Marjorie Aunos (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 Hilary Brown. Hilary is an Assistant Professor at the University of Toronto. Her research looks at maternal and child health, with a focus on populations with disabilities and chronic illness. We started our conversation with Hilary telling us how she got into this field of research.

Enjoy! And don't forget, for more information about where to find the full recording and additional resources, check out the show notes!

Hilary Brown (01:12):
When I was, um, an undergraduate student, like many undergrads really had no idea what I wanted to do after my degree. And by chance I ended up, uh, in my fourth year of undergrad applying for a part time job to transcribe interviews for this researcher at Queens University who was completing her PhD and needed some extra help at the time. And that was Helene Ouellette-Kuntz, who's a researcher who does a lot of work around intellectual disability. Um, and I had never heard of epidemiology before.

You know, I, I was interested in public health and health broadly, um, and I was interested in kind of child neural development, um, but hadn't really thought too much about, um, you know, health and well-being of adults with intellectual disabilities until I met Helene. And then working with her, I was just really struck by how our system is so focused on kids with disabilities. And then, you know, services drop off. And then after my master's, I sort of started thinking that I was really interested in maternal and child health broadly. Um, and so I ended up going to Western and doing something completely different, focusing on, you know, determinants and outcomes of preterm birth, which felt sort of night and day from what I had done in my master's.

And then towards my end of my PhD, somebody from Helene's world reached out to me, Virginie, who I think you know, Marjorie, and said, I'm working with someone, at (Chem H) Yona Lunsky who's doing this project on health and healthcare for adults with intellectual disabilities. We have this huge dataset of all Ontarians, all Ontario adults with intellectual disabilities. And we're really interested in how many of them had pregnancies. And she said, I know you have training in intellectual disability from working with Helene, and I know you're doing your PhD in perinatal epidemiology. Would you be interested in doing a postdoc with us? And I remember at the time sort of thinking, wow, that's really cool. Like that really does sort of marry my two interests. But I also had this big fear of they didn't know how many pregnancies there were in the cohort. I did a little bit of Googling and, you know, found the work that you and David McConnell had done on mothers with intellectual disabilities. And I thought, you know, this is neat, but there's so little out there for a postdoc. It felt like a really big risk to be honest, in terms of, you know, what if we only find a hundred moms? And my postdoc project sort of falls through. Um, but it felt so serendipitous that I thought like, I just have to do it. And we got into the data and discovered that we had a cohort of about 4,000 pregnancies over, I think it was about a 15 year period. And we just started looking into things and it kind of grew from there. Um, so it's, yeah, it's sort of interesting how, looking back a lot of those things, like if I just hadn't happened to work for Helene or hadn't happened to, you know, bump into Virginie again towards the end of my PhD, it never would've, um, happened, but it did.

Marjorie Aunos (04:41):

I find that most of the stories of like the journey of what led us there, um, is sort of like a little bit like you, it's, it's not necessary a conscious choice mm-hmm. <affirmative>, but something that led us there. We're very happy that you're part of this community because you do amazing work. Today, you submitted three articles which I think are, like, a great foundation in terms of what it tells us about the situation for moms with all kinds of disabilities. Cuz you touched upon all disabilities, not just intellectual disabilities. So I thought maybe we could start with the first one that talks about the rates of pregnancy, um, and then you can link to the other two.

Hilary Brown (05:21):

For sure. Yeah, and I should mention as well that, you know, after I did my postdoc, which was focused on moms with intellectual disabilities, that was sort of the next step was expanding that work to also include parents with physical and sensory disabilities. And that's been really interesting as well, kind of having this cross disability perspective and working with people from different communities.

So the pregnancy rates paper was one of the first papers that we did as part of a large, um, study funded by the National Institutes of Health to try to understand pregnancy outcomes and care experiences in moms with physical, sensory, and intellectual and developmental disabilities in Ontario. And we wanted to start with pregnancy rates because again, like my own assumptions going into my postdoc, there's been this big assumption in the medical community that perhaps pregnancy is not very common in people with disabilities.

And I think there's a lot of reasons for that assumption, including a lot of the really, you know, kind of horrific, um, historical practices that have been imposed on people with disabilities including, um, involuntary sterilization through much of the 20th century, which, you know, leads to these sort of assumptions and, and preconceived notions about how common pregnancy is. But we really wanted to challenge that and actually look at how many pregnancies there were in the province. And so in Ontario we have access to anonymized health records data for the entire population of residents. So it's a really good way of having sort of a census of, of every kind of measurable health event in the province. And so we took data from, I think at the time it was 2003 to 2018, and looked at pregnancy rates over time in people with physical, sensory, and intellectual and developmental disabilities compared to those without.

And what we really see is that pregnancy rates in the general population have remained somewhat stable and even maybe declined slightly in the last couple of years. But we do see increases in pregnancy rates in people with sensory as well as multiple disabilities over time, which is interesting. Um, we also see that pregnancy rates in people with physical and sensory disabilities are not that different than the general population. Slightly lower, but not really clinically meaningfully so, just a little bit lower. Um, they are somewhat lower in the population with intellectual and developmental disabilities, but again, not uncommon. Um, and what's really interesting to me is that in total, one in every eight pregnancies in the province is to somebody with a disability. Um, and that's been a really important data point for us in talking to physicians because it's, they're always surprised, by how high that is. And that's only among people with, um, diagnosed disabilities. We're only able to capture diagnoses in health administrative data. So that doesn't even count people with either undiagnosed disabilities or, or self, you know, reported disabilities and that sort of thing. So it's, it's sort of the minimum. And so I think it really does sort of lay the groundwork to make this argument that obstetric care and resources for new parents need to consider the people, the needs of people with disabilities, because one in every eight do have a disability of some kind.

Marjorie Aunos (08:54):

I came across well because you, you sent me the articles, that one in eight, and we have been using it in several, uh, conversations with physicians, with prenatal care professionals lately in, in Quebec with one of your postdoc, student, Evelina Pituch, um, that was also on that this podcast. And it's fascinating because the reaction is, is the same every time. What? One in eight? It's sort of like, okay, I guess I better, you know, focus on what, how I can shape my services or my programs or my interventions differently because it will happen. One in eight. It's, it's a lot of people, and like you said, it's the minimum.

Hilary Brown (09:48:

Yeah.

Marjorie Aunos (09:49):

I know that this was done, you know, with a population in Ontario, but we could certainly expect similar results, you know, certainly like across Canada.

Hilary Brown (10:02):

For sure. Yeah. And in fact since then there's been a number of studies that have come out in the states that have suggested similar findings, even survey research. And again, surveys also sometimes exclude people with certain disabilities. So it's also an underestimate. But there's been, um, some recent survey studies as well, suggesting that past year pregnancy rates are pretty similar in people with disabilities compared to those without. So I think there's certainly a growing body of evidence supporting that.

Marjorie Aunos (10:28):

And this is the power of population-based data mm-hmm. <affirmative >. Because previously we, we've done, you know, sort of more clinical samples and this is the power of having large data sets. So that's incredible. You have two other articles that you submitted. I'm curious to see which one you're gonna pick to talk about next.

Hilary Brown (11:01):

As part of this project, again, we wanted to understand health outcomes at a population level, um, and specifically measuring outcomes, um, that are indicators of,kind of, the health of the healthcare system. We know that in industrialized countries, severe maternal morbidity and maternal mortality should be preventable, largely. And they're really important indicators of population health for that reason. Um, severe maternal morbidity is sort of, you know, life-threatening pregnancy complications that are along the spectrum that could have led to death had there not been a successful intervention. Um, so although these outcomes are rare, again, because they're avoidable, they're really important to consider, um, and to understand whether there are disparities in, in certain populations. Um, so that again, was one of the first papers that we, um, did from this project to try to understand. Again, because we have this really novel resource of population-wide data where we have the power to look at these rare but serious outcomes, kind of what the disparities would be.

Um, and so we looked at, uh, severe morbidity and mortality both in pregnancy and within the first year postpartum, again, across those groups with physical, sensory, intellectual, developmental, as well as multiple disabilities. And we do see important disparities between those groups and people without disabilities. Um, the largest disparities were for people with intellectual or developmental as well as multiple disabilities. Um, but the, the disparities for all groups did persist even after accounting for things like sociodemographic characteristics and underlying chronic, um, illness. Which again suggests that, you know, whatever risk is left, there perhaps is some kind of, um, modifiable, uh, you know, healthcare types of interventions that could be helpful.

Um, the other kind of important takeaway point from that study was that risk was elevated not only in pregnancy and immediately after pregnancy, but also up to the end of the first year postpartum. Um, and this is really important because typically, in Canada, at least, if you receive obstetric care from a physician, your last, um, official kind of maternity care appointment is at six weeks postpartum. And after that, you're considered to be physiologically and psychologically recovered, which of course we know now, um, is not necessarily the case. Um, and indeed, we, again, we do see these risks kind of persisting beyond that point, uh, for people with disabilities. And so I think what that really suggests is that having just a six week postpartum visit is not adequate for this population. Um, and that they really could benefit from kind of longer term care.

It's really interesting because around the time that we did this study, there was some work being done in the US to extend health insurance beyond that six week postpartum period to the end of the first year postpartum. Again, recognizing that people's needs do extend beyond kind of immediately after giving birth. And so it's interesting kind of juxtaposing that policy work kind of south of the border with what we're seeing here in terms of, you know, people having elevated risk of severe complications and mortality kind of to the end of that postpartum year. Again, it does suggest that more could be done to support people kind of longer term after they have their babies. Um, and again, just to emphasize, of course, these are rare outcomes. The vast majority of moms, whether or not they have disabilities, don't experience this kind of, you know, life-threatening pregnancy complication, but it's just the disparity that we see between the two groups. That's important.

Marjorie Aunos (15:02):

Yeah. And I hope that this, you know, can be used to talk to, you know, each provinces and sort of go to the health ministers and sort of, you know, mentioned that, um, maybe there is something that we could do in terms of organizing services or having sort of that network around women who need it during that time.

And the third one is on prenatal care. So it sort of links perfectly with what you just mentioned in terms of some of these things are preventable and prenatal care might be one of the solutions or one part of the solution.

Hilary Brown (15:46):

In terms of the administrative data, we have these kind of broad markers of being able to measure prenatal care adequacy. And what we do is we look at the timing of the first prenatal care appointment and the number of prenatal care appointments that were received throughout the pregnancy. And we compare these to the guidelines that are put forward by the Society of Obstetricians and Gynecologists of Canada. And based on, kind of, an algorithm that looks at that number and the timing, we're able to, uh, consider whether people have inadequate or adequate, uh, prenatal care relative to guidelines.

Um, and so one of my master students, Fariha for her, uh, MPH project, she looked at prenatal care adequacy across those disability groups that we've been talking about. Um, and it's really interesting because what we see is that people with intellectual and developmental disabilities tended to enter prenatal care later than their peers and receive fewer than the recommended number of visits. Um, and I think this fits with what we see from prior literature of just some of the barriers that that population experiences. Um, you know, even things as simple as recognition of pregnancy because of a lack of sexual health education. You hear, um, kind of qualitative studies about people not recognizing they were pregnant until later. And I'll talk about this in a moment, but also, uh, from our own research, we've also heard lots of stories of people being very fearful of accessing prenatal care because of prior involvement with child protective services.

And so I think there's a number of different layers and systemic issues that act as barriers, but we do see it kind of come through at population level. Um, for the other groups with physical, sensory, and multiple disabilities, um, differences between groups were much smaller, and in fact, some of them tended to have, um, sort of super adequate or, or more than the recommended number of visits, which in itself is also interesting because it suggests that perhaps there is some, um, surveillance of those kinds of pregnancies, perhaps an acknowledgement of, um, an understanding of elevated risk of pregnancy complications. But what the data don't tell us anything about is the quality of the care. So we know they're getting more quantity, um, but not necessarily what the quality of that care, uh, is. And I think that's where the qualitative piece of the data is really interesting. So if it's okay, maybe I'll kind of put in a plug for some of Lesley's work. I know you're talking or you've talked with her as well. But the other half of this, uh, NIH study was, um, a qualitative investigation that Lesley Tarasoff led looking at interviews with people with disabilities and healthcare providers about their pregnancy care experiences. And it was really, really fascinating kind of seeing how those interview data complemented what we were seeing at a population level. Um, and we heard lots of stories of, you know, barriers accessing care in terms of the physical inaccessibility of the care environment, you know, not being accessible to mobility devices. We heard about communication barriers for people with sensory disabilities, um, as well as intellectual disabilities, um, and then negative healthcare provider attitudes about disability and pregnancy. Um, and I think when you put those stories together with what we heard from healthcare providers of their own lack of resources and training, many of them really wanting to do a better job at just not having, you know, the, the toolkit, uh, to do it. Um, and that together with the population-based data, I think it really shows that there's a lot of need for improvement at a system level.

What we heard from a lot of parents as well as professionals, is just the need for multidisciplinary care. And it's not just within the healthcare system. Like we heard a lot of stories of, oh, you know, I wish my obstetrician had talked more to my rheumatologist. That was part of it, but what about your obstetrician and your rheumatologist also talking to your social worker or your housing coordinator or, you know, whatever the case may be. So I think there's a need for bridges not only within the healthcare system, but also between the health and social services system. And that was particularly true for the parents with intellectual disabilities that I think really could have benefited from just better coordination of kind of social supports that would've made their pregnancies a lot easier.

Marjorie Aunos (20:45):

Yeah. I remember one case where this mom was pregnant, I think six months pregnant when we found out. And you know, her, her mother kept saying like, well, she can't be a good mom. I mean, she, she didn't even, like, notice that she was pregnant. And when I talked to this, this mom or this future mom, she said, well, the last two pregnancies she told me to abort and we ended up, you know, sort of aborting. And so I knew that if I wanted to keep this child, I needed to hide it as long as I could. So that I would be too late for an abortion. And so I think your data compliments sort of what we see in practice and what we can see, you know, happening. And, and because they make that choice or because they end up sort of delaying the time that they disclose or find out that they're pregnant, they're missing out all the prenatal care that are, that is necessary. And that has an effect on their health and the health of the baby potentially.

So, amazing data. Now I know you're also a very busy lady, because you, you keep looking at new data, uh, you keep looking at the frontier and like getting us sort of like closer to, um, new groundbreaking information. So I'm curious to hear from you, what you think the research world and potentially the clinical world needs to go.

Hilary Brown (22:20):

Yeah, good question. I think, you know, we started this project, um, in 2017, so it's been, you know, five or six years now. And over that time there's been a lot of really similar parallel work coming out of the United States and other places that has been remarkably similar in terms of, you know, regardless of the health system, we're seeing the same health disparities, we're seeing the same stories. Like the exact same barriers, um, that we've reported on others, um, of our colleagues have reported on in other areas as well. And so I sort of get this sense that we've kind of almost done enough disparities research at this point. Um, I think certainly replication is always helpful in terms of building that body of evidence, but now I think the question is more: what do we do about it? Um, and so I think the important areas going forward will be, you know, the research on, um, toolkits to help healthcare providers, healthcare provider training and education, um, resources for parents themselves. Because often we hear of, you know, I was pregnant, and I was looking for all this information on how pregnancy might impact my disability or my disability might impact my pregnancy. And so I think developing those resources and making sure that they're evidence-based and tested and appropriate will be important.

Um, because it's one thing to identify disparities, but then you have an obligation, I think, um, to address them. So I think that's a really important area. I think another really important area that's, um, starting to be looked at in the States as well is, again, I guess more focused on disparities, but, um, from different angles. So understanding intersections of ableism and racism, for example. There's some really neat research coming out of the United States on that. And I think that's really important because again, those resources and interventions that we might develop, I don't think those are a one size fits all kind of piece either. I think there's a lot of heterogeneity within the population that needs to be acknowledged, and diverse community perspectives that need to be, um, drawn upon as well. So I think that sort of, um, intersectionality type of research is gonna be really important as well.

Marjorie Aunos (24:43):

Yeah, definitely. Um, the toolkit is definitely something that, for me, who's a clinician at heart or at the beginning, certainly, think that it's, it's what people need and there hasn't been much that was created. So using or having tools. The training is always tricky cuz you know, the training doesn't necessarily change attitude. So to link it to like, yeah, you know, ableism, racism type of information and, and sensitization I think is definitely necessary as well. So those are great, um, great ideas for the future and future researchers and, andI look forward to seeing what you do cuz you are able to bring us, you know, to the next step every time. So, it's fascinating to see. And what is also incredible, which I think is, represents, a little bit who you are, uh, is that you always find incredible partners to work with you. And I think that's a great reflection of who you are as a person and as a researcher. So I thank you very much for taking the time today to talk with me and to share about your data and about the field and, and what you are doing. So thank you so much.

Hillary Brown (26:04):

Thank you.
New Speaker (26:08):
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