Marjorie (00:06):

We all know that parenting is hard. So how do parents with disabilities do it? With creativity. And because we know of the value of interdependence. Come hear about ways experts say we can best empower these families, and let's all learn about how parenting can be done differently. I'm your host Marjorie Aunos and today my guest is Monika Mitra. Monika is an associate professor of Disability Policy and the Director of the Lurie Institute for Disability Policy at Brandeis University. Using large population based data sets, her research studies focus on health disparities in pregnancy and healthcare access among people and parents with different disabilities. There is power in numbers and Monika's research is allowing us to demonstrate the need for representation and equity. Enjoy. And don't forget for more information about where to find the full recording and additional resources, check out the show notes.

(01:25):

So today I'm really excited to talk to Monika. So Monika, I first met her in Vienna or at at least this is like the memory that I have of her. And we were in this like old historical building. And we were on the Eve of her, uh, publishing the results actually that we are going to be talking about today. And I think everybody was so impressed because for the first time we were actually talking about parents with intellectual disabilities, but on a population based length. So we were talking about a sample that was much larger than any of us at that time had done. So we were quite excited to meet with Monika and to talk with her and to have her come and do research in our field. So, Monika, it's so great to see you today and thank you for being here with us to talk about research.

Monika (02:21):

Thank you Marjorie I actually remember that conference very well. It was my first IASSID conference and, what I remember clearly, because I'd written that paper with Susan Parish and everyone we had cited was actually sitting in that, in that room. And that was one of the first times I was like, oh my God, this is fantastic to be able to talk to all the people that we had, we had cited, we had read about. So it was a great conference. And I remember meeting you there as well. So

Marjorie (02:49):

Yes, it was one of my, um, first conference on wheelchair. So it was quite, quite a challenge for me to just like show up and be there in Australia. So I'm gonna start by just trying to get to know you in terms of how you got in the, the field, cuz we all have a story of a mom that we met and that's how we started. We're all clinicians, at first usually. Um, but in your case I think it's a bit different or maybe I'm wrong. So tell us how you started in the field.

Monika (03:22):

So the field is I guess I'm thinking, is it the field of disability and health research or the field of pregnancy and parenting? So I'm gonna start with the field of disability and health research, which is really how it was my entree into this. And I was straight out of my you know, I was actually an immigrant at a foreign student at that time. I was doing my dissertation. I was doing my PhD and I wasn't quite sure about my dissertation topic. When my advisor got a grant looking at examining employment opportunities for disabled people in the United States. And it was a comparison between the US and Sweden. And as I started doing the literature review, I very quickly realized that this was a population. So we're talking early nineties, mid nineties. A population that really was missing was missing in the pedagogy, in any of the classes I'd taken was missing in social.

(04:24):

I mean not social media, but in mass media. In representation. And it was really a population that no one discussed. And so that really got me intrigued. And then as I started doing the research, which was using at that time, a population base was the survey of income and program participation. I really quickly realized that this is a population that faced incredible disparities. So this was sort of this disconnect between the incredible disparities that people with disabilities were faced, both in terms of employment and socioeconomics, but also the lack of recognition, understanding, examination, of these disparities. So that sort of got me into, into the field of discipline health research. And if I can fast forward to sort of pregnancy and parenting, um, you know, years later I was, you know, I had written, I was writing this paper on physical abuse and women with disabilities during pregnancy, using a population based data set as well.

(05:28):

And, and my focus was more on the physical abuse than the, the side of, you know, the pregnancy. But again, looking at the literature, I very quickly realized while there was an emerging body of literature of studies on violence and violence victimization among disabled people, there was nothing on pregnancy and, and it was shocking. And yet not shocking because, you know, as soon as you unpeel the first layer, you realize this was a manifestation of our genetic history. This is a manifestation of social economic policies that prevent people with disabilities from becoming pregnant. And Marjorie, if I may, if I may, I wanna talk, you know, you refer to as this one person you met as a clinician, so I'm not a clinician, I'm a researcher and I've been studying and working on pregnancy and parenting for a while.

(06:28):

And until quite recently, sort of, I didn't realize quite why I was so involved and taken with this topic until I've been thinking about my mother and my mother had this skin pigmentation disease. You know, I grew up in India and she had the skin pigmentation disease, which realized, you know, she's a brown woman and she slowly lost her skin color. And this was when I was very young and as a re, and this is a genetic disease and as a result of which she was socially ostracized and this is something we lived with, you know, and it was both embarrassing for me, but also I was very protective of her and I was very, you know, embarrassed for her also. So it was it, you know, and I think, I didn't realize that I was a child of a parent, a disabled parent, you know, because we all have, even, even for someone like me with the kind of lens and with the work that I've been doing, it's quite a recent recognition that my mother had a disability and I've really grown up with that.

(07:36):

So,

Marjorie (07:38):

Wow. That's an incredible story, actually. Monika, I love that. And I love that you were able to sort of reflect back and sort of find that, you know, that might have been a contributing factor certainly in terms of making, and doing research that is very socially justice driven. I know that when I read your papers, I often sort of feel like, you know, there's a call to action and there's, you know, an urgency to do something in terms of policies or systems, you know, organization, I think that's one of the, the best part about your papers and your research, for sure. And so that would be like a great segue to start with the first paper that you submitted for, for today, which is basically, pregnancy outcomes for women with IASSID it was published in 2015. So one year after that conference in Vienna, do you wanna tell us a little bit about that study and, and the results that came about?

Monika (08:36):

Sure, so this was a study on, you know, we used, uh, state data set it's a longitudal link data set, which links hospital discharge data, as well as with birth certificate data. But really the background of this is by then I was in the midst of a national study on systematically examining the pregnancy outcomes and the barriers to perinatal care for women with physical disabilities. And as I was working on this, I met a really close colleague Susan parish, and we were, you know, thinking of a study on women with intellectual developmental disabilities. And this is a critical importance because if there is one disabled population that has really been impacted by eugenics, and I'm thinking buck bell, it, it is women with intellectual developmental disabilities. So it was something that we really wanted to do. We, and, and what we very quickly again, realized that there was a complete dirt of studies, particularly studies that were grounded in data, you know?

(09:36):

And so we wanted to really understand what are the experiences on one hand, you know, and what other outcomes in terms of pregnancy complications in terms of maternal and birth outcomes in terms of their prenatal care and their post-partum care. But the issue with, with that is, and Mar you know, this is that very few surveys actually identify disability, particularly IDD status. And so the question is, how do you get at outcomes? So we were writing this grant to NIH on pregnancy experience, as an outcomes of women with intellectual developmental disabilities. When we decided to use a backdoor imperfect backdoor approach to identifying people with I D D and that was using, I C D at that time, I CD nine codes and we all know the limitations of this, and I'm absolutely the first to acknowledge it, but it was one of those imperfect solutions because there was no other, and, and at that time, the, the surveys, which is the national survey, family growth, and again, this is us based, um, I realize, and all the pregnancy, uh, risk assessment monitoring system did not include disability identifies particularly identifies, you know, for women with, to identify people with I D D.

(10:53):

So this was one backdoor approach and what we came up with and what we published were really astounding, an unfortunate disparity, disparities. And, and there's been a series of papers since then by myself, but also my other colleagues on that women with intellectual developmental disabilities have higher rates of ed visits, emergency department visits, hospitalizations during their pregnancy, as well as, uh, at post part. What we also found that women with I D D had adverse were more likely to have adverse birth ups. You know, the question of course, is, you know, which, which is the issue with, a paper like this is that it gets at the very high level superficial, like, yes, he do the outcomes. What it doesn't get at is why,

Marjorie (11:42):

You know, since that paper there's been several ones. And like you said, from yourself, from some of your colleagues, all the, those studies really shows this disparities. It also shows also sort of the importance of intersectionality in terms of different identities and how that puts, you know, women potentially more at risk because they are overrepresented in those samples. Do you wanna talk a little bit about that in terms of the fact that they're more likely to be black and Hispanic, for example, in those samples than you found?

Monika (12:16):

Absolutely. And I think that really the research that we need to conduct as a community and as a global community. So let me just speak about maybe the us and north America is, is we really need to focus on these populations that have been largely underrepresented in this research, you know, which is what are the disparities, what, how do, black and brown women, uh, with disabilities and with different types of disabilities navigate the healthcare system, what are the systemic barriers that they face? You know, what are the pejorative attitudes, if any, that they face, you know, and what are the outcomes of this? So we really need to do a deep dive into this and, and, and, you know, the excuse of small sample size or difficult to reach is, is really something that we need to leave at the door, you know, and that's, again, I'm going with, you know, I'm gonna speak of the us because that's the, the country that I've really been focusing on in my research, but globally, you know, I think we really have to, and then again, Marjorie, you know, and I asked that this is a discussion we have in the parenting circle, for example, is where are studies, where are studies that have been focused on, uh, people in the global lab, you know, and, and this is something that we really need to find ways to highlight.

(13:34):

So our understanding in the literature has largely been on, uh, women and people in high income countries, you know, and, and also usually very white samples. And yet with, with all of that, we've found disparities that are, you know, incredible and wide, and again, disappointing, right. But I feel like we haven't scratched the surface. And what we really need to do is, is widen and also deepen our research.

Marjorie (14:07):

Definitely, I think like you said, we've had that conversation many times. It's really about finding the solutions and being creative to, to get to that and to get that information. One of the, the studies also that you, brought forward for this, podcast is the perinatal health framework which I thought was interesting, because you're bringing sort of a lens or a framework to be able to observe and understand what is going on in women with physical disability in this case, but it could have be applied with all women with disabilities and all women really, in terms of like pregnancy care and, and understanding postpartum follow ups. So do you wanna talk to, to us a little bit about that?

Monika (14:52):

Sure, sure. So this was actually, I'm going to take this back a few years when we first wrote this grant, you know, on pregnancy, among women with physical disabilities, which was before our studies on women with intellectual development disabilities. This was a group of colleagues, including Linda Long. I, Dr. Suzanne Selzer and Dr. Lisa. So this is really the four of us who were, you know, had, had conceived the study, but as we were going into this, and again, on one hand, there was really very few studies, empirical studies on pregnancy outcomes of women with any disability. But what we also realize that there was no framework, you know, there was no kind of attempt at sort of understanding or frame, the issues around pregnancy for people with disabilities. So we decided to, you know, embark on this, you know, as you were writing this grant, but also kind of, you know, you know, using chalkboards and, and, and whiteboards and trying to kind of you know, work on this framework.

(15:55):

And it was really exciting actually at that time. And, I, in order to develop this framework, we really built on the work, for example, of Don Misra and colleagues, when they wrote of our perinatal care perinatal health, they use a life force perspective, and that is particularly important to people with disabilities, particularly important to women with disabilities, right? Because pregnancy, the interactions with the healthcare system, for example, don't begin at conception, don't begin at the first prenatal care appoint. Right. Um, the second piece that we also is, Michael Lewin colleagues that had looked at, you know, what they call the cumulative burden, and which is really about, you know, it builds on that life course perspective, but their work focused again on black and brown women and, you know, women of color and talked about how sort of this, this a lifetime of racism, you know, has, you know, so it, it, it really is carried the impacts of that are carried to pregnancy in perinatal health.

(17:04):

So the same thing, I think for women with disabilities, where we felt like it was, again, not, not, it didn't begin the issues didn't begin during the first prenatal care appointment or at conception, or even at a preconception appointment, but it is a systemic ableist, you know, that is, you know that, that sort of, creates this cumulative burden. So by the time a person is engaging for during their first prenatal care appointment, they already have this, this cumulative burden that they're carrying. And, and that could have several impacts, for example, in their lack of desire to engage with, with the clinicians or in terms of their hightened awareness of the ableism that they're facing during their prenatal care appointments. And at childbirth, we also wanted to, in this framework take into account, obviously the environmental factors, you know, we wanted to place, pregnancy and perinatal health, both in terms of the life course perspective, but also in terms of, the, the built environment, we wanted to place it in terms of the policy and the legal environment and the cultural, and, and as well as, you know, in this, again, in this case, the, the, the social environment and the social attitudes towards pregnancy and towards parenting for disabled people,

Marjorie (18:31):

I like your framework. And of course, um, one of the shows here was interviewing Maurice Feldman. So we talked about his model in terms of understanding parenting. What I like is that there's, you know, definitely parallel with the framework that you're talking about, but there's an extra layer of a lens, I think, in your framework where you really look at the perspective that society might have, and you bring answer that notion of ableism, that is not, you know, so obvious in the hypothetical model from Selman. And that to me, is something definitely that we need to talk about a little bit more, how ableist and preconceptions really have an impact on everything, which then sort of, you know, it's a disparity, but not just like one time, it's a disparity that comes in and comes back and comes back, you know, at different moments of their lives. And it's just, you know, talks about accumulated risk. And, and I think that that's one of the greatest, uh, contribution of your research, for sure. So the third one that you, uh, brought forward is basically talking about the pregnancy of women with physical disability and looking at the unmet needs, but also focusing on recommendations. And so, because, you know, this podcast is for childcare workers and clinicians. I was wondering if you could sort of talk about those recommendations that we should all be aware of and, you know, put in practice.

Monika (20:00):

Absolutely. So, that paper, if I remember correctly, we interviewed, about 25 women with physical disabilities and really to understand, you know, what were the barriers to they took care. And we also, you know, at the end of the interview, asked them if they had recommendations to other disabled women and as well as to clinicians, you know, and I just wanna tell you, we also, later in the grant interviewed conditions about their, and these were conditions who were relative experts in providing, uh, perinatal care to disabled, physically disabled women, and about sort of the similar, uh, you know, kind of a mirror to what we asked disabled, women what were their barriers to care? What were their recommendations to inclinations? And, and what we really found is that it was actually a mirror image, you know, of what women disabled women, discussed and spoke of in terms of their barriers to care.

(21:04):

And their recommendations was very similar to clinicians. So, you know, the interviews were both shocking, surprising, and then again, not so shocking and not surprising in terms of the pejorative attitudes that they faced in terms of the access barriers that they faced in terms of the, their, the lack of information, the lack of information, both in terms of, you know, books or at that time, any written material, as well as from the clinicians. So really women, disabled women, you know, what they wanted was one is, you know, training, and, you know, both in terms of her conditions is an understanding of the needs of disabled women, you know, and, and they, they said, treat us like anybody else, you know, and, and sort of not focus on that disability. So, you know, it really comes to the need for training during their medical education, during their training for clinicians to be exposed and understand the needs of disabled people.

(22:11):

The second, what, you know, disabled women talked about was their need for information. What they recommended was, you know, give us information about the interaction about our disability and our and pregnancy, because at that time, I mean, this was, you know, this, these interviews were done. You know, I, I think about maybe seven years ago and, you know, social media hadn't exploded the way it has right now. So women really were frustrated by the lack of information, you know, by the lack. And so they needed more information in order to navigate and not everybody lives in a metropolitan area. Right. And so particularly women, for example, in rural communities and communities that were, you know, more isolated, where they didn't have a disabled, or a peer, peers that they could reach out to. The other was, just the accessibility of offices.

(23:07):

I mean, this was, you know, now we're 31 years past the, ADA, the Americans with Disabilities Act, we're still seeing it. It's not like things have changed in the last five, seven years. For example, women who had congenital disabilities spoke about how they had never been weighed in their entire lives, they had never been weighed. And, and many of these women, for example, a number of women that we interviewed, were women with dwarfism. They were little, little people, and they had talked about, for example, the lack of accessibility. For example, I remember one woman talked about how she would take a step stool, you know, so she had a cesarean and she would take a step stool from her bed and kind of take that stool after having a, you know, the day after having a cesarean, it take it from her, you know to climb, uh, out of the bed to get out of the bed and then carry it to the bathroom so that she could wash herself. A simple thing, like a stepstoool so that, you know, the lack of accessibility, the, and, and the pejorative attitudes, the lack of information, and also, women talked about was, you know, ask us, you know, we are the experts in our body.

(24:26):

We live with this, you know, don't make assumptions. If you have a question, ask us, because we know what's the best way to transfer, you know, we know what, you know. Oh, and so I think this was something that was really that, that disabled women felt very strongly about. And, I think finally, also just care coordination, you know, reach out to the other clinicians that were part of their care network and ask about this instead of making again assumptions, or actually not even taking the time to do the research. So there were several really important recommendations that came out of this.

Marjorie (25:09):

It was interesting because as you were talking about the results and sort of like the moms and what they brought forward, as, you know, I, you know, 10 years ago I became paraplegic. So I was born in an able bodied, you know, and, then ended up sort of disabled and the incredible amount of places that I can't go to because I'm on wheels now. It's just incredible. And that starts with some hospitals, some like healthcare clinics and every time I'm baffled, cuz I'm sort of like, wow, like we're in 2022. You talked about the ADA in the states, in Canada we have similar sort of policies. We are countries that have, you know, ratified or at least sort of been part of the Convention on the Rights of People with Disabilities, we know about sort of Article 23 about the Right to Family, about the Right to anything like to be able to do what anybody else does.

(26:15):

That's pretty much what the Convention, um, you know, is, is stating. And yet we have all of those little things that nag us because it's sort of like every time I felt like, okay, well I'm not welcome here, obviously they're stairs. Right? And so if I'm not welcome, then it means that a child who's in a wheelchair is not welcome. It means that a, you know, a mom with even like a stroller, you know, might have a difficulty getting in and these are healthcare facilities. So I think this is also a very important seminal paper. And I hope that you know, we continue to work towards using those recommendations and making sure that they're applied. So that's my wish as both a researcher and a person with lived experience now. That will lead us to sort of what's next, where should we go from here? You alluded a little bit of that earlier. But I would let you sort of talk about what you think would be the next step in terms of research or practice or policy, cuz I think you touched on all of those areas.

Monika (27:24):

So, what is next? There's a lot, there's a lot that we, as researchers, as practitioners, as policy makers that we need to do, I'm gonna speak with my researcher hat on. And I think, you know, as I mentioned earlier, I think in terms of really what we need to do is investigate, understand health for people with other marginalized identities. So we really look at the intersection for example of disabled people and trans disabled people and you know, who are, have LGBTQI identities. We need to understand what other, you know, of black and brown women with intellectual and developmental disabilities. So I think we really you know, on one hand need to delve deeper and really, you know, bring out, the needs and the experiences of disabled people with other marginalized identities taking this globally.

(28:24):

As I mentioned before, really on the global south, I mean it is, A call to action is an understatement, you know, because obviously the needs of disabled people and I'm just going to use the example of India, of women who are living in rural India, who have, for example, physical disabilities are very, very different. And how much of that do we know? I think that's so that's one body of work that, you know, is, is really looking at, you know, both global south, but also are women with marginalized, other marginalized identities. The other, which is what we are trying to do both with our, I think, you know, this, we, I co-lead two centers, one is the National Research Center for Parents with Disabilities, as well as something that we've just recently launched, which is the National Center for Disability and Pregnancy Research and Marjorie you're involved with both.

(29:21):

And so what we really are trying to is get at that next step is, you know, trying to build a body of evidence-based interventions, evidence-based practices, so that we can support disabled people during their pregnancy and during their parenting. Because on one hand, you know, we know that there are disparities, but the question is, what do we do? You know, what do we do with this? And how can we change, both, how can we support people with disabilities during their pregnancy, but also, thinking about how can we support policies that, you know, how can we, you know, what research can we do that can support policies? So there's, again, you know, there's plenty, plenty for us to do. And I really am very appreciative of the collective body of researchers that, and both, for example, the ISSAID served has brought together so that we can do this collectively and we can inform each other and we can work together.

Marjorie (30:28):

I'm really happy that you talked about, both the centers, because I think that's really important and that's definitely a place where we can sort of all come together and collaborate and partner up, to make a difference. And I think that that's, you know, what drives us all. So I'm happy, you mentioned that you also sort of have this beautiful website that now has information on pregnancy that's, just out I think, yes. So do you wanna just briefly talk to us about that one, cuz I think that's important.

Monika (31:00):

So they're both, you know, the National Research Center for Parents with Disabilities, as well as the National Center for Disability and Pregnancy Research. They're both funded through NIDILLR, which is, the National Institute of Disability, Independent Living and Rehabilitation Research. And again, this is, you know, funded, even though they're both based in the United States, what we are really trying to do is, and hopefully over time is take the work globally and be more inclusive. And so this time, for example, you know, you know, Marjorie you are involved and Hillier is involved and Maurice Feldman and is involved. And so that's been, you know, we are trying to have a more you know, get out of the United States. For the Parenting Center, for example, we've actually started this consortium of researchers who are working in the area of, you know, to support parents with disabilities.

(31:55):

And that's, I think going to be, you know, I have, I'm very excited about that because it's similar to what I'm trying to, emulate is the SERGE right. But really expand our focus from parents with intellectual developmental disabilities, to parents with all disabilities. But going back to the website, yes, we have two websites and the one with the Pregnancy Center, which is, was just launched two weeks ago or maybe last week. And what we are really trying to do with these websites is what I is really is to inform parents or prospective parents, inform other stakeholders, including child welfare professionals, including advocates, including community organizations that are fighting for rights and, and really trying to, and as well as researchers and multiple stakeholders, and I'm, maybe we are trying to do too much, I don't know, but, we have to start somewhere. And disseminate the research that's ongoing, you know, and we have researchers again, you know, in involved in both centers from all over. And so what we wanna do is really disseminate it's sort of this portal to disseminate our information. So, you know, I welcome feedback. And, and we, you know, we're very excited about it. And I think this is absolutely the first website that I know of, which is really focused on, pregnancy and disabled.

Marjorie (33:20):

Yeah. Right after it launched. I shared it on, my social media accounts. And I have to say that I got so much traffic on that post and comments. People were just, you know, amazed. And when I see people, it's, it's women who have a disability and it's women who are moms. And they were like, oh my God, thank God. Like now maybe there's, you know, a place where we could go or direct sort of our OBGYNs or our healthcare professionals towards. So I think, it definitely has potential for changing the game. So, that's really exciting.

Monika (33:56):

And as part of that, we wanna do trainings and webinars for women with IDD or women with different disabilities, but also for example, maternal and child healthcare professionals, to clinicians, to child welfare professionals. So we are really over the years is, you know, our research, but also thinking about trainings and other types of information to different stakeholders.

Marjorie (34:18):

That's awesome. So it leads me to the last and final question, if you could speak to childcare workers, what is the thing that you would like to tell them?

Monika (34:31):

So, it's a great question. And the one I'm gonna start with, I don't have a pithy one word, one sentence, but I'm gonna start with that disabled people, disabled women live in fear of child welfare professionals. Throughout the work that I've done for all the interviews that I've done, whether it's women with who are deaf and hard of hearing, women who have intellectual developmental disabilities, women with physical disabilities; they live in fear of their children being taken away from them. They feel collectively that they have to be better parents. They cannot afford to have a hysterical child in a mall, a grocery store, which being the parent of two kids, I have experienced, myself, but they cannot afford to have that happen in case a person down the aisle calls a child welfare professional. And so this is really, really important for child welfare professionals to understand, and also at least in the United States that they need to be aware that they cannot use disability as the grounds to terminate parental rights.

(35:48):

And the third I would say is find ways to support parents with disabilities that you're involved with. Don't use disability to discriminate, but use disability to find ways to accommodate, to support, to bring the child and the parent together. So I think that we really collectively, again, and I, this is something that I'm working with Liz Lightfoot on developing trainings, that this is through our National Research Center for Parents with disabilities is trainings for child welfare professionals, that, you know, and, and trainings on disability, trainings on, you know, who are people with disabilities and how do you work with people with disabilities and really about disability rights and disability justice?

Marjorie (36:34):

I think that's, you know, going back to each of us being creative in our roles, you know, we each have a role to play in all of this, certainly as researchers, we need to be creative in finding and making sure that there's representation, you know, of all women, of all parents, cuz it's

Monika (36:54):

All people.

Marjorie (36:55):

Yeah, all people and, you know, workers, that are in the trenches. It's about sort of being creative in finding resources or ways to, to adapt and support. So I think that's a great, way to sort of end our conversation. I just wanted to thank you so much for taking the time today. And for everybody just to know that, everything that we talked about today will be in the show notes and you'll have links to all those wonderful website that we were talking about. So thank you so much, Monika.

Monika (37:28):

Thank you, Marjorie. This was a pleasure.

(37:32):
This podcast was supported in part by a grant from the Minnesota Department of Human Services, Children and Family Services Division.