

Family Perspectives on Developmental Monitoring: A Qualitative Study

Matthew Wappett

Hey everybody. Welcome to the DDNJ author insights Podcast. I'm Dr. Matthew Wappett, the *Developmental Disabilities Network Journal* Editor in Chief and Executive Director of the Utah State University, Institute for Disability Research, Policy & Practice. It's my privilege to host this podcast. This podcast is a relatively new undertaking and it's called author insights because we really wanted to create a forum where we could visit with the authors of articles in the journal and have a more informal opportunity to explore their article, to talk about their research, to understand a little bit more about what it is that they do. So, kind of along those lines, we include some fun behind-the-scenes insight on the process of designing, implementing, analyzing, and writing up research. And then we talk a little bit about inclusion and accessibility and how these authors are trying to incorporate those aspects into their personal work as well. Another reason is that we really want to acknowledge that authors are more than just a name on the page. And we want to help you get to know the people behind the publication. We want you to get a better understanding of the many diverse voices who are working in the developmental disabilities field today. So, I think that maybe most importantly, the big reason we launched this podcast was that it increases the accessibility of the information that we publish in the journal.

The launch of the podcast is part of our ongoing commitment to increasing accessibility of the journal for a wider readership. We acknowledge that not everyone has time to sit down and read an entire article these days and, in some cases, people are unable to read an entire article. More and more people are choosing to get their information through podcasts, audiobooks, and alternative means. So, the launch of this podcast means that you can access DDNJ's content. While you're on the go. You can share it more readily across social media and other online platforms. And it gives you a chance to just get a different perspective than just the written word on the page. We hope that this is useful and worthwhile and something that you'll find value in. Before we jump into today's show, I want to remind you to please be sure to subscribe to our podcast feed on Apple podcast, Spotify, Stitcher, overcast, pod bean, wherever you get your podcasts, and as you hear on every podcast, please leave us a rating and a review on whatever platform you use. That actually helps us improve and know what's working, what's not working. We'd like to hear from, from our listeners. Also, please be sure to share this podcast with your friends and colleagues.

If you're interested in more information on the journal, you can learn more about the *Developmental Disabilities Network Journal* at our website, which is <https://digitalcommons.usu.edu/ddnj/>. You can download episodes of this podcast, podcast transcripts in English and Spanish, or learn more about our podcast guests at the Institute for Disabilities website. This is a longer URL, and I am sorry about that but it's

<https://idrpp.usu.edu/about/developmental-disabilities-network-journal>. So anyway, we will be sure to embed these also in the show notes and that should help you get this additional information and additional resources.

So, without further ado, let's talk about our guest today. Today we are talking with Dr. Sarah Behrens, from the Kansas University Juniper Gardens Children Project. Dr. Behrens is one of the authors on an article entitled "*Family Perspectives on Developmental Monitoring: A Qualitative Study*" that was published in the Spring 2022 issue of the *Developmental Disabilities Network Journal*. In our conversation today, we focus on the importance of involving families in the developmental monitoring process and the remarkable depth of knowledge and experience that parents have regarding their children and the importance of respecting and honoring parent perspectives.

Dr. Behrens is, as I mentioned, one of several authors on this article. Unfortunately, she was the only one who is going to be able to join us today. The other authors on this article were Evan Dean and Marisol Torres. Unfortunately, they were unable to join us for the conversation, but we want to acknowledge their work on this article as well.

So, Dr. Behrens is a recent University of Kansas Medical Center graduate in therapeutic science, and she has a research emphasis on early identification practice for young children and their families. She has a master's in social work and is a former LEND trainee. She has been serving families and children with Autism Spectrum Disorders for many years. In fact, Sarah was the project coordinator for the Autism Diagnostic Initiative with the Kansas State Department of Education's TASEN project, and the Kansas University Medical Center's diagnostic clinic for 10 years. Currently, Sarah is a coach on the PRISM project at Kansas University's Juniper Gardens Children's Project. When she's not working, she enjoys spending time with her two daughters and her husband traveling and thankfully listening to podcasts. So, without further ado, I would like to present my conversation with Dr. Behrens.

Welcome to author insights. Thanks for joining us today. We are excited to have Dr. Sarah Behrens with us from the University of Kansas. Sarah is the author on an article from the recent *Developmental Disabilities Network Journal*, spring issue, its Vol. 2, Issue 2, entitled "*Family Perspectives on Developmental Monitoring: A Qualitative Study*." We're excited to visit with you today. Thanks for joining us.

Sarah Behrens

Thanks, Matt, for having me.

Matthew Wappett

Yea. One of the purposes of this podcast is to make research a little more accessible, but also put a personal face on it. So, tell us a little bit about your background and the path that brought you to this developmental monitoring study.

Sarah Behrens

Well, by degree, I'm a social worker, bachelor's and master's and I was introduced to the AUCD network through the KU LEND programs during my master's year, when I was doing a clinical rotation. I'm also a family member to an uncle who has autism spectrum disorder. So, I've always had an interest in the disability field. And KU LEND was a great match for me. At the time, when I was graduating, I had ample opportunities to learn just more about the disability field. Upon graduating...at the time, the CDC was doing the Act Early Regional Summit, and they were hosting one in Kansas City. I was able to participate at the Kansas table where we had leaders in autism discussing the needs and the gaps across the state. And if you're familiar with Kansas at all, it's very rural. We have a lot of frontier areas and accessibility to services happens primarily on the eastern side of the state in Kansas City. We do have more down in the southern part of the state in the Wichita area, but other than that, everything's very remote. So, one of the huge needs was timely and accessible diagnostic services for children at risk for autism spectrum disorder. From this conversation, collaboratively, the education-based Technical Assistance Network, through the Kansas State Department of Education, teamed up with the Diagnostic Center at KU Med Center in Kansas City. They created a position to oversee the training of agents, educators, and providers across the state, working with kids who were at risk for ASD, specifically on the tools that they were using to diagnose.

I knew nothing about...I was...it's funny, I was sitting at the table, and I heard what was going on. I did not know what happened after everyone left that table. Upon graduating I reached out to a few people to network, you know to find a job, and they passed me along this position, and they said you need to apply. So I, I did. I had no idea what I was getting myself into. It was probably the best decision I made. So, I spent 10 years as the Project Coordinator, and connecting families and teams through telemedicine to our clinicians at KU Med. They were able to get those timely and accessible diagnostic services. So, we were able to fill that gap in a very streamlined way. It was a very collaborative project and I loved my time on it, working across the state, really helping the children the most, and the families, but also the educators and providers. It was from a social work lens, it was very macro based, which was right up my alley.

So, my interest in early identification practices and developments of monitoring, has kind of always been at the epicenter of my work. It really came full circle these last 5-6 years, as I was working on my PhD. I really started to focus more on developmental monitoring in his early childhood years. I knew, for the purpose of this study, I had to start with families. They're the

ones who know their children best. I believe they're the ones we learn the most from when it comes to figuring out practices. So that's where I started with my research.

Matthew Wappett

Well, you were doing telehealth, then, well before the pandemic. Telehealth has become a huge deal since the COVID pandemic. It sounds like you were really trying to establish models and practices way before we even knew there was such a thing as COVID.

Sarah Behrens

Yeah. Yeah. When COVID hit and zoom became very popular, I was like, "Well, I'm familiar with that. I've been doing that." So, it was really interesting to kind of see the headlines and the stories come out of it. Because it was a very familiar thing for me because we did it for a long time before anyone else was doing it as much as they are now.

Matthew Wappett

That's, that's really, that's kind of incredible. And it really positioned you I think, a good place to help inform kind of the world we're now living in

Sarah Behrens

Correct. Yes.

Matthew Wappett

So, give us a quick 2-minute overview of your article, kind of the Cliff's Notes version.

Sarah Behrens

So, our study, the main purpose was to really better understand family experiences with developmental monitoring. I can go into more detail on that a little bit later. So, we wanted to show those experiences of families with medical professionals specific to developmental monitoring, and then also how families obtain and develop a knowledge on child development. So, we interviewed family caregivers of children, ages birth to 5, and then we analyzed the data from a qualitative lens using a somatic approach. We ended up identifying three core themes. The first was that "developmental monitoring with physicians is not common." The second was "families use diverse support to learn about child development, including community-based programs." The third that kind of emerged from the data was "contextual factors, which included maternal health, work demands, and demographic components." They influenced and shaped that child development experience—those first few years life within the family unit. Our findings really indicated that there is a lot of variability and developmental monitoring

practices. There's also a huge need to include families—especially from the pediatric physician lens, and then the importance to consider the individual and unique factors and needs of children and families really stood out as well.

Matthew Wappett

So, when you talk about developmental monitoring, a lot of folks may not be as familiar with... especially if they're working in more of the adult arena or school age or something else. How is developmental monitoring different from what happens under like IDEA Part C? Or is it the same thing?

Sarah Behrens

So, developmental monitoring is more of an informal process. It's really guided through conversation, I would say, and observations, I think those are the two components of it. It's different from screening in that you're not using a formalized tool. So, when you talk about IDEA Part C, they use evaluation tools to determine if services are needed. Developmental monitoring is something everybody could do, you know, including families. I believe they do do it from a natural standpoint as a parent. It's just conversing about it is the next step in that process. The American Academy of Pediatrics do have six components specific to developmental monitoring to kind of structure it a little bit more for physicians. I have yet to find...my dissertation goes into looking at home visiting practices. From that research, I did not find recommendations for home visiting programs for developmental monitoring. So, we have it mentioned, and there's a big push for screening, which kind of led me to this study to begin with. But I think we have a little way to go to just get recommendations in place across national organizations that work with our young children and families. Because right now, physicians are the only ones that have those recommendations in place.

Matthew Wappett

Right. Right. So, you address this a little bit. But, you know, developmental monitoring is that informal process of tracking a child's development, everything. Maybe this is question answers itself, "Why is family involvement so important in that process"? It doesn't sound like a great question at this point in the conversation.

Sarah Behrens

You know, some people may believe that that is an important question. It's one that I think we continue, at least in my work, and I know, other researchers that I work with, we reemphasize, you know, families know their children. They are the source of information of their child's development. And you know, what the families are seeing what their kid is, I think, the utmost important information that we can gather as perhaps providers to figure out is there

something going on? Do we need to dig deeper? Or is this typical development and, you know, the kids just developing in their own way. That family involvement is critical.

Matthew Wappett

So, a lot of the work that you're doing by focusing on families, is very similar to the trend that's happening within disability in general. The shifting that sort of "locus of control" from the professionals to the people with the lived experience—whether that self-advocacy, or whether that's family experience, or anything else. It's really valuing and trying to elevate that lived experience as opposed to just relying on the professionals to tell you when something's "wrong."

Sarah Behrens

Yes.

Matthew Wappett

So, a lot of the research that happens, I'm sure, well, we know this, especially when it's medical research, is quantitative. Right? We know the gold standard for quantitative research is sort of the randomized control trial. Right? So again, the idea that a lot of the research in this area is probably quantitative and so finding the qualitative studies, is a little bit odd. What insights does the qualitative data that you collected provide that isn't usually found in these quantitative studies that are done? Does that make sense? I know, that's a surprise. I added that one.

Sarah Behrens

No, I think it's a great question. I have a one-word answer to get me started. I think the "detail" is in the qualitative study. While I'm a new researcher, and this was one of my first studies, I was really taken aback by the willingness of the participants to share through the interviews, and the level of information they were able to provide was so valuable. I don't think I would have gotten that through, like a survey, for instance, from a quantitative perspective. So I think that level of detail just really provided rich context to the questions that we were asking and ultimately led to the themes that we identified, which answered our research question. That to me is what really stood out from that qualitative lens was just the context and detail that we're able to obtain from the interviews.

Matthew Wappett

Well, it is amazing that it's taken us this long to recognize that the lived experience is just so incredibly informative. We've overlooked it for so long.

Sarah Behrens

Yeah. Yes. I will speak to just my perspective from working with the participants I had in the study. And granted, it was a very small sample size, but the willingness.... I mean, I was able..., I had a waitlist of parents who wanted to take part in it. So, the fact that they wanted their voices heard and they wanted to share their stories, just really...it really did stand out as something that we really took away from the study from a qualitative perspective.

Matthew Wappett

That's incredible. I mean, usually we hear stories of trying to get larger sample sizes because there's not enough people who want to participate. Having a wait list? That's amazing.

Sarah Behrens

Yeah, no, it was. For the purpose of what I was trying to do, I had to keep it on the smaller side. But I now know that it's possible to do a much larger study, knowing that I don't think I'd have any problem finding families to speak to their experiences.

Matthew Wappett

So, as you were going through this and kind of doing the research, were there any big surprises as you were collecting and analyzing the data?

Sarah Behrens

The biggest one, Matt, was that parents know a lot. We can't take them for granted. They know so much information—especially about their children. But even as a parent, you know, they were able to speak to developmental milestones and child development and their experiences through the lens of a parent. For me, and even the team of master's students that I was working with, if Marisol was on, I think she would be able to speak to this. But we were able to piece together what they were saying with child development and map it—if that makes sense. So, if we were able to use our child developmental background and knowledge, and confirm, like, “oh, my gosh, these parents know, a lot.” We were talking with parents from all different socioeconomic backgrounds, ethnicities. So that really spoke out to us. I think the other big surprise...we had a focus on finding out how the relationship was with their medical providers when it came to developmental monitoring. All the families really spoke highly of their physicians that they worked with and had really good working relationships with them. But they did not rely on them for education and information about child development—they relied on other resources. That to me, really spoke to “wow, we've got these great recommendations out for doctors to practice,” but there is a disconnect there between child development and those well-child visits that are taking place with the families and children. So,

I would say those really stood out. There was one other surprise as I was kind of going back through my notes, because I kind of took informal notes as I was collecting information, and we were analyzing the data. The other system that could play a huge role in monitoring development is the childcare system. So, some people refer to it as childcare or daycare programs. We found that of the families who had children in daily childcare programs, there was minimal involvement with developmental monitoring from that system perspective. So, those are kind of our big surprises from the study.

Matthew Wappett

Those are incredibly informative. I mean, especially as you think about how we better create systems that are more coordinated across the different contexts where children are growing up. I mean, that's really amazing. Reading the reports is one thing, but going through the process, there's always---well, the research in itself is an event. It's a process. There's memorable things that occur and so part of the purpose of this podcast is to kind of put a face on that research process. So, is there a memorable story or event that occurred is you worked on this project?

Sarah Behrens

Well, the most memorable was that COVID hit right in the middle of data collection. Yeah, I thought about this one. Through that process, we had a big life-changing event occur, you know, for everyone involved. At the time, I was collecting data, I was doing the interviews in person at the family's homes. So, one of the biggest things for me was to be accessible to the families. So, I offered a variety of ways to collect the information, but in person was our preference. So, I was traveling to the family's home to do the interviews. When COVID hit, we had to shift, and we had to shift fast. So that was probably one of the most memorable things that occurred, because looking back, even when I talked to Evan, who is also an author on the paper, he was in the midst of other research projects, but he was amazed at how adaptable our families were to move to Zoom and phone interviews. They had no problems doing that and they stayed committed. Even with the final five interviews I had, there were kids in the background. They were at home taking in this new life event. Now here we are, two years later, that has been life changing. The family stuck with us and we were fortunate to get all the data and to move forward and analysis. We were very grateful for everybody's contribution.

Matthew Wappett

Yeah, no, I mean, and you're lucky. I know a lot of research ground to a halt when the pandemic hit. The fact that you could adapt and keep going is really pretty incredible.

Sarah Behrens

Yeah. And our IRB—that was the one thing we were a little nervous about. They approved us moving to phone and Zoom pretty fast. I know many researchers kind of ran into that as a speed bump as they were collecting data. IRBs were figuring out how do we best work around that?

Matthew Wappett

Oh, yeah. Well, that's a whole other rabbit trail we could follow—IRB responses to the pandemic. We could probably do a special episode on that and we can all compare notes. We've covered a wide range of things. Although you've given us a summary of the article, what is the take home message from your article? What is it that you think that you want readers to remember?

Sarah Behrens

I think the number one thing that I'd love for readers to take away is that families matter. Their voice matters, their experiences matter, their opinions matter—especially when it comes to their children, whether they're typical developing or have a child with a disability. I think our results really speak to the valuable insight that families provide—not only to developmental monitoring, but really any topic around child development. Another big thing is contextual factors really play a role in family dynamics. Ultimately, that child development experience so from a visual perspective, I kind of think of that trickledown effect, right? If you have a parent who is facing some challenges within the family unit, it can play a role and impact their children and that phase of development that their child might be in. That looks different across the board. So, I really think contextual factors are something that we need to really pay more attention to and learn more about as we talk to more families and research. I think those individual factors, whether it's physical or mental or emotional needs, they need to be considered, especially in the early identification practices arena that we're trying to improve for families and young children.

Matthew Wappett

This has come up multiple times in this conversation, but I really do appreciate that notion that it's the families and the context that matters. It is ironic, as you brought up earlier that a lot of times our interventions are focused on the professionals, because that's the easiest to target. Frequently, the biggest impact is coming through the families, their lived experience, and in the settings where they live and learn and work and play. So, everybody who does this work has a story, and has a reason why they do it. Nobody goes into the disability field because they stumbled into it. What motivates you to do this work?

Sarah Behrens

Currently, I think my own children—now that I'm a parent, my own children. They are the future. And it is so vital. I've learned just from personal experience, that having a strong foundation in place for them. And that means a strong support system around that family unit really can lead to positive developmental outcomes. And I speak now, after working in the field for quite some time now, if we put more into supporting those families from the beginning, I think the trajectories of our kids developmentally and into their school years, can look a lot different. I'm just going to speak from I think a societal perspective right now, especially what we've experienced last few years, and even the last few weeks, Matt, I think it's showing that we need more support for families who have young children. Our society as a whole has a ways to go and that really motivates me. I know that my time will come to an end at some point, but I hope that my motivation and this work can leave an impact to those foundational systems so that families just feel equipped—families with unique needs, families with children with a disability, families of all ethnicities—to really have that knowledge and support to best support their children as they go through those developmental phases.

Matthew Wappett

I think that is certainly the takeaway that I got from your article, and it's coming up over and over here is just that the family unit is so incredibly important to the outcomes for our kids. I think any parent knows that. Unfortunately, I don't think that that's always reflected in the research.

Sarah Behrens

Yeah. That's what I'd like to see you moving forward.

Matthew Wappett

Great. So, last question here. One of the focuses of the journal, and the podcast, and some of the things that we do with our plain language summary, is to make research more accessible. So, we'd like to end with a question and ask, “What is one thing that you've been doing to make your work—and that's work at large—it could be your workplace, it could be your process, it could be your relationships—what's one thing you've been doing to make your work more inclusive and accessible”?

Sarah Behrens

Yeah, I think this is a great question and it's one of those top five questions when I get started on something like “how can we include more people”? I think, for me, personally, as a social worker, and I mentioned this earlier, I kind of take a macro approach to my work. So, I have always worked hard to be inclusive of all the systems or the people or the organizations surrounding a young child. As I look at my current work, and even into the future, that is

something that's really important to me, like how can we learn about developmental monitoring and early identification across systems and providers and different organizations to ensure that there is a cohesive approach and that it is cohesive across systems and those systems that all kids are touching—if that makes sense. I think that's one of the biggest things for me for that inclusivity around this work. And then just inclusion of people and participants in the research—broadening that. Now that I'm kind of on the other side and starting my, “new career” as a researcher, I think it's really important to figure out innovative recruitment strategies to ensure that all people have an opportunity to participate in research. Because I think there's value in it, and I think they would see value in it as well. It's just we, on the research end, need to figure out how can we market it in a way that pulls more people in to participate?

Matthew Wappett

I really love that. Because the research is only as good as the people who participate in it. If it's limited to just folks who have access or have privilege or have connections, then the data that we have is not reflective of what's actually happening out there. I think that's such an incredibly important point. So, thank you. Thank you. I think that was the end of my questions. I don't know. Do you have any last thoughts, Sarah?

Sarah Behrens

No, I think you touched on everything, Matt. This is a good summary of the article.

Matthew Wappett

Cool. Well, and now we have a bit more of a personal face behind it. We understand a little bit about you and your process. That's why I love doing this because it really does give you a whole different perspective. So, thank you. Thank you. Thank you.

Sarah Behrens

Yeah, no, thank you. I'm excited too.

Matthew Wappett

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Thanks again for listening today, and in the words of Margaret Mead, *“Never doubt that a small group of thoughtful committed individuals can change the world. In fact, it's the only thing that ever has.”* Have a great day everybody.