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Far From Care: Children with Medical Complexity in a Rural Setting

In this Complex Care Journal Club podcast episode, Dr. Chelsea Bodnar and Dr. James Bohnhoff discuss a cross-sectional study of children with medical complexity and their access to care in Montana. They describe challenges and inequities in access to care, implications for practice, and next steps from this work.

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Initial publication:

April 7, 2025

Kilby Mann *00:04*
Hello and welcome to the Complex Care Journal Club Podcast. My name is Kilby Mann. I'm a pediatric physiatrist at Children's Hospital Colorado, and your host for this episode. In this podcast series, we seek to discuss emerging evidence from the care of children with medical complexity and its implications for practice. I am delighted to have Dr. Chelsea Bodnar, a pediatrician, clinical informaticist and mom of three from Missoula, Montana. She is the CEO of Montana Pediatrics, a not-for-profit provider group in Montana, working to improve access to care for all children in Montana through the use of collaboration and technology-enabled care. I also have Dr. James Bohnhoff, a general pediatrician and health services researcher with Maine Health in Portland, Maine. His work centers around the barriers that reduce children's access to pediatric specialty care, and the strategies that health systems can use to overcome these barriers. They are two of the lead authors of the article "Medicaid-Insured Children with Medical Complexity in a Rural State" published online in Academic Pediatrics in December 2024. Chelsea and James, thank you so much for being here.

James Bohnhoff *00:59*
Thanks for having us.

Chelsea Bodnar *01:01*
Thank you.

Kilby Mann *01:02*
I do have a connection to Montana. I previously lived in Salt Lake City, and now live in Denver,. And I've also done outreach clinics up to Billings. So I have a little bit of sense of kind of the breadth of Montana. I think maybe before we even get into your research team, Chelsea if you could just talk about how big Montana is. For context, I've driven across it once, and it took me over a day to get through Montana.

Chelsea Bodnar *01:25*
Yes, it is vast. Some of the ways we try to help people place that are, Montana is the fourth largest state. So easy to think, Texas, California, Alaska, then you're quickly at Montana. And we have, we've had a growth in our population, but we still are around a million folks. So that puts you at about seven people per square mile. And you're right. If there was a road that connected from one side of Montana to the other, and you went straight, you're still going to take about 10 plus hours to really pull that off, and no such road exists. So the vastness of those distances and just the small number of kids, about 250,000 kids in the whole state, really impacts our ability to reach people, to aggregate resources and to serve families.

Kilby Mann *02:18*
Thanks for sharing that. Now we can get into the work that you've done. Can y'all tell me a little bit more about your research team?

Chelsea Bodnar *02:26*
This one I get really excited about because I think it's a part of what you were kind of pointing out about the context of this work, which I hope people can appreciate. Montana does not have a free-standing Children's Hospital or really even a center of pediatric care. We do not have a publicly funded medical school in the state of Montana, so a lot of the structures that we've all learned to lean on in our training, to really understand the populations that we serve, or to feel like it is their job to delineate the needs of the community, don't exist for kids in Montana. And so the really exciting part about this team is that it is federal funding from HRSA [Health Resources and Services Administration] looking at, how do we improve systems of care for children with medical complexity, but in a place where there really are no systems to even study or improve that care. And so it has been this incredible combination of the University of Montana's Center for Population Health Research, the

Department of Health and Human Services in Montana working to provide data and work together in a way that is very rare in this state. And then, of course, Dr Bohnhoff, living in Maine, thinking he understands rurality, but what he really does understand is specialty care and access, and then Montana Pediatrics, which is this not-for-profit entity really trying to do the work. So in the room every day, when we think about, how do we look at data? How do we answer these questions? What are the important questions? What is academically rigorous and what is meaningful? I just am so delighted by the fact that this funding allowed that group to come together and focus on this population and I think it's kind of unique.

Kilby Mann *04:02*
Yeah, definitely so. It's interesting to hear how all the different people came together for that. I wonder if you could just give us a brief summary of your research, kind of like the gap you were addressing your research aims and your methods?

Chelsea Bodnar *04:15*
This research set out to fill a gap, a fundamental gap, of, are people asking and answering questions on behalf of these families in this place? So that's a gap that our research sought to fill. I think also, there's a lived experience of what does it take to get to specialty care in Montana? But sometimes we need to fill that with data as well. So we've been able to sort of pull these sources together and try to start and ask and answer that question. I think James can speak specifically to this paper and what it's contributing.

James Bohnhoff *04:52*
Sure. We got into this because Chelsea and Montana Pediatrics had been working with a larger HRSA grant that was aimed at supporting complex care within a number of different settings, including Montana. One of the first goals was doing what they called an equity analysis, to understand how access to complex care varied and was inequitable throughout the setting. And I think one of the first big ideas that you had and contributed that changed the direction of the work was in pointing out that there really wasn't an understanding of all of the people that even needed to get to care. And that kind of baseline was a huge first step that needed to happen. That maybe might have not even occurred to somebody in a big city where that kind of understanding was a given, was a baseline that they already had. And so that was really our goal. It was understand all of the kids in Montana who had complex conditions and needed more higher levels of medical care, and then to start thinking about where they were and how the vastness of the state impacted their access to that care. Our data source for that was we had six years of Medicaid data. And we wanted to use that data to describe all of the kids in Montana in terms of their age, race, ethnicity, but also medical complexity. And for that, we used the PMCA, the pediatric medical complexity algorithm, that kind of divides kids into no chronic complex conditions or non-complex chronic conditions, or kids with more complex chronic conditions. And we were trying to understand both how all of those demographic factors related to medical complexity, but also how medical complexity related to kids' distances from specialists. And so the location of care, was hard to get out of Medicaid or any kind of claims data alone. And so we supplemented that with this additional data source, where a group had been contracted by Montana Medicaid, and I think some other groups, to call around and verify all of the different kinds of medical providers in the state. And we had data on all of the pediatric specialists in the state of Montana in 2021. We put that together to ask all of the kids in Montana, how far were they from any kind of pediatric specialist? Just to summarize the results. So rates of medical complexity were lower in kids that were in rural areas, they were lower for American Indian kids, they were lower for kids that were more distant from care. Also, rates of medical complexity in Montana were a lot lower than in other comparison or studies that we looked at, one was, the big one was from North Carolina, where I think that the rate of complex kids was 13%, for us it was closer to 8. And then I think the other big thing that stood out was that American Indian kids of all levels of complexity were a lot farther from care than all other kids. So although the time to medical specialists for kids overall was 39 minutes, and for medically complex children of all races, it was 28 minutes. And so we're definitely a little bit closer, but for American Indian children, overall, their distance was 83 minutes. And for CMC [children with medical complexity], it was still 73

minutes. And so American Indian children of all levels of medical complexity were just really, really far away from care compared to the children of other races.

Kilby Mann *08:21*
Yeah, when I first read this article, I was actually surprised at those numbers, thinking that was a lot shorter than it was going to be. Again, not based on evidence, but on my experience of working in Billings and having families still drive two to three hours to come see me. And so I don't know if you want to talk a little bit about American Indian kids who are IHS [Indian Health Service] eligible, not being included? So I don't know, maybe that's more a question for you, Chelsea, about kind of how those numbers play out when we again, think about how big rural Montana is?

Chelsea Bodnar *08:50*
Yeah. I mean, I'm so glad you've had that experience and bring that, that perspective. There's a couple of things hiding in here that made this a much rosier picture than the experience you would have had as a specialist in Montana, and, most importantly, what a family would experience. So one of the things to realize that we're working on right now, and is really fun to try to get to the bottom of, is when we said "access to a specialist", we basically said, sometime during these five or six years, a pediatric specialist or two, turns out that was a completely overlapping set of criteria, was in this city. If you take that to a community advisory board, that does not equate to access to the pediatric specialist that you needed when you needed it. So take that with a big grain of salt, that this is a best case scenario, and we're now starting to delve into what does it really mean in a given week or a given timeframe to present yourself as a system or a community or a town that has pediatric subspecialists? And is that really like you had a neurologist once in three months? So hiding behind this access number is not only maybe a sense of distance that might be skewed by whether these kids are being diagnosed appropriately. Is that because kids in Montana are less complex, or is that we're less likely to see them? Is also basically a bold-faced lie about whether or not there was access, there was a specialist available to you, if you are a primary care provider needing to make a meaningful referral, or you are a family who happens to need timely access to a specific specialist.

Kilby Mann *10:47*
Yeah, well, definitely guilty of the 'there every three months specialist'. I think you've started to share, but what do you think are some of the other implications for clinical practice? And what do you recommend for members of the interprofessional care team for children with medical complexity based on your findings?

James Bohnhoff *11:06*
One response to that is that the people in Montana who are caring for these kids, many of them probably already know what we said, and we're just taking that lived experience, both of families and of providers, certainly primary providers who are trying to coordinate care or to put in referrals. And we're putting it out in the open so that people outside of Montana, and so that health systems, and you know, the policy makers, can see that and can comment on that. And so I hope that maybe one result of this is that both patients and providers can feel seen and feel heard and know that there's some effort to understand the challenges that they're up against, but maybe also there are some providers, whether they're in outreach clinics or whether they are in Montana themselves, that could appreciate the great distances and the great hurdles that there are to specialty care, and could try to figure out ways to accommodate that or to react to that on the part of their patients. Other things Chelsea?

Chelsea Bodnar *12:06*
Yeah, I have two kind of feisty responses to that. One is, I think understandably, when you're a primary care doctor in a state like Montana, and you're a primary care doctor in general and a pediatrician in general. You work really, really hard just to do your really important clinical job really well every day, but there's limits, and it's important that we as providers, we learn different ways of knowing how we're doing our job well. And one of those is data, and in what we can point to in a journal article and say this is true, and therefore it as part of best

practices to engage with this data. So I like the idea that this type of data can infiltrate the thinking of providers, because they know it from their lived experience, and they know it from their families, but I think sometimes, if it's in an article, and they are a part of it, it might push us to actually change our systems in a way that deeply acknowledges this incredibly real burden. So I think that's one piece of it for me. I also, again, like come back to this is a bit of a rosy reality, and so I hope that hiding underneath this, in what's coming next speaks to the existing, sort of larger entities in the state, because we sometimes have a tendency in our decisions to compete with one another, to represent our capacity to kind of puff our chests about our ability to do the work that we do. And I think that is the opposite of acknowledging patients' lived experiences, or the fact that someone is only here every three months, or that they're never here on the same day, and you're going to have to come six times in order to achieve what we've presented as the ecosystem of care that we're offering. And so I hope that this type of data and the continuing engagement with this, encourages us to be less about over-representing what we can do for a family, and get more accurate about what we can do for a family, so that we don't waste anyone's time going down an inaccurate rabbit hole of what it would mean to come here for care. So that's kind of very deep in the Montana realities, but those are things that I hope this type of inquiry brings to the table for practice and the people in charge of practice.

Kilby Mann *14:29*
This might be a little tangential, but I maintain my Montana license, because in current state, at least, Montana has a pretty open telehealth practice, so that, you know, as a provider in Colorado, I can still see kids in Montana. So a whole separate conversation of telehealth and access to care.

Chelsea Bodnar *14:48*
Well, keep your license in Montana, I think we've proven how much we need you, and we'll, we'll reconnect on the improvements in the telecommunications infrastructure, because it has gotten much better, and we do have great luck connecting with kids in the most remote parts of the state and using things like schools and other local places where kids gather to make meaningful connections to subspecialists. You know, the more that for families, I think it is really important to be articulate about what the real impacts are of what you're being asked to do and to not be intimidated to feedback to your primary care doctor or the referral base, what it takes for you to follow through on sort of the orders that have been given. And I hope that that type of clear voice and articulation does help push the needle on things like for me, telemedicine, technology enabled care. You know, what would it mean for a primary care doctor to say, 'you know what, you can always come here and use this room and reach the Colorado subspecialist on our internet', right? I think clear feedback around ,I've tried that. I did that. Do you know that that means three trips to Billings? Those types of things, I hope that we're backing up that voice, and that would be my message to families is it's okay to speak your experience and truth back to the primary care providers, because I think that is a place where we can innovate and serve you better.

Kilby Mann *16:28*
What are some of the opportunities and challenges you identified while developing and conducting your study? And do you have any advice or lessons learned to share with other researchers in the field?

James Bohnhoff *16:39*
Chelsea is probably the best to describe what I think was the really huge triumph of this, which is bringing a lot of people together and building a team. That's a huge talent of hers, that was, I think, really important to make this happen.

Chelsea Bodnar *16:51*
Yeah. I mean, if you just were in a typical sort of research setting, right? I think you would look at this and be like, that is impossible, we were really far apart, to pull together the team that would have the expertise to work with this large of a data set, move this large of a data set, manage the data appropriately, use the correct algorithms have the contextual passion, have the experience that James has in this type of research. It really is a product of

all of those voices. So I think one of my, you know, pieces of advice, I guess maybe I would like to speak to people who wouldn't identify as researchers, maybe right now, right but like, you're in a community, and you are a part of serving kids, and you're a provider, and you know there's unanswered questions that if you could put a bit of, you know, heft behind it, it would be meaningful to validating your experience and helping you make change. I think that that's what's the coolest part about this baby step, is it is bringing together people who otherwise wouldn't have been able to do that. So that is a huge barrier, but I hope it speaks to people who don't already see themselves as researchers. And then people who do see themselves as researchers, like James, you know, the ability, the bravery and the willingness, to hop on and join a team out in the middle of Montana, I hope to researchers, it is also an opportunity to be brave and to know that what you know is so meaningful and so important to places who don't have you. And so looking for teams and data in environments where you can combine with lived experience and with local capacity to do analysis and brilliant mathematicians, that's a really cool opportunity, too.

James Bohnhoff *18:39*
There's this idiom where they talk about how the vast majority of healthcare takes place in the primary care setting, but the vast majority of healthcare research takes place like in academic hospitals, and there's this huge juxtaposition. And Chelsea, you and I have been working together now, I think five years, on a couple different projects. And I think one of the really, really cool things about that is that I'm able to look outside of the not huge, but the academic center that I'm in, and get to partner with people who are in a place where I think care is very different and that isn't seen by big academic lenses. So that's been a really, really fun and awesome partnership for me to be part of, and just to kind of as I moved to Maine, too, when we met, I was in Pittsburgh, but I've moved to Maine, and it's been really, really cool to think about rurality and distance in two places that have some similarities demographically, but also have some huge differences. And so I've been so grateful to have a partnership, even though it's across the country that we've got to continue to build. And then I hope we can find other projects to work on together. In terms of big challenges and big opportunities, one of the really cool dynamics that we've been talking about all the way through is if our goal is to understand how do distance and rurality and the other challenges within the state of Montana affect people's access to health care and their health, children with medical complexities, access to healthcare and their health. We started with this very broad brush that was just, where are the kids and where are the specialists? It's a version of that truth, but it's a very thin version of that truth. And we've, I think, constantly been trying to ask, How can we both understand, on a broad level, thinking about the whole state, but also understand something that's a lot closer to people's actual lived experience. So the next step is going to be to look at the actual care that people receive, but then that still doesn't understand the burden of that care, or the choices that people make in getting that care, whether it's choosing not to see a specialist because they're too far away, or choosing to go see a specialist that is the nearest one, but still three hours away, or choosing to go see a specialist who's all the way in Utah or Colorado, and what that means for them. And so I think there's this need to dig deeper and deeper and deeper to find measures that are closer and closer and closer to how the healthcare system actually impacts people's lives on a day to day. So that's been a big challenge for us, and I think something that we'll continue to wrestle with. And then I think of this as just kind of one incremental step along that pathway.

Kilby Mann *21:19*
Yeah, I think that's great. I think thinking about the "whys" and we'll dig a little bit more into what it means to be living in such a rural state.

Chelsea Bodnar *21:28*
Yeah, it's such an important conversation, it will continue to be true that folks in academic, medical centers. And I think this is a good thing from a quality perspective, most of the time, we'll be taking care of families and kiddos who live in this environment. And so I think the more we can do to articulate those realities and build those bridges so that you can be as effective as humanly possible. From Colorado to someone living in Wolf Point, Montana. It's an enormous opportunity for all of us to be better at what we do, too.

Kilby Mann *22:02*
Yeah. Kristie Malik, one of the other podcast hosts, and I, were both really interested in this article. And I think one of the points that really interested us was also thinking about children of medical complexity and American Indians, and that that is also a huge gap on the research and and what's out there, and that people aren't talking about it. So I thought that was another important piece to call out in this work, looking at that demographic specifically.

Chelsea Bodnar *22:25*
That was, I thought the meatiest back and forth we had with some reviewers too, was sort of trying to help understand the policy implications or the work that needs to be done. And who does that work for when you can see a disparity like this? You know, disparities in Native American populations living on reservations are vast, right? They're like 24 years of a different life expectancy. You know, if you're born on the reservation and you're Native versus, like the adjacent counties. There's much, much more to it than, you know, an extra half hour of driving, obviously. But I thought one of the really interesting questions that we went back and forth with a reviewer who didn't have as much experience with the intricacies of how IHS, the Indian Health Service is funded. Or what are tribal health programs? Or how do local, private or not-for-profit entities engage on reservations, right? It's something I don't think a lot of people understand, but it is a really important thing to understand, these disparities, and how do we as a medical community engage with the right organizations to address those? And it's important and complicated to think about the historic role of the Indian Health Service and the federal government, to think about the movements within our state and across the country around sovereignty and around the assumption of healthcare services into a local community, and around what gaps that will still leave.

Kilby Mann *23:57*
Thanks so much for your time, Chelsea and James and thank you to you and your team for advancing the field of complex care.

Chelsea Bodnar *24:02*
Thank you.

James Bohnhoff *24:03*
Thank you.

Kilby Mann *24:04*
Thanks 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-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 this podcast using the form provided on the OPENPediatrics YouTube channel. Thank you for joining us.

Journal Club Article

Bohnhoff J, Bodnar C, Graham J, Knudson J, Fox E, Leary C, Cater L, Noonan C. Medicaid Insured Children with Medical Complexity in a Rural State. Acad Pediatr. 2024 Dec 24;25(4):102628. doi: 10.1016/j.acap.2024.102628. Epub ahead of print. PMID: 39725002.