, you know, the care that they outline as patients needing.

and the care that patients are actually needing. And while this gap has narrowed, we don't have updated national survey data right now, but while this gap has narrowed, the gap still hasn't closed. And so there's a long way to go.

And that's where conversations like these are important.

So with more than 90% now of chronically ill children surviving well into adulthood, this process of transition has become a very unavoidable step in their development.

And so as we said, while these guidelines exist, there's still a lack of consistency in the extent and the comprehensiveness of transition care that's provided.

And so while handoffs and transfer to adult care are common and are inevitable for a lot of our patients, a planned and a supported transition is still relatively rare.

So the process of transition is notorious for being complex and requires extensive support and care coordination. And that's true. But as we go through our talk,

hopefully towards the end, I'd love for us to talk about how do we still move the needle towards, you know, making changes, making incremental changes in this, without just being weighed down by, you know, the complexity and the enormity of the barriers. So we'll talk about barriers briefly, and they're important to consider. But the conversation about healthcare transitions shouldn't really stop at what the barriers to healthcare transitions are.

So let's hear again from Audrey about the process of transition for her and Bennett.

Okay, no audio. Let me try that again and see if you can hear this time.

Was that any better?



Akbar, Asra 14:23

No, we cannot.



Kamat, Deepak M 14:23

I can hear her.



Calderon, Delia 14:27

I can hear.



Kamat, Deepak M 14:27

I can hear her, yeah.



Azara Singh 17:13

And so that also, you know, captures so many of the barriers that we hear our patients talk about and that we also, you know, that we also know about as barriers to transition from literature. So as we talked about earlier, a lot of these arise from that, from that

the push and pull between the two different models of care. So let's examine the two different models of care. So when we think about pediatric models of care, right, they tend to be very family centered. Parents and caregivers are the primary decision makers. There is a focus on gradual autonomy. So as a young person grows older, They're able to share more and more in the decision making. They're able to express more of an opinion. But the responsibility is still...

Can everyone hear my audio?

I mean, can you hear me and see my next slide?



Kamat, Deepak M 18:16

We are still on the comparing modes of care.



Azara Singh 18:20

Gotcha. Okay, perfect. Because I was just getting some, sorry, I know you told me not to look at the chat, but I was just, it looked like some people were still on the video. So just making sure that you can see me. We should be on slide 11, comparing modes of models of care now. So.

In, you know, in the pediatric model of care, we work towards improved shared decision making. But the onus is still very much on the parents to act as, you know, the primary decision makers. And they do get a lot of support in terms of care coordination.

So coordination in pediatric models tends to be much more team-based. So you have a combination of pediatricians, specialists, schools and school services and social services, all playing in and all kind of working together and talking to each other to help care for our pediatric patients.

And care tends to be very development focused. So it adapts as children grow, as cognition maturity changes. Because this is such a normal process, even for children who are not medically complex, our care just organically adapts.

to where they are in those developmental stages. Now, contrast that to adult models of care. So in adult models of care, there's a sudden shift to this greater need, this greater emphasis on individual patient autonomy. So adult models tend to be very patient-centered.

where the individual is the primary decision maker. And this can lead to a lot of anxiety, especially for a patient who hasn't been in that role before. It also really focuses on, you know, really prioritizes self-management and autonomy, where patients are expected to schedule and

adhere to their care and advocate for themselves. And we really expect independent consent and independent responsibility are expected as the norm. And this can be hard for caregivers too, because especially as we heard from Audrey,

Now, they still have to perform these care coordination roles, especially as a lot of those team-based coordination services aren't always available on the adult side, right? But now they, not just from what the patient needs, but from what the system and the models expect,

They're also expected to take a step back and have, you know, still have to do it, but have to do it with less visibility, which also adds more attention.

The other thing with adult models of care is that it really is very conditioned focused. So we tend to focus less on what the overall developmental trajectories are. And the emphasis is much more on managing chronic or acute illnesses. And then it also tends to be more fragmented because it's more specialty driven.

So there's less coordination. So an example of this is as a pediatric neurologist, I might see a patient who has juvenile myoclonic epilepsy, and they also have migraine headaches, and I also have ADHD. And so I'm managing all three of those. They also have insomnia, and so we're also managing that. Now, when I transition them to an adult model of care, often that care, because it's so subspecialty driven, means that now you have multiple transitions rather than a single provider to provider handoff.

Right. So now I transition them to an epilepsy specialist. I transition them to a headache specialist, a sleep specialist or sleep neurologist, if their PCP, you know, or their PCP for those concerns. And often sometimes a psychiatrist for management of the ADHD.

So now where things used to be more self-contained, they now are a little bit more fragmented. And the scare might be in different systems that don't speak well with each other or communicate well among themselves. So one of my colleagues described this as a patchwork model of

a patchwork quilt model of care, right? Where you have these different pieces coming together to form, you know, an overall care plan. And this isn't to say that one is better than the other, right? This is, these models have arisen out of what our patients needs have been, also what our provider needs have been, and also sort of the needs of the systems in which we practice. So this talk is not to say, you know, pediatric models of care are clearly superior and everyone struggles for a good reason when they go to the adult model. That's really not it. Because fundamentally, I think the models of care are what they are, because the systems we practice in are

are larger and have a lot of factors that play into them. But when we really focus on preparing our patients and preparing our families for this transition and trying to anticipate proactively what barriers they might encounter,

That's when transitions tend to be more smooth. That's when people tend to feel more supported.

So when we think about the barriers to transition, they exist at various levels. So they exist at the individual level, the caregiver level, the level of the medical provider, the level of the system of care in which medical care is provided, and then also at the societal levels. And you know, the societal levels are where the social negative social drivers of health, can be so impactful, where policy is so impactful in determining who can receive care and whose care gets compensated. And so these barriers exist at all these levels. So at the more individual level and the caregiver and provider level, Strong relationships often exist with their pediatric provider, because these are patients who have been in the medical system for so long. And the providers, as we, you know, we have a reluctance to transition them as well. There's also sometimes a lack of social support. So the vulnerability of young people with special health care needs and young people without special health care needs is compounded when they're contending with negative social drivers of health. Young people with special health care needs who also have negative social drivers of health tend to just receive less transition care services that are offered to them. And so these lead to those discrepancies in access. as well. And then a short runway to transition also is challenging, right? Because it often leads to... negative beliefs about the transition process. So there's a lot of apprehension. There's a lot of fear of the unknown and a fear about that transition and a fear about change. There are also often feelings of abandonment towards, you know, caregivers and patients have those towards their pediatric providers. And then, you know, we also talk about another barrier is a patient's ability to navigate the medical system, their capacity to make medical decisions independently. Patients who have a greater need for services have more care coordination needs that may not be met. You know, Adult providers may not have access to as many care coordination resources, because from a neurological perspective, there are a lot more adult neurology patients than there are pediatric neurology patients. And so resources tend to be a lot thinner on the ground on the adult side than for us. Knowledge is also, you know, it plays an important role. So it's, and it works on both levels. So there's patient and caregiver knowledge about their condition, patient and caregiver knowledge about what transition will entail, and then also adult provider comfort in managing patients with childhood onset diseases.

Some of which, you know, again, I'd like to point out some of these conditions, it's only been recently in the last five or 10 years that people with childhood with specific childhood onset neurological diseases are now surviving into adulthood.

And so...

Also, a lack of knowledge about the need to address medical decision making proactively leads to a lot of these gaps in care.

And then in the system of care levels, access and insurance can sometimes be a huge barrier. So sometimes finding adult providers can be hard, particularly for patients who have developmental or genetic or cognitive or behavioral disorders. It can be very hard to find an acceptance.

physician. As they go through medical transitions, they also go through other life transitions. And these come with changes. They come with changes in insurance coverage, changes with, you know, Medicaid or supplemental Medicaid with the children's special

health care program, a lot of these school and social supports that exist in the pediatric world just fall off once a patient turns 18 or sometimes once they turn 21. So now they aren't just contending with this change in expectations of them and by them.

from the pediatric to the adult setting. Also, you know, dealing with these very, very real logistical challenges in accessing care and getting care paid for and covered.

And I think it's important to note here, as you know, I alluded to it briefly earlier, but medical care really is just one branch of a patient's care map. As a neurologist, pediatric neurology care is an even smaller branch of that, right? Because they have all these other care needs.

that are often undergoing transition around the same time. And so this really is a period of high vulnerability, where it makes sense to target more resources and caring for patients to, excuse me, during this time. And which leads to better healthcare outcomes for hospital systems, and for individual patients.

So now let's talk a little bit about achieving successful transitions. And I'm aware of the, I think we're 30 minutes in, and so I might have to skip some parts, but I'll try to be as comprehensive as I can.

So how do we start doing that here, right? So one framework that we have is the six core elements of healthcare transition that are codified by GOTT transitions. And these are now what, you know, what we, these are now what we use as a gold standard of

transition planning. And the six core elements are we really start early. So there's a long runway to prepare for transition. As you see, you know, in this image, the conversations actually start at 12. We introduced the concept of transition at 12, so people aren't blindsided when, you know, when they get to that point. point of the handoff. And then we really need, you know, they focus on tracking and monitoring their progress through the transition process, often using standardized instruments when they're available to assess transition readiness at these consecutive checkpoints. Then there's a focus on developing a transition plan, and this is developed in consultation with the patient, their self-identified needs and preferences. And so this includes identifying adult providers, insurance coverage, and identifying and addressing social work needs. And now is when, you know, 16 to 18 is now when typically we start coming close to that point of the actual handoff.

And this is when they really prioritize compiling A dossier of documents that are related to transfer to ensure that communication between pediatrics and adult providers is as seamless as possible. And all this happens for a few years before that actual formal transfer around 18 to 21, or in some cases, 25.

And then it's important also after three to six months to make sure that the transfer was successful and that they have been able to follow up and that they have been able to establish care. Because again, as we saw, this tends to be a vulnerable period in that transition process. So we need to make sure the transition's been successful. So the key components of transition planning.

And we may not have time to go through all of them, but I just want to introduce them at least, are to prepare the young person to both understand their illness and take responsible for its management to the extent that they are capable of doing so. Then empower patients and caregivers to function as independently as possible. Notice it says and caregivers, right? Because now you're preparing them to function as independently as possible, even in the absence of some of the care coordination supports that are currently available to them. Then identifying appropriate adult health care providers for transfer, and then making sure that communication with the accepting providers is effective and seamless.

So in this first stage, right, we introduce the idea early, we educate them in the pediatric setting where there are still, you know, safety nets. This is when we start

assessing and documenting transition readiness.

When we talk about allowing them to function as independently as possible, we really, you know, assessing transition readiness then helps us formulate transition goals in, you know, consultation with them and making a plan for long-term health care needs. This is also the point at which we start the conversation about what decision-making supports might they need in the future.

It's important to note that in the context of pediatric neurology, right, and a lot of this is reflected in other subspecialties and in general pediatrics. Transition planning should still occur even if a specialized adult neurologist isn't identified.

For example, and our cardiology colleagues do this very well, for young people, say people with congenital heart diseases, where pediatric cardiologists are often the people who are most familiar with these conditions and tend to keep their patients well into adulthood.

A transfer of care may not occur for that disease, but it's important to note that a transfer of care is only one goal. Even if that transfer of care isn't going to happen for some time, it's still important to focus on transition planning. And then continuing to collaborate on complex cases can really help

adult providers being more comfortable with taking care of especially some of our more complex patients. And then making sure, you know, communication is effective and seamless, remaining available until the transfer of care has been completed, and then maintaining ongoing collaboration can be very helpful.

Transition documentation in the form of medical summaries are also very helpful and really contain a wealth of information. So a detailed summary of their medical issues, what their goals and preferences for adult service, excuse me, requirements might be, what timing of...

The transfer is planned, what needs to be done before they're ready for handoff, what the patient knows about their condition, then emergency plans, advance care planning status, and if appropriate, plans for establishing guardianship.

And so, as I said earlier, the Child Neurology Foundation's 8 common principles of care transition were, you know, founded and based on a lot of these recommendations about, you know, from God transition. So there's a lot of overlap there.

Now, this is just an example of some of the toolkits that we have available. So this is something that we use in our clinic that we developed, which is a transition

guidelines. I hesitate to call it a policy because we're in the process of working on an institution-wide policy.

but which requires a lot of coordination between, as you can imagine, multiple sub-specialties, each of which have their own sort of sub-specialty specific needs, as well as the sub-specialty specific processes. But what we can do in the interim is we've created really a what to expect from the pediatric neurology transition clinic document, which is given to our patients so they have a roadmap of what the next several years look like.

These are transition toolkits, sample transition toolkits. These are available, got transitions at the QR code. And these, and so the transition readiness assessment is there's a version for the patient and there's a version for the caregiver. As much as possible, when it is possible,

It's great to have the patient fill it out. If the patient isn't able to fill it out in their entirety, it's always helpful to also have the caregiver, the caregiver track. There is a track for patients with intellectual disability, intellectual and developmental disabilities.

It's not the most holistic tool, but it's really, you know, the goal of this is to one, see how people are progressing through this process of transition planning. But then two, also to collaboratively identify what goals, you know, they prioritize in that process of moving towards maybe an eventual handoff, or at least moving towards more autonomy and independence.

To the right is an example of a transfer of care checklist, so we make sure all our ducks are in a row before the transfer of care happens.

The big question also is how do we know that a transition was effective? And this is a challenging question because right now there isn't a clearly defined and universally accepted

indicator of what a definition of what a successful transition is, right? One possible way to think about this is to think about the quadruple aim, now the quintuple aim. And, you know, when we look at outcome measures that we look at in the transition process,

A lot of these fall, you know, trying to look at outcome measures that represent each of these different categories can give us that more holistic picture of was that transition successful. And these categories are population health. So this includes like disease specific measures. So when we're talking about disease progression, you know, that's something that is a population health metric.

Are they able to be more independent? Are they able to self-manage their condition? What is their quality of life? These fall under population health. Experience of care is what is the experience of receiving care in the system and receiving transition care? What is that for patients and caregivers?

It's important to note that, sorry, the color scheme makes it a little hard to read, but it's also important to note that the quintuple aim also looks at the experience of providing transition care, so healthcare provider satisfaction, how sustainable that is. So those are some metrics, you know, that's, we could look at metrics under what is the experience of adding on transition care as an additional, you know, clinical service we're providing on top of other things. So that would be a possible outcome measure. So as we're thinking about, you know, transition initiatives and things like that, it helps to have a framework to organize them in.

But an also cool new development is at the Hospital for Sick Children in Toronto, Sarah Muncie's group, they're working on basically a
You know.

transition quality measures and a consensus document on transition quality measures that then bring us a step closer to really agreeing on what is a successful transition for our patients.

We're going to skip ahead. And so, you know, this came up from a qualitative study where they looked at patient and youth priorities during the transition to adulthood for young people with special health care needs. And I thought this was really lovely. So the goal is not just medical stability, right? The goal is not just keep them from going to the ER. But what patients and families really hope for themselves is that they're able to engage with the world meaningfully. They're able to find joy. They're able to find success in this more holistic sense that transcends just their medical diagnosis.

I'm going to skim through this bit a little bit, just because we're a little short in time. But, you know, generally speaking, there are specific barriers to transition in neurology. They're honestly shared by a lot of pediatric subspecialties and general pediatrics.

Sometimes as a sense, because some of our patients are more medically fragile, there's a little bit of increased resistance to taking on or taking ownership of them. It's also important to know that, you know, for patients with neurological diseases, there are some conditions where they may not need transition, right? Like childhood onset absence.

childhood absence epilepsy, or CELETS, which used to be called benign reallandic epilepsy. These are very age-limited syndromes, and so they may not need transition. Transition planning should still occur for other parts of their, for, you know, other parts of their medical care, but they may not need neurology-specific transition. And then the other specific focus, especially for epilepsy patients, is can they drive, right? And then the need for reliable contraception and reliable family planning, because a lot of our anti-seizure medications have a high teratogenic potential. And so we need to make sure that there are long-acting, you know, that their own long-acting, reversible contraceptive methods that are effective. and reliable. And also interactions between oral contraceptives and seizure meds need to be well understood.

Neuromuscular disorders are a particularly unique sort of setting in neurology transitions, because now with newer therapies, at least 40% of, you know, patients with DMD are now alive at 40, which previously was unheard of. The same thing with things like spinal muscular atrophy.

right, where people used to, the idea of surviving into adulthood seemed very distant. And now, you know, with early treatment and gene therapy and oligoclonal antibodies, they are surviving well into adulthood. But sometimes there's disease progression into adulthood as well. So their needs are often higher, they're often more medically fragile, and the level of independence that they are able to take on is also very intricately linked to the progression stage of the disease. It's also important to note that for a lot of our neuromuscular diseases, physical limitations

are frequent, but they aren't always accompanied by cognitive limitations, right? So a lot of our patients with neuromuscular diseases may still have capacity. But often when we think about transitions and when we think about assuming independence for your care,

It is not unusual for a lot of us to have a more ableist lens about what they are able to participate in and maybe make decisions for them that they may be able to participate in more actively if we give them an opportunity to make it for themselves. And so this comes into play also when we think about transitions for young people with intellectual disabilities.

or autism spectrum disorders, I saw someone mentioned in the comments.

You know, specifically, a lot of these barriers to transition are shared with the other barriers to transition that we discussed. But specifically also, as I mentioned, you

know, young people with IDD and negative social drivers of health also receive less transition planning services, despite having sometimes more needs.

A lot of the social transitions that happen around this time mean a loss of services that go in tandem with these medical transitions. And so it becomes really important to have a very proactive conversation about determination of capacity. Guardianship can sometimes feel like an anxiety-provoking conversation.

right? Because when you're talking about guardianship, you're also talking about essentially removing rights. So if someone needs a guardian, they can't vote, right? They can't sign on sign a lease. So these are these are big things, but guardianship is a wonderful help and resource for the families who need it the most. And so these things really have to be anticipated and thought of well in advance. Powers of attorney are, and so we'll talk really briefly about the differences between these. So guardianship is essentially saying someone doesn't have the capacity to make decisions. So

you have a guardian who will make decisions for you. Now, this isn't to say that the patient cannot weigh in on their decision making. And in fact, for a lot of our patients who need guardians, we really encourage them to share as much in that decision making and voice their opinion and their needs as much as possible.

But that responsibility for decision making falls in the guardian. A power of attorney, an activated power of attorney, is something that comes into play when someone is incapacitated. So if someone was in a car accident or was intubated in the ICU and they're unable to make their medical decisions,

the power of attorney that they have on file will then be activated, and then someone can make decisions for them. And then supported decision making is a step down from guardianship. We often think of it that way, where they can make their decisions, but they have

you know, identified people who can help them. And supported decision making can be tricky because medical legally, the supported decision makings aren't really medical legally recognized. They can still be helpful tools to help guide that discussion in the room about who do I need to

you know, loop in to help you make these decisions rather than expecting them, you to make them by yourself on the spot.

And this is also when, you know, it's important to be aware, especially when we're thinking about, you know, young people and young adults with intellectual disabilities, to be aware of our own biases. The paper cited here is a really interesting

paper, which looks at the attitudes among physicians for caring about caring for people with disabilities. And it really, you know, sort of highlights how we do have inherent biases against care. You know, a lot of us have inherent biases that we may or may not recognize about, you know, the quality of life of people with disabilities, but also our abilities to care for them and the meaningfulness in terms of caring for them. And so it's important also to be cognizant of the fact that a lot of the barriers to transition exist and come up because of ableism. So, you know, when we're thinking about designing a transition program, We really want to, you know, meaningfully involve all the key stakeholders in decision making. And this includes individuals with intellectual disabilities and developmental disabilities. They're also important stakeholders, and we should be trying to include them in decision making and in these program designs to the best of their ability.

So.

This again just kind of brings together everything we're talking about, right? So without these structured guidelines, without these indications, patients and families often feel abandoned. And when we think about transition programs, we should think about the holistic things that patients are involved in. And ideally, think about strategies to improve function and engagement and joy rather than simply just the medical part, although the medical part is very important and plays into their abilities to participate in these other areas as well.

So in terms of future directions, you know, there's a lot of conversation happening in many parts of the country and many parts of the world. There's a lot of really interesting and valuable transitions, you know, research from in Canada. So Sarah Muncy's group at the Hospital for Sick.

kids. There's a lot of work in terms of design thinking and human-centered design in transitions that is coming out of Australia and New Zealand and the UK. And so these, you know, really borrowing these frameworks and these toolkits from other disciplines does help us

create and develop more customizable workflows and more thoughtful workflows for our patients. There's also work being done on more standardized outcome measures and definitions of success. And then, you know, when we think about models of transition, a lot of us have this, and it's natural to have this

you know, idea of what the correct way to do transitions is. And I think the other thing that I want to, you know, challenge you with today is that there isn't a one-size-fits-all model for transitions of care, because there isn't a one-size-fits-all model for a patient or a practice.

But there also isn't for an institution. Because so much of it depends on what institutional priorities are, what resources are on the ground, what kind of stakeholder support you have, what kind of ancillary support services you have. And so when we think about doing transitions right,

I feel like we often get stuck and then we don't do transitions at all.

And so I'd like to let Audrey take us out.



Calderon, Delia 53:03

No audio, it's coming through.



Kamat, Deepak M 53:18

Is that the video is not working? At least I don't see video or audio, yeah.



Azara Singh 53:21

It's not okay.

Oh, gotcha, maybe it just hasn't loaded.

Is it working now? Okay.



Kamat, Deepak M 53:29

Yeah, so.

Yeah, it is working now.



Calderon, Delia 53:32

There you go.



Azara Singh 53:48

I'm so sorry. That was my fault.

And so I think, you know, as we close this out, what I really want to encourage us to do is...

The same way, transitions is probably never going to be perfect for everybody. We're probably never going to completely fix transitions. But there are some small

incremental things that we can start doing that align with our best practices and that align with what we know to be helpful and effective.

And then we can figure out a way to make these things work in our institutional contexts and then gradually, incrementally move that needle towards, you know, a more complete and a more, a more fully rounded transition process or our pie in the sky transition process.

And so in that journey, it's helpful to have some resources. These are just a few of the transition resources that are available. For pediatric neurology specific things, the Child Neurology Foundation is doing a lot of work on transitions. Got transition is really our gold standard, and that's another great resource.

The third is basically just an example of the transition readiness assessment questionnaire, which is freely available online. And then, you know, for our neurologists, we have our neurology subspecialty specific tools as well. And so I'd like to really thank Audrey

for allowing me to interview her for this talk. I think that her insight really reflects a very lived experience that illustrates so many of the things that we're talking about more academically in these talks. I've linked some of their, you know, the Pediatric Epilepsy Surgery Alliance is also doing a ton of great work for patients who are transitioning to adult care. And even though it's the Pediatric Epilepsy Surgery Alliance, their resources are really accessible and available for anyone with, you know, complex medical needs who's navigating that transition. So I'd encourage you to look at them because I think that they still could be very helpful, even if it is in that specific clinical context.

So now I'd like to invite you, I know we're right at time, but, and I saw a few questions in the chat, but I would love to hear whatever, what, you know, if any questions or anything I can answer. I'm also happy to talk to you about the process of setting up our transition clinic over here in pediatric neurology at Madison.



Kamat, Deepak M 56:59

Yeah.

Thank you, Dr. Singh, for that wonderful presentation on transition of care. You already saw the question by Dr. Weimer. Common, it is a transition care for use for autistic children. They need help with communication, with relationship. Is there any research using hypnosis?

 **Azara Singh** 57:20
Mhm.

 **Kamat, Deepak M** 57:27
possibly affecting improvement in communication by assessing additional areas of consciousness and revealing A deeper area of their cognitive abilities.

 **Azara Singh** 57:37
Yeah, unfortunately not that I know of, but also my knowledge of this tends to be less focused on specific, you know, communication needs for young people with autism and more on, you know, our larger scale, more holistic models of how what that could look like and how these can be integrated. But, you know, you bring up a good point in that these specific tools, there's room for them, there's place for them to live within many of these transition frameworks. And so this is also just a good illustration of if there is, you know, a tool or a resource that's being effective and helpful in your practice.
This, there's there are ways to integrate that into a transition workflow as well.

 **Kamat, Deepak M** 58:26
Thank you. There is a comment again by Dr. Weber regarding use of designated team of case managers devoted to specifically to particular disease or condition.

 **Azara Singh** 58:32
Mhm.
And thank you for that comment, Dr. Weber, because I completely agree that we need more resources that are like dedicated resources that are focusing on transitions. And having a transition care coordinator is such an immense resource. To have someone who is owning tracking a patient through, you know, their journey on that transition process, seeing where they are in that, and then, you know, being able to connect them to community resources is so, so important. I hope one day we get to that point. I think centralizing transition resources makes a lot of sense.
But again, you know, the thing we keep running into is state-specific or institution-specific resources and priorities. So, but I agree. I think if we could centralize some of

these services in the future, that would be amazing. In the interim, I think trying to collaborate among the silos that we work in and encouraging more sort of inter-specialty collaboration with transitions is going to help us move the needle towards that. But thank you for that.



Kamat, Deepak M 1:00:03

Thank you, Dr. Singh. Any other questions or comments for Dr. Singh?



Tran, Hoa Thai 1:00:16

Hi there, good morning. Hi there, Doctor Singh.



Azara Singh 1:00:20

Pei.



Tran, Hoa Thai 1:00:21

Hi, my name is Hua Tran. I'm a general pediatrician with UT. I.

I have a few patients who have like chronic conditions and so I start talking to them about transitioning with and you know, they're not the neurologically, they're normal. So I started talking to them about transitioning when they were maybe like 15, 16. Do you feel like, but sometimes like.



Azara Singh 1:00:39

Yeah.



Tran, Hoa Thai 1:00:45

You know, I've seen the first checkups, feel like sometimes it's just too much to do all in one visit. Do you usually have a separate visit to talk about transition?



Azara Singh 1:00:47

Mm.

Yeah, yeah.

Yeah, no, thank you for that. And first of all, also thank you for doing the great work of talking to them about transitions at 15 or 16, because I feel like just broaching that subject and having that conversation goes such a long way towards preparing them. Yes, so, you know, as I go through these frameworks and, you know, I alluded



Tran, Hoa Thai 1:01:05

Oh, okay.



AS Azara Singh 1:01:15

this a little bit before now, but I really want to highlight this. These frameworks sometimes seem unattainable, right? Because it's, you have your clinical visit and then on top of that, you're also expected to transition plan. And that, you know, that's a lot to ask. Here, the way we've done it is I have a separate transition clinic. So patients who are seen in pediatric neurology, our peds neuro providers can refer them to me. Our visits are me, a pediatric social worker, and an adult social worker. And they actually act as the bridge and the warm handoff. This isn't a model I've seen elsewhere,



Tran, Hoa Thai 1:01:45

Mm.



AS Azara Singh 1:01:55

But again, you know, pragmatically, it's the model that we ended up using because those were the resources we had and it's been working really well. So yes, I think separate appointments are important because I think it's important to, you know, for the patients who need that much care planning, it's unfair to ask providers to do that in their limited clinical time.



Tran, Hoa Thai 1:02:05

TV.



AS Azara Singh 1:02:19

The caveat to that is, you know, one thing we're running into is we have, so I have our transition clinic is 1 half day a month, and now we'll scale it up to two half days a month, which means I can see 72 patients a year. We have 1000 something patients who are eligible for transition planning.



Tran, Hoa Thai 1:02:32

The.

AS **Azara Singh** 1:02:41

Right, so how do you scale up in terms of services? And I can't tell you yet if this is going to work or not, but what's something we're planning to try is doing is just giving people transition readiness assessments. Any patient above 14, they're roomed, they get a readiness assessment, they fill it out while they're waiting for their appointment to start, and they leave it.

there. And then my team will look at them, you know, in bulk once a week, identify the patients who are have seem to have higher needs, either identify them for like social work touch points, or identify or prioritize them for transition clinic visits. And for the other patients who may not have such complex, you know, management needs,

 **Tran, Hoa Thai** 1:03:06

Mmh.

Hmm.

AS **Azara Singh** 1:03:22

possibly just a short discussion or an educational module or just like self-directed educational materials would suffice. So that's what we're planning to do to scale. But it's, but I thank you so much for asking that because that's something that we're, that's a challenge that's very real to me right now.

 **Tran, Hoa Thai** 1:03:41

Right, yeah. And sometimes, you know, I used to do it earlier, but sometimes it's jarring for them because they feel like you're pushing them out. They feel like you're doing it before that they're ready. And you know, they are, it is, if no one's talked to them about, oh, like this is not going to be your doctor, like their parents don't talk to them. It is jarring. It is abrupt.

AS **Azara Singh** 1:03:43

Yeah.

Yeah, yeah.

Yeah.

Yeah.

Yeah, yeah.



Tran, Hoa Thai 1:03:59

But I feel like, if I, if I give it a few years, it gives them time.



AS Azara Singh 1:03:59

Yeah.

Yeah.

Absolutely. Absolutely. I think it is right. And those feelings of abandonment are so real. Something that I found as helpful is like couching it more as a graduation and less as an, you know, as you can't see me anymore. But it's like, you know, once you turn 18, at some point in the future, we'll have to think about how we move you to adult medicine.



Tran, Hoa Thai 1:04:20

Yeah.



AS Azara Singh 1:04:28

Things are very different there. So this is a script I use. Things can be different there, and you can be expected to take on roles you aren't used to. So we'd like to do this to set you up for success early so that you're prepared when the time comes. That's usually how I lead those, how I broach those subjects.



Tran, Hoa Thai 1:04:45

Well, thank you, Dr. Singh. Thanks for your time.



AS Azara Singh 1:04:46

Yeah, absolutely.



Kamat, Deepak M 1:04:48

Doctor Singh, thank you very much for that wonderful presentation. We are already over time by 5 minutes, so thank you. Thank you all for attending this morning's Grand Rounds. We'll see you next Friday. Thank you again, Azar. I will get back.

AS **Azara Singh** 1:05:03

Thank you so much, Dr. Kamat. Thank you all for attending and for participating. I really appreciate this opportunity.

● **Calderon, Delia** stopped transcription