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Practice-Changing Research in Complex Care at the AACPDM Annual Meeting 2026

In this special Complex Care Journal Club podcast episode, host Dr. Kilby Mann interviews presenters of posters and educational sessions relevant to the care of children with medical complexity at the American Academy for Cerebral Palsy and Developmental Medicine (AACPDM) 80th Annual Meeting, September 27-30, 2026, in Philadelphia, Pennsylvania. Speakers describe their key lessons learned and the value of partnering with people with lived experience in training and program design.

SPEAKERS:

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Kilby Mann *00:04*

Hello and welcome to the Complex Care Journal Club podcast. My name is Kilby Mann. I'm a pediatric rehabilitation medicine physician at the University of North Carolina in Chapel Hill, and your host for this episode. In this podcast series, we seek to discuss emerging evidence in the care of children with medical complexity and its implications for practice. I recorded this episode at the annual meeting of the American Academy for Cerebral Palsy and Developmental Medicine, or AACPDM, in Philadelphia, Pennsylvania. AACPDM is a multidisciplinary community of physicians, therapists, nurses, dietitians, psychologists, researchers, and people with lived experience. They share a focus on children and adults with cerebral palsy and other childhood-onset disabilities. I talked with three groups of presenters. First, Dr. Esther Lee describes a communication workshop for pediatric residents that was co-designed and co-led with family partners. Next, a team from British Columbia and Nova Scotia in Canada talk about prehabilitation. Prehabilitation, or "prehab," means getting a child ready before a major surgery, including optimizing medical issues like nutrition, meeting functional and equipment needs, and supporting psychosocial readiness. The team created a toolkit to help clinicians screen for and plan to meet these needs. Finally, a team from the University of Wisconsin talks about microaggressions. These are everyday actions that communicate bias, often unintentionally, including ableism. They share a curriculum that teaches residents to recognize and interrupt microaggressions, and they explain why practicing clinicians need the same training.

I'm here with Dr. Esther Lee, who's going to talk about her poster presentation, Building Connections: Caregivers of Children with Medical Complexity, Co-designing, Co-leading, and Co-delivering Communication Training with Pediatric Residents. Thank you so much for taking the time to talk with me.

Esther Lee *01:42*

Oh, you're welcome.

Kilby Mann *01:44*

So, tell me a little bit more about how you developed this curriculum?

Esther Lee *01:48*

Yeah. So, since 2016, I have been teaching medical students, and part of my lecture, I invited a parent to share their story about their journey with a child with medical complexity. And I was doing that every year, and having more and more family partners join by doing small groups. And one consistent feedback from parents that I got was that they wanted reassurance that sharing their story was worth it, and that it was helping students be better doctors. So my latest endeavor was to take that further and do this project, where we co-designed, co-led, and co-delivered with the parents, who I will call family partners, in creating a workshop for pediatric residents. This project was led by pediatric resident Judy So, and I had my long-term family partner colleague Cynthia Vallance lead as well. She is a person with lived experience as a mother with a young woman with medical complexity, so she co-led with us and supported the six family partners we recruited. And we started with a question: What do you think is most important for future pediatricians to learn when it comes to caring for children with medical complexity and their families? Through many virtual meetings, lots of wonderful discussions, we narrowed down the focus of the workshop to two themes: building partnerships and strength-based communications. So, for the workshop, which was for first and second-year pediatric residents, we watched videos of the family partners that they had already recorded, and then had small group discussions. We did a pre-survey and post-survey, where the pre survey of the residents showed that only 50% were satisfied with the training on complex care, and by using self-entrustment scores around specific communication topics, the post-survey results showed that their confidence increased in eight out of nine topics, and 91% felt more confident in caring for children with medical complexity and their families, and they mainly valued the patient and family voices that they got to hear directly.

Kilby Mann *03:59*

Yeah, I think it's been really nice over the years to see more and more the value of that person with lived experience voice, and that we're bringing them in, not just as in that, like you said, that power differential in the clinic, but just like teach me so I can do better.

Esther Lee *04:12*

Yes, yeah. And you know I think one of the cool things that also came out of this because we had such rich discussions with the family partners, and because we focused on communication, we also wound up creating a language guide. We were already aware of a wonderful language guide created by medical students called "Am I Ableist?" So we used a similar format with all the things that we learned during the meetings preparing for the workshop, and created a preferred language guide as well, which has two sections. One is how do you use language with families and patients, and then how do you also use language with health professionals in having suggestions, like instead of saying somebody's suffering with something, saying the person has that diagnosis, right? And the key point was that there's actually no one right way, and that if you're not sure, you need to ask. Really giving that permission to residents, saying we know you don't know everything. Actually, nobody knows everything about my child, right? And that if you don't know, just ask, right? And I think it just gives that permission to residents who I think are under extreme pressure to be perfect and not make mistakes and not be offensive. Our hope for how it would apply for clinical practice is that pediatrics residents would have more confidence in interacting and supporting children with medical complexity and their families,

Kilby Mann *05:44*

You said you built the communication guide. Is that something that you envision sharing more broadly, or your curriculum? For those of us that might want to do something similar.

Esther Lee *05:53*

Yeah. So we have put the language guide on my research website, and so we've already put that out, and that was shared with the residents prior to the session, and now I share with every kind of teaching interaction that I have. And we ask for feedback, and everybody's welcome to give feedback, and we want to keep updating it, and recognizing that there's actually many groups who have language guides, so we kind of compiled resources at the back as well.

Kilby Mann *06:22*

Oh, that's awesome! Well, I will look forward to reading that. What were some of the challenges you encountered as you were working through building this program?

Esther Lee *06:30*

I think initially, you know, we had these rich discussions with the family partners. We realized, okay, we can't teach everything, we can't do everything, right? There's just so much to teach, but we we do have to focus. And the other part was that we applied for grants and such so that we can provide compensation for the family partner's time. So we were actually applying for grants, not knowing what the actual topic was, right? So often grants ask you like you know what's your structure of the workshop and all of that. We didn't want to put that in because we wanted to design that with a with a family partner. So I think that's a bit of that challenge because often the grants expect you to have already set out, but we didn't want to actually do that until we have the family partner. So we had them actually really volunteer without a guarantee of compensation, but thankfully we had many grants and we were able to compensate.

Kilby Mann *07:26*

Oh nice. We're here at the AACPDM annual meeting. I wonder if there's one session that you've really enjoyed that you just want to talk about a little bit? Or we are currently recording at the end of the meetings. There might be a not not be there might not be another session you're looking forward to, but I wonder if there's one that was really impactful for you this year?

Esther Lee *07:44*

Yeah, I had the pleasure of presenting with my team around prehabilitation, pre-optimization prior to major orthopedic surgery. What my main goal for this conference was to go listen to Juliana Mariani in her experience with her team in Boston Children's, where they shared their experience in doing the pre-operative assessment. It was amazing to kind of see what their preliminary results were and how they went through the process with such a ethical and shared decision-making model, and made me kind of reflect that you know, as with all kind of

complex care and palliative care programs across the world, we're all at different stages, and we have so much to learn from each other.

Kilby Mann *08:33*

Those connections here are just so important. Again, thank you so much for taking the time to chat with me. That was really interesting to learn about.

Alright, I'm here with a group of people who presented one of the educational sessions here at the AACPDM annual meeting, "Preoperative Optimization for Pediatric Orthopedic Patients with Medical Complexity: A Multicenter Experience and the Future of Pediatric Orthopedic Prehabilitation Practice". So, I wonder if you want to each introduce yourselves and then talk a little bit about why this work is important and the toolkit you're able to share from this work?

Jordan Sheriko *09:06*

I'm Dr. Jordan Sheriko, I'm a pediatric rehab medicine specialist at IWK Health, which is Children's Hospital in Halifax, Nova Scotia, Canada, and assistant professor of pediatrics and medicine at Dalhousie University.

Dynai Eilig *09:20*

And I'm Dr. Eilig Dynai, orthopedic surgeon, clinical associate with the pediatric orthopedic department at BC Children's in Vancouver, British Columbia. Clinical assistant professor at UBC, and the medical lead of our prehabilitation project program.

Catherine Jones *09:41*

Hi, I'm Catherine. I'm a dietitian at BC Children's Hospital in the Orthopedic Surgery Department, co-lead with Dr. Eilig on our prehabilitation project.

Kilby Mann *09:53*

One of the really interesting parts of your session was kind of taking there's three different centers represented and kind of how you all came together, kind of seeing a similar problem and coming up with a solution. So I don't know if anyone wants to talk a little bit about kind of how that grew and how you got to the point of having this like final product that we'll have the link to as we send out this recording.

Catherine Jones *10:13*

Yeah, I mean, I guess from my perspective, so before I worked in orthopedic surgery, I worked on our inpatient surgical floor, so I was seeing a lot of these patients after their surgery, and seeing kind of the issues that cropped up, that delayed discharges for things that that could have been prevented. And then I was the first dietitian with orthopedic surgery, so they hired me specifically to help nutritionally optimize these patients prior to going to surgery because that was a problem that was recognized with the surgeons as well, but I very quickly figured out that you know nutrition doesn't work in isolation if you don't have all the other parts as well. And so I was very lucky also to have Dr. Eilig join around the similar time that I was thinking about this, and I think we had similar ideas around the multidisciplinary approach to prehabilitation. That's kind of how it all got started. And then, I

guess you know, initially we started with trying to build the clinic. Then quickly realized, oh, we don't really have a lot to go on, you know. So we were looking in the literature, and that's you know when we decided to start trying to to build this toolkit, which was sort of a mix of the expert opinion as well as the literature review, Dr. Eilig can speak more to that part of it.

Kilby Mann *11:32*

Yeah, I think it's so great to have a dietitian embedded in orthopedics. It's like such an interesting model that I don't think I have seen before.

Dynai Eilig *11:39*

If you look across the board with prehabilitation services. I think there's a key emphasis on the multidisciplinary team and the value they bring to the whole holistic approach to the patient. And to add to what Catherine said, so interestingly enough, my background before coming into Peds was adults, and in the adult domain, the number of services and funding and programs and conferences around prehabilitation, the whole concept of prehabilitation is very well developed and very well accepted. As you move into the pediatric domain, you find significant scarcity in the development of of this field. This is something lacking, especially that some of my practice is managing kids with cerebral palsy.

Kilby Mann *12:35*

Yeah, and I think that's such an important part of what we're doing, trying to improve care, improve clinical workflows, is like we've got to share what we're doing because we don't all need to like reinvent the wheel. But also, you've got to incorporate that we're all practicing in different locations and we all have different resources. I don't know if Jordan from you talk a little bit about kind of your setting and how it's working for you.

Jordan Sheriko *12:54*

Just the idea of needing to think about your local context and what might be unique about your catchment area, the population that you serve, and how do you take those ideas of prehabilitation and apply that in in your specific context is important to understand. While we share the important pillars and values and aspects that go into prehabilitation, one of the things for us that we've learned in our journey over the last nearly 10 years of thinking about prehab and going through our iterations, where we first started with more high burden interventions like SEMLs [single-event multilevel surgeries] and Selective Dorsal Rhizotomy, and really focusing our efforts on preparing children and family really well for those interventions, was also recognizing that there is great value in thinking through a lot of the similar steps for even low burden interventions, and really being purposeful in that journey. A child and family maybe going for what we consider something a relatively simple surgery, but to them, surgery is a big deal. And sometimes we can have the poorest outcomes in those more low burden to us low stakes surgeries, but not so for the families. So, really understanding the family context, and all the pieces of medical rehab, psychosocial optimization that we can do. I've certainly been fortunate at our institution to have a really robust interdisciplinary team, including a wide variety of our allied health partners and and the piece that we we think that was somewhat unique that we have really focused on being the psychosocial prehab and so leveraging our clinical rehab psychologists and social workers to dive into the unique aspects of the child but also

their family where are they at, what are the ways that we can support them in getting ready, foster that engagement, understanding, readiness for an intervention in a rehab journey.

Kilby Mann *14:47*

I think this toolkit you've created is a nice way to organize thoughts. So I don't know if each of you want to talk a little bit more about the toolkit and kind of how that can impact practice for others?

Dynai Eilig *14:59*

I think the toolkit for us, at least, came from the place that we were seeking knowledge. Basically, we were set out to start our own service, but basically, we wanted to see what other places have been doing, what the literature has been showing, collect the data, and really build it the right way. And quite frankly, the more we kind of researched and looked at other services and into the literature, we found that there's more missing than actually knowing out there. And so we felt, okay, some standardization is in order. And we felt this is a gap we can step into. So we started with massive lit review led by a clinical librarian. So we collected a large team of multidisciplinary professionals, physicians in allied health patient and family partners, indigenous consultant, and then we took it wider to across Canada, and we identified key pillars we really want to focus on. And basically, the toolkit is a screening tool, and then provides an algorithm for the provider, mostly the community provider, but basically we use it as a scaffold for our program to build in a standardized way to really get basically the knowledge and output on what to do, especially patients with significant medical complexity going into major surgery.

Catherine Jones *16:38*

One thing I really want to shout out with this toolkit that I think is unique is the multidisciplinary aspect of it. There is an adult surgical toolkit that also existed within our province, and I know that the first version was basically written by anesthesiologists, but I think we were really fortunate to have, you know, the participation of you know PT, OT, social work, multiple different specialties like cardiology, respiratory, the whole package. I just wanted to point that out. I was thinking about, you know, what I was talking about earlier with the multidisciplinary prehab approach, this is a situation that comes up often. For example, where you have a kid who is malnourished, but their parents can't lift them, yeah, and they don't want them to gain weight because then they won't be able to lift them anymore. so I can improve the nutrition, but I can't improve that part. So you might probably also need the participation of PT and OT to help with the equipment they need, and then you need the participation of social work to help with the funding. You really need that whole team. And I think that's what the toolkit really emphasizes: is all the different pieces that go together to help that child be in the best state that they can be, and I also just wanted to point out, you know, that we had the participation of patient family partner who had two medically complex children that had gone through the system in this toolkit, as well as our indigenous consultant, and I think they really added an important piece to that because it's very easy to think about things from a clinical lens. But having that perspective, I think, adds a lot of value to that toolkit as well.

Dynai Eilig *18:13*

I must say that having the patient's perspective while writing this a bit changed the way we kind of looked at things, changed a lot of things in what we wrote, and even changed the format of what we wrote or what the structure of it. Cause we eventually, what we end up doing is first of all give the patient safety and the patient perspective its own pillar, which they didn't have first, and we put it the first. So everybody goes through the toolkit. Basically, has to go through this section, not because we're trying to educate people about the patient's experience. That's not the the purpose of it. Just to keep it in mind. Doesn't matter what we do, whether it's academic or clinical.

Kilby Mann *18:57*

I think one of the awesome things for those of you listening is please click on the link to open the toolkit and explore it. I know when they presented it yesterday, they also had a feedback link, and so use it, provide that feedback so that this can continue to improve and improve care for our patients. Well, thank you so much for chatting with me. I wonder if you can each kind of talk about either a session you've been to that you really enjoyed, or a session yet to come at this meeting?

Dynai Eilig *19:25*

One big shout out, and something I super enjoyed it's the SIG. It's for the adaptive sports. I think the dedication and experience that people bring in is inspiring.

Kilby Mann *19:37*

Yeah, awesome.

Catherine Jones *19:39*

I think the plenary lecture yesterday about the growth and nutrition in CP. I have a lot to think about going back home with that because we go back and forth on whether or not to use the CP [Cerebral Palsy] growth charts. The other one that I went to yesterday was the bioethics presentation in regards to you know, decision making in in patients with CP, and I think it gave again, you know, giving more of the lived experience perspective and how we how we talk about people with with disability and the words that we use, and it definitely gives me some time to reflect on how I approach things.

Jordan Sheriko *20:19*

Coming to the academy meeting every year for me is really about reconnecting with all of the people that come to the academy, the connections that you make, and for me, living in a place where I have been this whole sort of rehab physician provider really nice to be able to make those connections and then be able to reach out throughout the year and say what do you think about this. So I value the community in the academy. That's what I look forward to most. And hearing from all the people and their updates and fostering those connections.

Kilby Mann *20:56*

Yeah, you're you're preaching to the choir with us. This podcast exists because we were all part of the complex care committee at AACPDM, and then had this opportunity to work together more. And so, agree for anyone

listening who's kind of think about where their academic home might be, or scholarly home. I should say, this is a great, great academy to be part of. Well, thank you so much.

Catherine Jones *21:17*
Thank you.

Kilby Mann *21:20*
Alright, I'm here now with the three presenters for a session on microaggressions and how we can all feel more empowered and have the right skills to interrupt those and address them. So I'm going to give these three speakers a chance to introduce themselves.

Lauren Fetsko *21:35*
I'm Lauren Fetsko. I'm a pediatric physical medicine and rehabilitation physician at the University of Wisconsin in Madison, Wisconsin.

Melissa Villegas *21:47*
I am Melissa Villegas. I am also pediatric rehabilitation medicine physician at the University of Wisconsin and assistant professor of pediatrics.

Sara Liegel *21:55*
And I'm Sara Liegel. I'm also in the Department of Pediatrics at the University of Wisconsin and pediatric rehab medicine physician.

Kilby Mann *22:04*
Well, thank all of you for taking some time to sit down and talk with me. I thought this was a really interesting session, and I really appreciated coming back with some tools. But maybe just talk a little bit about kind of why you presented this work.

Sara Liegel *22:16*
In our Department of Pediatrics there is a curriculum for the pediatric residents on interrupting microaggressions, and we were able to help debrief these simulation sessions, and found that was a really wonderful learning experience. And we wanted to bring that to the rehab residents that we work with, and so we adapted the curriculum, and kind of made the situations in the simulations to be a little more applicable to the rehab population. Added in a little more ableism touch that we often see. We realize even in our own training, we didn't get a lot of direct training in medical school or in residency in interrupting microaggressions or even acknowledging microaggressions. And so we wanted to bring that forward because we spend a lot of time learning about how do we give the best medical care, the best treatment to our patients, but then we don't really think about the social side of it and all the implications. And so we wanted to give a curriculum to empower our residents to address this head on.

Melissa Villegas *23:11*

And I think we wanted to then bring it to the session here because we'd also done various iterations of this at our institution, and so we were hoping to then be able to bring this to a wider audience.

Lauren Fetsko *23:26*

I think at the core of microaggressions, I really think about like what are the situations that I've dealt with that felt uncomfortable, and how can I kind of take those to make sure that I'm supporting myself, the staff that I work with, the learners that I work with, and the individuals that we care for, kind of on a daily basis. To make sure that the interactions everybody have on a day-to-day basis are welcoming as possible. We're trying to adapt the program so that we're providing the residents with that simulation center practice to kind of really act those out in a safe environment where we're setting the example that we're all learning and that this is a safe space to kind of learn these skills and we're all trying to kind of make things better. And then we're then as a second part. Taking that to the actual department itself and doing grand rounds to kind of focus on that as well, so that they have a better understanding of what the residents have gone through, and then hopefully can have a little bit more acknowledgement because it wasn't part of our training.

Melissa Villegas *24:27*

I think the curriculum is nice, and I feel like I saw this especially as I've debriefed kind of multiple sessions with the pediatric residents, and actually got to debrief a session with the surgical team as well. That you can kind of enter it from various like places of knowledge and still get something out of it, and the goal isn't necessarily to move everyone to the same endpoint, but just to move them forward, because I think sometimes it might be just that they understand and recognize the microaggressions more than they maybe did if it wasn't something they had necessarily heard about before or really recognized was happening to the frequency that maybe it was.

Sara Liegel *25:09*

I think the challenge that we noticed pretty quickly was we were teaching the residents what to do with microaggressions, how to interrupt them, and they felt comfortable interrupting microaggressions. But then they came back and said, "Well, this isn't real life because if this happened and I was with an attending or a superior, I would never say this. I would never interrupt. So we really quickly realized we need to also train the people that are supervising them so they feel comfortable doing this in their daily life. And so we realize we need to bring this show on the road. We need to tell other supervisors, attendings, other physicians that maybe are in, you know, that perceived place of power in a way that you can also be one to set an example and to interrupt the microaggressions so that other people also feel comfortable doing it.

Lauren Fetsko *25:58*

We're taking a three pronged approach. So we've done a kind of didactic session with the residents where we co-facilitated some cases, just you know with trainees and an attending kind of facilitating. We're gonna do the simulation center, so they'll do four cases in a simulation center with varying kind of focuses, and then, we realize that that's obviously a heavy lift. Like not every place might have a sim center, so we're trying to delineate like

which one of these interventions may be the most effective, and then, I think our goal is to hopefully bring that just to the groups that we're involved with, and see if this is something that could be incorporated into other trainings.

Kilby Mann *26:40*
Well, thank you so much for talking with me. I wonder if y'all could share a session you've been to that was really great, or sessions that you're really looking forward to?

Melissa Villegas *26:40*
There was a session yesterday that I thought was awesome and engaging. It was on CVI [cortical visual impairment], intellectual disability, and autism, and trying to discuss some of the challenges with those diagnoses when they converge, and the ways that they're different. It was just nice to have a conversation because I think it's something clinically that I have a challenge with.

Sara Liegel *27:06*
One session was about inpatient rehabilitation for patients with progressive neurologic disorders, and I found that very interesting. Just to think about all that we can add, even when this might be something is much more progressive. It's not the traditional type of inpatient rehab that we're thinking about. For me, it's pertinent. I do a lot of work in inpatient rehab, so it was interesting to kind of get the perspective from other institutions on what they're doing for some of these patients that you know have a lot of changes that are happening rapidly.

Kilby Mann *27:37*
Yeah, that's great. I think I was intrigued in all of the sessions, and ultimately shows something different because there's so many great offers during every session. Okay, thank you all.

Sara Liegel *27:47*
Thank you.

Kilby Mann *27:50*
Thank you for listening to the Complex Care Journal Club Podcast. We aim to highlight research that has the potential to be practice-changing, that values patient and family engagement, is relevant across disciplines and diagnoses, and uses high quality or novel research methods. We invite you to join the conversation by suggesting an article that you would like to see discussed in the podcast using the form provided on the OPENPediatrics YouTube channel. Thank you for joining us.

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