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 Lesley Tarasoff. Lesley is a Postdoctoral Research Fellow at the University of Toronto. Her research focuses on the reproductive and perinatal stages as experienced by women with physical, hearing, vision, intellectual, and neurodevelopmental disabilities and sexual minority women. We started our conversation talking about the barriers to prenatal care for women with physical disability.

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

Lesley Tarasoff (01:20):
So the title of this paper is *We Don't Know, We've Never Had Anybody like You before, Barriers to Prenatal Care for Women with Physical Disabilities*. And this quote of, we don't know, we've never heard, or we've never had anyone like you before, was from one of the participants who went, you know, she was pregnant and she had a physical disability and went to the doctor and they didn't really know what to do with her cuz they hadn't <Yes> seen or, you know, cared for someone with disabilities before. And a number of participants had similar experiences of being kind of the only one that their provider had encountered.

This has come up a lot that most providers do not receive any training around disability. And so it's not surprising and very unfortunate that, you know, we haven't seen anyone like you before cuz they don't, you know, have the education and training around disability, just in general. So many things about disability, you know, there's so many different disability groups and different needs that people have, but also, um, understanding how different disabilities might impact pregnancy or pregnancy might impact disability. So there's a lot of education and training that needs to happen. Um, and that was a common theme in this one paper based on my dissertation data, how many of the women of physical disabilities encountered providers, either when they first announced they were pregnant or wanting to become pregnant, negative attitudes from providers kind of surprised, um, that they were pregnant or wanted to be pregnant, or did they wanna keep this pregnancy, you know, was it a wanted pregnancy? And we know there's so much research and things around women with disabilities experiencing high rates of sexual violence, but there's actually women with disabilities who, you know, are in sexual relationships and want a pregnancy and plan a pregnancy. Um, so a lot of, you know, stigma and myths to bust there around, um, negative attitudes.

And then participants in my PhD work and also postdoc work, too, talked about how there was a real lack of communication and collaboration among care providers. And this I think again relates to lack of training and education around disability and pregnancy. So someone's obstetrician, for example, somehow missed the importance of also talking to someone's rheumatologist and/or another disability related care provider and how important, you know, having those connections and communication across providers is so important. And, um, I think this is especially true for women with physical disabilities or if they have other complex health needs or they have diabetes or something else. I think women who are born with a disability or have a disability for a long time and throughout their life, you know, they're seeing a certain type of provider and then they become pregnant, maybe let's talk to that provider who knows them and their body like this is important.

And then related to that, several participants talked about misunderstandings about disability and disability related needs. So making assumptions about certain types of disabilities or sort of thinking two types of disabilities are the same, or even not acknowledging the diversity even within a disability type. So someone with cerebral palsy, you know, that could be a range of experiences and function. And also just assuming that, certain aspects of disability are more important or relevant. So, um, providers really worried about falls or worried about certain things, but not paying attention to things like fatigue or chronic pain.

So just not really having a nuanced understanding of disability. And I think in turn, failing to really ask people with disabilities, you know, what's your main concern or what should we be worrying about? It's all sort of wrapped up in providers not having a lot of education and training around disability in general, and then disability and pregnancy and then just sort of the larger system not being set up for people with disabilities in mind. I remember telling someone, I was doing research around pregnancy and motherhood and disability, just kind of looked at me in this puzzled look and said, oh, I never really thought about a woman in a wheelchair could be a mom. Like, it just isn't on people's radar. Right? <Yeah.> Like the system, the pregnancy care system, even, you know, daycares, playgrounds, like, they're not really set up for parents and people with disabilities. So people I think, and even when I talk about the work that I do, sometimes people still kind of pause and think like, oh yeah, like they can be a parent, too. <laugh>. Yeah. So, yeah.

Marjorie Aunos (05:52):

And it's also sort of like not understanding what that means and the accommodation needs mm hmm. <affirmative>. I was talking to another mom actually this week who is also in a wheelchair and she was saying, oh yeah, we waited two years to have a park that is adapted, near my house. And she said, oh, they put a beautiful ramp, but at the end of the ramp there's like wood chips. And so she says, like, there's no way I can go anywhere. So the ramp does, it's, you know, useless. Yeah. But it's sort of that understanding that there is no understanding of what <affirmative> exactly is needed for, for each disability or for each person, and that that might be very different from one person to the next.

Lesley Tarasoff (06:41):

Mm-hmm. <affirmative> and how it really, like, excludes parents from disabilities from being involved in their children's lives. So I had similar stories of playgrounds being inaccessible, how sidewalks aren't shoveled with snow. How, you know, I can't go trick-or-treating with my kid, or go to the door cuz they're stairs or I can't go see my children's art in their classroom cuz the school isn't accessible. Like so many of these stories of that's just physical accessibility, but like so many ways that spaces are not set up for people and parents with disabilities.

There's a quote, I don't know if I'm forgetting her name now, but I, I think I cited it in my dissertation, but it was, it's probably like 20 years old now, but someone who said, you know, it's as if people have children with disabilities and then they kind of like fall off the earth. It's like we forget that they grow up. So there's so much, I think still so much more attention around children and youth with disabilities, but then we forget that they grow up and maybe wanna have a family of their own. So we, yeah, that's, it's just something that has stuck with me for so long.

Marjorie Aunos (07:48):

The theme of communication actually comes back in another of the three articles. So we're talking about barriers to and facilitators of effective communication in perinatal care.

Lesley Tarasoff (08:02):

Mm-hmm. <affirmative>. So this paper was led by a master's of public health student a few summers ago. And I worked with her. So this, this was drawing on some qualitative data from the larger study that I'm working on with Hilary Brown. And, um, this particular paper we looked at the participants who had intellectual and developmental disabilities as well as those with sensory disabilities. So those who had, were hard of hearing or deaf or blind, to really look at how, like, the importance of having good communication in their pregnancy care encounters.

And I think, you know, some things we found are not very surprising. So there's just a lack of resources around accessible care. Many providers just don't know the different sort of communication accommodations or needs that people with disabilities have, or they just make assumptions or often I think put the burden on the individual person with a disability to make sure their needs are met. So, you know, people, sometimes people need an ASL interpreter and that's not available. So, and people feeling like they can't access certain services or engage in certain things like prenatal classes because they're not accessible. There isn't an ASL interpreter or there isn't technology or something else that would aid them in being able to participate. So some people just don't participate or they have to, you know, spend their own money to be able to participate. And then, healthcare providers just not having experience around meeting communication needs.

So a lot of unfortunately like barriers to effective communication really on the provider front, but also I think the larger health system or institution, again, not recognizing that these are people who become pregnant and are parents in need, these needs met.

But then we did find, um, you know, some examples of providers who were knowledgeable or, you know, were willing to learn about how to make sure their patients with disabilities needs were met. So really, you know, advocating to make sure they had an interpreter or some other sort of resource to make sure they were able to communicate. And I think just taking, again, the time to listen and get to know participants, especially those with intellectual and developmental disabilities. Like giving that time and maybe more appointments or longer appointments to explain things or to use pictures or do things in different ways than you might to someone who didn't have a disability. Um, yes. Yeah, I think just, just taking the time, more simple instructions.

So one thing participants with intellectual and dis developmental disabilities talked about is healthcare providers using medical jargon and know these big words. So that was something, a barrier. And sometimes this doesn't, this isn't happening even in Canada where we have some, you know, legislation policies around equity and accessibility and language and it's just people's needs are not being met. And it's resulting in really horrific and I think traumatic experiences for some people. There's a participant in this study who is deaf, and she had twins and unfortunately one of the twins was born stillborn. I can't remember, I think we have this quote in this paper. But what happened was one of her twins was born stillborn and there was no ASL interpreter in the room. So it ended up being this emergency C section situation, you know, both babies were delivered, but one of them was stillborn and there was no interpreter and there was, you know, a flurry of activity. <Yep.> And it was, unfortunately, her husband had to sign to her D- E- A -D that her baby had died. And I just like, this story is gonna stay with me forever.

And I just, you know, I was, I was in this woman's living room, with her and one of my peer researchers and the ASL interpreters and she's telling this story of how, you know, this is supposed to be this amazing experience, you know, having twins and first of all it was just a flurry of activity and then ending up to have a C-section earlier than anticipated. And then her husband sort of had to rush from work to get there and they get there and there's no interpreter. And then one of the babies is stillborn. And having, you know, that burden on her partner in that experience, you know, in that flurry of activity and experiencing grief himself and have to sign to her that one of the babies has died. It was just like, how horrible is our system that that partner had to be put in that situation to communicate that. And, you know, there should have been an interpreter from the beginning and many participants talked about, you know, like there should be an interpreter in every appointment throughout pregnancy, especially in labor and delivery when there's so much going on. Um, you know, to be able to communicate your needs or understand what is going on. Not knowing what’s going on.

I just…the communication part is so important cuz it can make an experience that is incredibly hard, even harder, um, when those needs are not met. And similarly, like a participant, who was blind to, she had a number of children and after she had lost one child when she was pregnant again, she was in an ultrasound appointment for this next baby. Like usually an ultrasound tech isn't supposed to tell you too much information, but she really wanted some description of what the baby, the next baby, you know, growing inside of her look like, what was going on. And, you know, she couldn't see cuz she was blind and so she wanted some information just so she could, you know, feel okay about this baby and just not having that communication is, yeah. It was just, like, really hard for her.

And again, in that situation, her partner was in the room so she could ask, you know, is there a foot? Is there a hand? Those sorts of things. But not having that communication and understanding for that person, because of their previous experience losing a child and also, just because she was blind, like more communication needs to happen to just tell people what's going on. You know, she can't see the screen for the ultrasound. <Yeah.>

So that the communication piece, and I think it, it's really, it's rooted in around, like, respectful maternity care and having, you know, all the information you should have and being able to make decisions together with your care provider. But if you're not even communicating information to someone, how, how is that happening? How are you having exactly a good respectful care experience? So the communication piece is so big and I think for people with disabilities it's one, having communication needs met, but also having providers who can really like slow down and take the time to get to know the person with a disability and, you know, maybe have an extra appointment or have longer appointments, get to know them and figure out what their needs are and how to best communicate so they understand and feel like they're, you know, part of that care experience.

Marjorie Aunos (15:06):

Because in what you're saying, definitely, you know, being part of your own care experience is really important, for several reasons. But if we were to look at it in a very medicalized way, it is also sort of like so important cuz it affects sort of the outcomes. Yeah. Like it affects sort of like the future treatment that may be needed or it affects, you know, when the baby comes out and, you know, something happens like you mentioned. And so there is the experience and then there is also sort of like what, what comes out of that experience and the, the potential risk if we're not communicating properly, basically.

Lesley Tarasoff (15:52):

Yeah. Like we don't, unfortunately. So for a lot of the health outcomes data, we know that, you know, women with all types of disabilities unfortunately have, you know, higher risk for a number of pregnancy delivery and postpartum health complications. And then our qualitative data really kind of provides some context about not great care experiences. And we can't say directly, you know, bad care equals bad health outcome. But I think we can, I think in some situations, not having a great care experience may contribute to some of the poor outcomes that some women with disabilities experience or it could have health implications for mom and baby down the road. So if I didn't have a good care experience, maybe next time I'm going to avoid accessing care or I'm gonna access care later, or. I think it can have a real, there's real health implications if care isn't good and if, if needs aren't met.

For example, there was, um, I know one participant with an intellectual disability who had some involvement with child protective services with her previous children. So for her most recent pregnancy, instead of, she really wanted to have, first of all midwives, but she didn't wanna have a birth in hospital cuz she was scared that having a birth in hospital would sort of flag, you know, child protective services. So there's things like that where people are like choosing to have care in certain ways because they're scared of, you know, they might be judged or having a bad experience. And like I said, there's some evidence that I think some people with disabilities are avoiding or delaying care because of previous bad experiences or perceiving that they could have a negative care experience.

Marjorie Aunos (17:42):

The third article that you submitted, do you wanna talk about this one? It's more of population based data?

Lesley Tarasoff (17:50):

Yeah. Yeah. So this is a paper, um, that I worked on with Hillary Brown and really her and others who have more quantitative research experience did the analysis. But I led writing up this paper and it's a descriptive paper looking at the preconception health characteristics of women with disabilities in Ontario compared to women without disabilities. So, when we talk about preconception health, we talk about, sort of, the health of all reproductive age individuals.

So we know that roughly about half of pregnancies are unplanned. And we know that your health before you become pregnant is important because it could affect your health during pregnancy and pregnancy and birth outcomes. So knowing, sort of, your health when you're a reproductive age is important. And I think, for people with disabilities even more important because there is literature showing that for women with disabilities they're at greater risk, um, for poor physical and mental health. So higher rates of things like obesity, asthma, diabetes, um, more likely to smoke, less exercise, poor mental health in terms of high rates of depression, anxiety, things like that. So all these things, we know are known risk factors for pregnancy related health complications.

So we looked at how we defined reproductive age from age 15 to 44, and we compared women with physical disabilities sensory. So again, women with low vision or blind or deaf or hard of hearing or hearing loss, intellectual and developmental disabilities including autism. And then we had a multiple disability group, and then we compared that with women without any of these disabilities in Ontario health records data. And so what we found and, and what we found is really similar to research in the US, is that women with disabilities across disability groups had poor preconception health compared to those without disabilities. So, they were more likely to have a number of chronic health conditions, such as diabetes, hypertension, asthma, as well as higher rates of mental illness. So they things, like mood and anxiety disorders as well as substance use disorders. We also found that they had higher rates of experience, a lifetime history of assault. And I think this is one thing that's probably underreported in the data. So this is health records data. So this is what's documented in, you know, when they go to their doctor, or an emergency department visit. And this is counting, you know, experiences of abuse or assault. But these are probably, underreported, as well as higher rates of medication use, medications that are known to cause birth defects. And, you know, people with disabilities use different medications for a number of reasons. And particularly what we found of all the disability groups for all of these different preconception health outcomes around physical health, mental health, abuse or history of assault, that those with intellectual and developmental disabilities and those with multiple disabilities were particularly at risk. And those with intellectual and developmental disabilities were also found to have, I guess, more risk or were more likely to experience socioeconomic marginalization as well. So on top of a number of, you know, health risk factors, they're also lower socioeconomic status compared to all the other disability groups. So again, these findings for us weren't very surprising. They're pretty consistent within the US, but I think it's important to know that, before pregnancy often many of them experience poor physical and mental health. And that these are things that are important to think about if they decide to become pregnant or parents.

And so being proactive about their health ahead of time is important, but I think we need to really not always, you know, put the onus on individual people with disabilities. So there's some things, um, you know, that are social structural, like why are rates of mental illness or chronic physical health conditions more prevalent among women with disabilities? What are, are, you know, what types of services and supports do we need to put in place to ensure that, you know, they're healthy throughout their life, but also if they wanna become pregnant, how can we support them? And I think Hilary's found this in some of our other work that we, there aren't a lot of preconception health interventions or, you know, supports and programs that include women with disabilities. So there's preconception health interventions, for example, for people, who have diabetes or they're sort of chronic health conditions, but not really around disability. So again, this is an area, you know, even before pregnancy, we're not really thinking about women with disabilities becoming pregnant or being, you know, part of that pregnant population.

Marjorie Aunos (22:50):

Exactly. We're not talking about it. There's also a whole lot of lack of information, um, you know, that they, that they don't receive basically. <Yeah.> And that it makes a big difference.

Lesley Tarasoff (23:02):

That's some of the things that we wrote about in the discussion of this paper and some more recent work that I'm working on now. Kind of the reproductive life plans of people with disabilities. So I've interviewed a number of women with disabilities, a range of physical disabilities and intellectual and developmental disabilities, asking them, you know, about their reproductive health generally as well as, you know. Do they have plans to become pregnant one day? You know, what are they thinking about? Are they not thinking about what, what might be barriers for them to be thinking about pregnancy or being a parent? And this, this has come up that, you know, they haven't received sexual health education that's specific to disability or, you know, when they go see their doctor, their doctor isn't asking them about birth control or not just not giving them a lot of information or considering that, you know, family planning or having children in the future is something to talk to them bout.

I asked them, has your doctor talked to you about preventing pregnancy or maybe being pregnant one day? And, you know, those aren't conversations that are coming up. So I think, yeah, there's definitely a gap there. And again, I think it relates again to healthcare providers, you know, biases and assumptions and just lack of education around disability and pregnancy. And that, you know, when they see a patient with a disability, they're not thinking about this is someone who might wanna get pregnant or have a family one day. We're focusing more on disability related things and maybe that's not why they're coming to see you today, but, there's assumptions about, you know, who they are and what their life might be like.

Marjorie Aunos (24:38):

And I find also, those are potentially linked to poorer outcomes, you know, as we discussed earlier. And, when there is issues in pregnancies or in birth and so forth, often what comes out is blaming sort of the, the person, the mom with the disability for not having, you know, prevented this or for not being a good enough mother. We have research that have demonstrated that, but it's really looking at it in a different perspective where it might not be the fault of the mother with the disability, it might be sort of the system making it <mm hmm.> That she's lacking information, lacking in, you know, support or not being able to communicate with her providers, not understanding what they meant or, you know, what she was supposed to be doing to mm-hmm. <affirmative> to protect her baby. And there's so many other factors, obviously, but it's good to know all of these research data and findings to be able to, to look at the situation differently.

Lesley Tarasoff (25:48):

For this study that I work on with Hilary, we have a new advisory committee that includes about 30 people, including many women with disabilities. And a number of them are mothers, and I think one of them is actually a grandmother now. So they're, you know, sharing their own experiences. And then we also have some people who work for different disability community organizations and really stressing, you know, even how we write about the healthcare outcomes data, how we write about like, this isn't the fault of individual people with disability, why these outcomes might be the way they are. There's number of system and, and other things that are contributing to why, you know, people with disabilities have low socioeconomic status or why they might have poor mental health.

Like it's not, about disability specifically. There's other kind of social determinants of health and other things to think about that might be contributing to poor health outcomes. Um, so I think that's so important. And I think we're working on so much, even how we write up our papers, thinking about the language that we use and that we really situated in all these other kinds of larger systems and structures that it's, again, not on the individual person with a disability.

Marjorie Aunos (26:58):

If we're looking now towards the future, do you have an idea of where the field should go or, or maybe what, you know, you would like to be able to touch upon research wise? To advance the field.

Lesley Tarasoff (00:46:37):

<affirmative>. So I feel like this sounds like a funny comment to make, but I feel like I don't need to talk to any more moms with disabilities to hear about the barriers there. Of course, people's lived experience and their stories are so important and powerful, but like, how many more stories do we need to hear that there's barriers and challenges? So for me, and one of the, some papers that I'm working on right now are looking at the provider perspective. So one paper I'm working on is around how a lot of providers just didn't receive a lot of education and training. So, like, to address that, that gap. <Yeah.> And hopefully we'll have some research moving forward that really can fill that gap and add more disability content into, you know, medicine, nursing, midwifery, social work, education. Because that's, that's really missing. And I think, in many, you know, health and social service provider training programs, there's more of an emphasis on equity, diversity, inclusion, you know, we're hearing about this all the time. And I think there's a lot of, and I've said this in a number of presentations and things now, I think there's more and more attention, which is of course important and great around anti-Black racism. Indigenous and first nations people in Canada, around LGBT communities and sexual and gender minority people. But disability is still not really in there a lot or isn't talked about a lot or included. But we know many people in Canada and elsewhere have disabilities. And in our work we know pregnancy is actually becoming a bit more common in women with disabilities. So having more of that disability content in education and training is so important.

So I think that's like one area that I hope to get into more sort of the intervention and how do we educate providers and make sure they're getting some disability training. And not only, um, educate, you know, trainees who are going through their program, but also continuing education cuz there's people, you know, practicing right now who need this education.

And then a little bit more kind of on the other side, and I talked a bit about preconception health. So talking to women and people with disabilities about, you know, what's informing their decisions about becoming pregnant and having families, what are, like, the barriers that they encounter? And I think a lot of it, like we've talked about is, is about a lack of information, a lack of support, and people just feeling, you know, unsure of, can I do this? Because there isn't a lot of information and support. So kind of understanding people's decision making around having families and not is something I'm interested in.

I've been doing this research for over a decade and hearing the same stories. Like there are some really great programs and initiatives that are happening. So at Sunnybrook, <yes> in Toronto there's the accessible care clinic and Anne Bernal who runs that clinic is doing some really great work. And I have some colleagues in BC, at BC Women's Hospital who have a good program there around women with complex cases including women with spinal cord injury. So I think there's some clinical programs that get it and are, you know, tailored to women with disabilities, but those are only a few in some larger centers. Like we need more education across the board in terms of integrating disability into obstetrics, midwifery, nursing. Um, so that's what I would like to see moving forward, that we were getting to a place where disability is included more in the conversation around diversity and equity and inclusion.

Marjorie Aunos (30:41):

And what I love about you going to get the perspective of the providers and the professionals, is that you're basically sort of saying like, there's no bad guy here. Right? Like, we each have our own perspective mm-hmm. <affirmative> and we each sort of have our own needs in this. And, and for providers, for professionals, well it is to getting informed and getting that information so that they offer better quality care for their patients. And I'm pretty sure, you know, I could assume that all of them or a lot of them did not enter their profession thinking, oh, I'm gonna sort of, like, avoid touching a certain percentage of the population. Like they wanna do a good job mm-hmm. <affirmative>. And so, you know, understanding that getting the training because this is happening and there are parents who have disabilities every day that give birth so they need to get that information for themselves.

Lesley Tarasoff (31:49):

And I think like it's sort of the papers I'm working on are, not that they're biased, but I talk to people who already, some providers who are already providing care to women with disabilities or they sort of get it. So again, there's a whole, whole slew of providers who don't do this work or don't really think about it, but those who are doing it, many of them didn't get training around disability, but through their own training or practice recognize that this is a gap, this is a population that, that needs support and needs care. And, you know, they kind of took it on themselves to learn about how to do this and, you know, work respectfully with people with disabilities, ask some questions, take more time. And they recognize sort of kind of the next level, the institution structural barriers that healthcare system isn't really set up for patients who have more complex needs and need more time. <Yeah.> So I think a lot of them are sort of educators and advocates in their own way, and that's really great to have those champions, but I think we just need more of them.

Marjorie Aunos (32:47):

Yeah. That's awesome. So most of the listeners of this podcast come from the child welfare system. So the last question that I ask is basically if there was one thing you could tell childcare workers or child welfare workers, what would that be?

Lesley Tarasoff (32:53):

Oh gosh. This is also like another, I guess future area, like in terms of educating providers, social workers and child protection workers need a lot of training around disability. I guess the number one thing is like, don't make assumptions about what people can and can't do. And I think some of the women and parents with disabilities I've talked to. And I think this has been really reinforced for me as a new parent, is like, we don't parent independently. So like interdependence and relying on other resources and supports are okay. So I think people and parents with disabilities get judged more because they need help, but like, we all need help. Like, my son's at daycare right now, like, I need help. <Yes.> Or I need my partner's help or so like this, this acknowledging that like this, it takes a village and interdependence is normal and important and we shouldn't judge people and parents with disabilities because they need more help. Or maybe they need help in a different way. You know, I can't, you know, if you have a physical disability, you might not be able to do certain things with your child, but that doesn't mean you're not a good parent or you can't do these other things or have this emotional bond with your child or, you know, children adapt. And, and I know you know this from your own experience. So I think acknowledging the value and importance of interdependence is something that social workers and childcare workers and child protection workers really need to understand because again, like I said, I think parents with disabilities get judged more harshly for asking for help. And when like they legitimately might need help, but then they might be scared to ask for help because they're gonna get judged. So it's kind of this catch 22, this cycle that doesn't benefit anyone. So I think acknowledging the importance and the reality of interdependence for all parents is so important.

And we need to kind of think about parenting differently after, you know, talking to many parents with disabilities. Like we, why are we so hard? Like even if you don't have a disability, like moms or parents are so hard on, like why are we doing this? It's not benefiting anyone. So, if there are supports out there that it's okay to access them and like this is helping the entire family when we're able to access more supports to, you know, raise our children.

Marjorie Aunos (35:12):

Yeah. One thing as you were talking that came to my mind is also we sometimes underestimate the bond and the connection that a child will have with their parents. <Yeah.> A child who is being raised by a parent with a disability may learn to be more patient mm-hmm. <affirmative> to get the bottle and so won't react the same way as another child who is used to having the bottle very quickly when, you know, they start fussing a little bit. And sort of that connection between, you know, that relationship, that teamwork between the parents and the child is also very important mm-hmm. <affirmative>. And so I just thought of that as you were talking, you know, the interdependence, but also that relationship with <Yeah.> With the child is very important.

Lesley Tarasoff (36:05):

I just wanted to add to that. It just reminded me of some of the mums I talked to with physical disabilities for my PhD work about how children adapt. They taught me so much in terms of how their children see the world and how their children would point out inaccessibility. I remember this one mom talking about how her son was like five or something and wanted to be an engineer and like change like the transit system to make sure it was more accessible so her mom or their mom could access, you know, like kids become more patient or like understand difference in a different way when they have a parent with a disability. I think, like, we can all learn from the children of parents with disabilities how to be more patient and, and, like ,see the world in a different way <Yeah>. And more creative and how they play and how, you know, just so many things. So that was, that was really important to me and how people talked about, you know, those children, I think see the worlds in what, like, a better world should be, that is more accessible and being more creative and patient. Yeah.

Marjorie Aunos (37:08):

I was smiling and laughing as you were telling your your example because this is exactly what my son wants to be–an engineer and he's creating, like, he has 3D printers and does like a whole bunch of different things, but I, I always have beside me, his Lego wheelchairs that he's had and I have like a series of them right near my computer because when he was, yeah, I don't know, he was four, five, you know, playing with Legos and he couldn't understand that his Lego didn't have a wheelchair. And so he created taking the wheels from, like, cars and stuff and, and created his own, because to him that was like, just something that was part of normal and you made it accessible and the big wheels to go, like, over the bumps and he had like an idea.

And so yes, our children, you know, react to their environment and they learn from that environment and can create. And it's pretty beautiful to see. Mm-hmm. <affirmative>.

I wanted to thank you for taking the time to introduce us and present us those three beautiful papers and the research that you do. I also wanna thank you for the advocacy in some sense that you, that you've done all of these years and you continue carrying, your voice. I see you on, on Twitter always sort of announcing, like, new research data and making sure that, at least on your end you are definitely trying to disseminate the information. And I'm grateful to you for that, so thank you so much.

Lesley Tarasoff (38:50):

Yeah. Thank you for having me and thank you for your work and I'm so glad that we're now connected.

New Speaker (38:59):

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