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 Laura Pacheco. Laura is one of my closest collaborators. We met about 18 years ago when she joined my team as a social work student. We connected over our passion to advocate for equity and justice for the moms we serve. Laura shares about the different parts of our identity that are bringing on stigma and how that might lead to several disparities. Enjoy. And don't forget, for more information about where to find the full recording and additional resources, check out the show notes.

(01:20):

I met Laura in a very, very small office that was mine for a long time in a rehabilitation center, and she was coming with one of my dear friends who is a social worker and who was going to be her supervisor. And Stephanie, my friend, was super excited to introduce me to Laura because Laura had said that she wanted to work with parents with intellectual disabilities. And of course it had been a couple of years that I had started the program with Stephanie to support moms with an intellectual disability at the rehabilitation center. And so we were thrilled to have a third person join in, especially a person who was as excited about this work, who felt advocacy was necessary, who felt a very strong sense of social justice to be had and to be worked towards. And so I am thrilled to introduce and welcome Laura Pacheco who was an estagiere, an intern who then became a social worker as part of the program, who then became a very, very good friend of mine and my partner, I mean, we're partners aren’t we, Laura?

Laura Pacheco (02:43):

We are partners in, we partners in crime and research.

Marjorie Aunos (02:47):

Yes, we've done this for a long time. We've known each other now for a long time. I think 15 years.

Laura Pacheco (02:55):

I literally calculated that this morning. Yes, since 2007.

Marjorie Aunos (02:59):

Wow. Oh, so it's really 15 years.

Laura Pacheco (03:02):

It's literally 15 years.

Marjorie Aunos (03:05):

And it's like, I don't know, it's been more years or it feels like it has been because we know each other so well. But in the same time, it feels like, wow, 15 years. It has gone by so fast at the same time.

Laura Pacheco (03:20):

Yeah, my internship felt like it was yesterday, but not like you're saying. And I remember that moment like it was yesterday. And I have to tell you, I was so excited but intimidated to meet you.

Stephanie talked about your research and this program that you created based on your research. And then when I met you, your intelligence and your passion and then you gifted me, I don't know if you remember this, but you gifted me with a stack of articles. I must have asked for them, and I brought them on vacation and haven't looked back since.

Marjorie Aunos (04:03):

Yeah. And I think I knew you were my kind of person when you actually took the stack of articles to read during your vacation. Yes. I was like, that's my girl.

Laura Pacheco (04:15):

That's right. Yeah.

Marjorie Aunos (04:16):

Well,

Laura Pacheco (04:17):

I think we knew it then that we were gonna be working together and that this was definitely the field.

Marjorie Aunos (04:24):

Yes, exactly. For both you and I. And like you said, we haven't looked back ever since. If you wanna tell us <affirmative>, because that's the day we met, but <affirmative>, you had experiences before that made you quite aware of disparities and the discrimination <affirmative> against parents with disabilities. So do you wanna tell us a little bit about what led you to the field in the first place?

Laura Pacheco (04:52):

Yeah, so it was my first internship for my bachelor's in social work. It was at a community organization and it was one of my first clients. So, my supervisor at the time assigned me to this young woman and she gave me very little information, but to say that she was a young woman, so I didn't really know her age that had an intellectual disability, who was a permanent resident from her country of origin and that I should explore her pregnancy experience and also abortion. So that was striking obviously right away. And at the time, I did ask my supervisor, Oh, is that a natural practice that you have that you ask all of the users about their pregnancy experiences and suggest abortion? She didn't have a lot to say after that. But just to say that when I met this young woman, it was in the office.

(05:56):

She came in, she was quite quiet and reserved. I was trying to build that rapport and then I asked her about her pregnancy and she lit up, she smiled, she looked at me and talked about how she was happy to be pregnant, how her family was really happy that she was pregnant. And she even said to me, and I remember these words she said to me in French, In my culture, a woman is made to have children, to be a mother. So it was something that she really valued. So it was very striking that my supervisor had these biased impressions of this young woman who had never had a child before. It was her first child. And then this young woman talking about how important being a mom was to her and to her community and to her family. She also gave me consent to speak to her social worker, to the disability organization.

(06:59):

And the social worker said to me how concerned she was and how she felt as though this young woman would regard her child as a doll. I left that experience and the internship continued, but I left that particular experience just really being impacted by the discrimination and biased attitudes that are not only out there but that are reinforced by people like social workers that are supposed to be able to support and provide resources and also provide some hope. So that was really striking to me and the different messages that were sent to her from these social workers, but also from her family and the impact that this had on her. So that was my first parent in the field, and I remember looking at trying to find some resources, and I think this was actually just before your program was created. And so at the time didn't find anything for her, but she did receive community resources and was able to have some success in the long run.

Marjorie Aunos (08:16):

I love it. But your story, there are very clear images when the social worker was saying the baby is gonna be like a doll. I mean, that's pretty striking as an opinion <affirmative>, especially when you think that this person has never been a mom before, which means they've never seen her parent. So they don't even know if she's capable or not. <Correct>. But also the part of the story where you say in her culture, parenting is sort of like what you do. I mean, if you're a woman, you are a mom or you are meant to be a mom. <That's right.> And how her family could be accepting when sort of society or the structure, the system that we have in place wasn't seeing that at all. You talk also about that strong sense of social justice. Do you think that this is the moment you realized that you had this strong sense of social justice or was that something that was in you before you met this mom?

Laura Pacheco (09:23):

I definitely think it was kindled in that situation with that mom, but I remember as a bachelor student engaging in some of the anti-oppressive readings and reading a little bit about mothering with a disability in general and the barriers that a lot of these parents face. So I think that's where it started. And then certainly within my internship, it's another instance where that sense of injustice is really emphasized. So this was in my master's internship, obviously with you, and it was a couple and the couple's family member had made a referral to your service and we got involved, and I was a part of the process. We got obviously all the assessments and the paperwork, and in one assessment that was written by a social worker that went to court, it stated that this mother's ability to learn parenting skills is as possible as a paraplegic's ability to walk it. I think to me, that will be one of the moments in my clinical career, I don't know about you, where it's just incredibly striking and obvious how there's bias and how that bias leads to interventions and outcomes.

Marjorie Aunos (10:55):

Especially in that case I think where we saw what putting in supports, having the resources made in terms of a difference, and when those resources were put in place, the couple was doing quite well with their kid–raising him and being able to parent adequately. And so it's interesting that in one person's mind, it's just impossible, right? Because a paraplegic will never walk unless you have an exoskeleton. And maybe that's the image. I mean, if we were to run with the image, if you have an exoskeleton of services and support, I guess a paraplegic can walk. So that image could be tweaked.

Laura Pacheco (11:39):

Oh, I like that. I like that could have been the counter argument to her.

Marjorie Aunos (11:43):

And sometimes that's what we need–an exoskeleton of services.

Laura Pacheco (11:49):

And I think you're also highlighting the power of supports and how if those supports, first of all, if the practitioner sees that there's no hope in order to improve parenting capacity, then they probably won't even offer supports. And we've seen that and in some of our research where parents with intellectual disabilities are less often offered reunification supports. And then of course there's the availability of supports, are supports available? And if they are, are they adapted?

Marjorie Aunos (12:21):

Now we're talking a lot about our clinical practice. What was the link to then come in into research and will then tie in into the three articles that you chose for today?

Laura Pacheco (12:34):

Yeah, it's interesting because I think it was probably a set of moments that kind of culminated into one event certainly throughout my internship and seeing all the research that you had done and the work that Maurice and David had done was really inspiring. And I did find myself thinking about ways that I wanted to contribute more, that I wanted to be able to be involved in research in order to make more of an impact related to social justice. That epiphany moment was when you had well, Dr. David McConnell, David and Dr. Feldman, and you had presented in Montreal and talked about the research that had been done and what the impact that has had on the field. And of looking at, okay, what do we do next together? And just I think hearing the three of you and hearing not only your commitment to the field, which to me was really important, but how the research was conducted and how it made an impact on or was meant to make an impact on people's everyday lives. That was something that inspired me, and I thought that's something that I wanna be involved in.

Marjorie Aunos (13:56):

Yeah, I remember that conference and having those conversations, which were quite inspiring, I have to say.

Laura Pacheco (14:04):

Yeah, absolutely. And dreaming about how can we further support these families? How can we create more justice and support families so that they are healthy and connected?

Marjorie Aunos (14:21):

So one way that you did that, obviously <affirmative>, is you joined into the research with us and you conducted your own research as part of your PhD. Do you wanna talk to us a little bit about that process, but in connection to the article that you chose that came from your PhD?

Laura Pacheco (14:43):

Yeah, absolutely. And it's actually, I think partly inspired by my interaction with the first mother that I met. And some of the critical reflections that I had that were still unanswered and around the time that I was doing my PhD was the IS acid cert position paper in 2008. And so one of the calls to action was around lower income countries and intersectionality and culture. So that's something that spoke to me.

So my PhD was a narrative study with eight mothers that identified as having an intellectual disability and who identified from coming from an ethnocultural community. So they themselves felt a strong connection to their cultural communities. So I had a mom that was from Portugal. I had another one that was from Vietnam, but identified as Chinese. I had another mom who was African, and I had two moms that identified as Indigenous and felt that they wanted to participate in the study and felt as though they were part of a cultural community based on their Indigenous identity.

(15:58):

So the purpose of the paper or of the PhD was to explore their everyday experiences through their life stories to identify some of these struggles or oppression, but also the resilience in strategies of resistance. And what came out is that these moms did experience a lot of loss. There were some really dark and deep depictions of violence particularly within the relationships–emotional violence, physical violence, and sexual violence as well. They also talked about the ways in which their culture and family and society had these expectations of them as a mom that they felt that they couldn't live up to, and the impact that this had more on the psycho-emotional level. So, these were some of the oppression that they experienced and the strategies of resistance. They talked about standing up to people in their lives that denigrated them. One mom in the middle of the hospital screamed at her cousin, used the R word and said, *This is how I am, and just leave me alone*. Sort of reclaiming that word and standing up and saying, What, This is my life and I'm not perfect. Sort of narrative. And then also some of the women spoke up to their husbands, to their family members, and some of the women decided to leave their husbands. And this was really in order to create a better life for their children. And the most, I think, significant piece of it was that their mothering identity was the most important thing to them. In that in itself was a counter-narrative based on society's ableist and negative discourses.

Marjorie Aunos (18:10):

Everything that you're talking about, it's not about the disability really. You're talking about everything else. You're talking about violence, you're talking about discrimination and how they're fighting and making sure that they have their space in the world and that it's respected, and their dignity is respected, and that they're offered the same human rights as anybody else.

Laura Pacheco (18:32):

Absolutely. Their real fight to be able to be seen in a certain way, to be seen also for their contributions and their positive parts of themselves and to be valued and loved. Loved was another big piece. Yeah.

Marjorie Aunos (18:52):

In terms of the research recently, I spoke to David McConnell and we ended up talking about Tim and Wendy Booth. What influence, or was there, well, I know there is an influence, that's why I'm asking the question. So yes, can you please elaborate what that influence has been on you in terms of their work?

Laura Pacheco (19:13):

Yeah, that I would say probably has some of the most important influence on my work. They just had this amazing ability to really narrate life experiences of parents and really document the contextual factors and really elaborate on life experiences. And that it's not about the intellectual disability, it's about these ridiculous living environments and the lack of resources and how that has a huge impact on everyday life. And the importance of seeing that context not only within the research so we can address it, but also within practice, their work, their life story approach the ways in which they were able to interview so many parents and really get at their authentic stories is that..It's seminal because of that.

Marjorie Aunos (20:16):

So that was your first, well, I don't know if it was the first article, but it certainly was one that was really important and key in your career. You've had a few since, and one of them is part of building systems capacity. Do you wanna take us on that journey in terms of how that came about and what that is, basically?

Laura Pacheco (20:38):

So that piece, again, was part of a larger study and the goal was to build systems capacity within Canada. So, looking at it from Ontario Quebec and Alberta at the time. And the larger study really looked at what are the support needs of parents with intellectual disabilities from the parents' perspective. And then there was another part of the study that looked at it from the worker's perspective. The article is based on semi-structured interviews with workers, so service workers in Canada who were nominated by parents with intellectual disabilities. So it ended up being disability service workers, so social workers or social service workers, educators, and psycho educators. David and Luellen had done a study in 1997 related to support needs. So there were some similarities there. I think what was striking maybe about this study is that workers did identify discrimination that parents with intellectual disabilities face. They identified the need for access to justice.

(21:58):

They didn't talk about the ways in which to gain that access and how to explore that, but they talked about that as being an important piece. And they also talked about the importance of workers. So whether it's child welfare workers, whether it's disability workers or mainstream workers being able to embed what we then together named as the three R's. So the first R is reflective practice. So the participants talked about the importance of workers being able to be reflective in their practice, to identify their social positions, to identify the privilege they may have and the biases that they could have and how this influences their work with parents with intellectual disabilities. And then the other R was related to research-informed. So these participants talked about the importance of using research, the importance also of having some sort of portal for workers because workers as we know are busy and can't necessarily read a full article while they're meeting families going to court.

(23:14):

So they talked about the importance of research in line with a sort of portal, an accessible portal that they can access. And the last one was the importance of relationship building. So relationship building they talked about. And something that I think resonates within us is that is incredibly important, particularly with these parents who've experienced individual and collective trauma, who have often had negative experiences with social workers or helping professionals. So they identified that piece in building rapport as really essential. They did talk about the importance of building rapport across, but that roles are influenced by mandates and policies and that does have an impact on the rule. So that also when we're building that rapport, that also has to be built in there, that there's also that transparency. So those were I think some of the most significant findings in that study maybe that were striking and contributed something that we expanded on a little bit more.

Marjorie Aunos (24:24):

And so the third article that you wanna talk about is discourse analysis. So again, sort of looking at stories, but this time using a medium that is publicly accessible that we didn't know. Cause this is a research that we've done together called court reports that apparently are on websites and available to everybody. So do you wanna talk to us about that project?

Laura Pacheco (24:53):

Absolutely. So for our larger study, we had, I think it was about 117 court reports that we analyzed. So there's a descriptive study that looks at outcomes and different components of these parents' lives. And then this study was more focused on the analysis or the discourse analysis of these court reports. So we chose 10 court reports, and again, it was in line with previous research that identified the number of reports based on saturation. And we analyzed these 10 reports on three levels. So the first level was really based on the textual level. So here we were looking at the descriptions of parents with intellectual disabilities within these court reports–what were the terms that were used to describe them, and what were they based on? Then the next level of our analysis was to look more at what they call the discursive practices or the power relations.

(26:02):

So whose voices are heard in these court reports, and how is evidence presented? Who makes these decisions within the court reports, and what are they based on? And then that final level was really looking at deeply embedded within these court reports, what were the larger discourses within society? And for us we certainly saw the professionalization of social work–we saw ableism, we saw the rhetoric of the best interest of the child as well. So those were the elements or the discourses that came out the most in our discourses. I think that in terms of some of the most striking pieces were related to the juxtaposition between the ways in which, and it was mothers with intellectual disabilities were portrayed versus the caregivers. So all of the children were placed out of care either with the father of the children with a family member or a child welfare caregiver.

(27:20):

The parents were described as deficient and unable, lacking insight, unfit. Whereas these caregivers were described as resourceful and resourceful in the way of being able to provide services and activities, but also financially resourceful, available, and desirable. So it was really striking the ways in which caregivers and mothers with intellectual disabilities were portrayed in the court reports and how that influenced, of course, the outcomes. There was a lack of position or lack of voice or their voice was devalued within the court reports. All of these moms had lawyers and most of them had contested the allegations and the recommendations by child welfare, but very little moms testified. None of them had anybody testifying on their behalf. And there were two lawyers that had brought up counter arguments and brought up the parents' perspective and tried to show that the mother was engaged during the visits. So that lack of space and voice was I think quite evident. But there was one mom who didn't attend court and she was really discredited for it. Basically the judge said that it was a lack of interest that led her not to come to court. So devalued whether you are there or not there. Yeah.

Marjorie Aunos (29:02):

For me it was also some around the voicelessness of these parents as if they're represented, yet they're absent and not absent because they wanna be absent. I mean, I don't know, we haven't met them so we don't exactly know. But certainly from a clinical eye or a researcher reading those reports, it was sort of like, well, did you ask her? Was there a problem in transportation that led her to not come? Is it because when she's invited to those kinds of meetings, she doesn't understand anyways cuz nobody's adapting to her level of understanding. Is that why she's not coming? Because she's feeling like helpless and hopeless in those meetings? So there was a lot of questions that we had on a clinical basis that offered alternatives to the opinions that was showcased in those reports. To me that was the most eye opening, even though we already knew that in clinical practice, but it was sort of seeing it black on white that was very powerful in terms of the silence was deafening. <Yes.> And I think that was very striking. So those are fantastic research and obviously in the show notes there's gonna be the references. So people, if they wanna go and check them out and read them, they're gonna be welcome to do that. We're gonna switch to the last portion of this conversation and say, Now we know this. What are your opinions in terms of what we should do next?

Laura Pacheco (30:45):

In terms of where do we go from here, I think that certainly increasing the diversity in terms of the research participants using intersectionality, so including participants from BIPOC communities from LGBTQ+ communities, from Indigenous communities. And I know this is something that we've said as researchers too, is also having parents that were recruiting first from our studies that are well embedded in the community that maybe don't have social services involved and that they're doing well and they have maybe family and neighbors and this sort of system of support going there. I also wonder how we could increase community participation approaches with parents with intellectual disabilities. So I know that they've done some of this work certainly in Australia and in England and with Tasp as well, but how can we have more collaborative research relationships with parents with intellectual disabilities that become co-researchers, but in a meaningful way? Also, looking at what are the positive contributions of parents with intellectual disabilities? And one of the things that we've talked about too, and that I'm really interested in is related to interdependence. So how do parents with intellectual disabilities also provide support? It could be in their interpersonal relationships, it could be with their parents, their children, their grandparents, but how can we also see them as positive support providers and not just care receivers?

Marjorie Aunos (32:33):

Cause ultimately we're not just one thing and neither are they, right? They're not just someone who has an intellectual disability. They are also a daughter, they're also a sister, they're also a community member. And so all of those relationships, they're not just one directional. Some of them are bidirectional in sort of exploring that. I think that that's definitely something that's missing in terms of looking at the positives. So I think that's a great idea.

Laura Pacheco (33:07):

Yeah. Cause then in that way we're actually looking for their contributions. We're looking at how they give and how they're appreciated to hopefully be able to challenge the normative discourse on just people with disabilities in general as being dependent. So.

Marjorie Aunos (33:28):

The other part also that you mentioned in terms of your sample and looking at elsewhere, not just rehabilitation centers or services or child welfare, I think we would also probably get a different view or different perspective. And I offer you and everybody who's listening to actually listen to Gwynnyth Llewellyn talk with me because there was a good portion of the talk where we did mention about, where did she find all of those parents who were not in services? And it was very eye opening in terms of we have a here else in the community directly.

Laura Pacheco (34:18):

One of the things, and this is a conversation that we had about why aren't we doing more research with self-advocates and community organizations where parents with intellectual disabilities are at the heart of the center? And one of the things that you mentioned also resonated with me and something that we need to think about, it goes back to systemic barriers. So a lot of our folks are struggling just on the day to day because of their social position. So we have to keep tackling those structural pieces, those inequities because we see not only does it have an impact on health, on parenting, on children it has an impact on everyday life. The social justice component I think is an important piece as well.

Marjorie Aunos (35:07):

I have one last question for you. If you had an audience of child welfare workers, what is the one thing you would tell them?

Laura Pacheco (35:16):

First I would say child welfare work is really difficult. It is the most difficult social work job across countries. There are multiple demands. We also live in a society where the system is less than, so it's neoliberal. We don't have a lot of resources. So I wanna acknowledge that before I say what I'm going to say because I know that it is quite difficult and certainly we value the work that that's being done. I would probably go back to some of the findings related to reflective practice. Child welfare workers are mostly social workers. I believe in Canada anyways. And so we have a responsibility to social justice. It's one of our values, and it's one of the core principles of the profession. So engaging in critical self reflection on a continuous basis. And it's a long term process. So whether that's something that's done individually or it's done during supervision, it's important to be able to explore that and to identify that the families or parents with intellectual disabilities that they will often meet, that their struggles are often rooted in structural issues and structural barriers.

(36:46):

I think that in reflecting upon that, and as practitioners we had to do that as well, is to reflect upon your power–to reflect upon the fact that your biases and your perceptions have an influence on your assessment and your interventions and ultimately the outcomes. Building relationships with families at the same time being transparent about what the limits of your relationships are and building collaborations with other workers so that not only can this family be supported but that the needs are being met if it's beyond your child welfare role. Also use research. So there are not only publications, but I'm thinking about the book that you did with Maurice on comprehensive assessments and the CW 360 booklet as well. That breaks down research and that can be used within practice and forwarding your practice. And the last thing I would say is the importance of reaching out. Whether that's reaching out to your supervisor for clinical support, but also to talk about what's being triggered and the difficulties of the job and your team as well is important. So make sure to reach out.

Marjorie Aunos

Those are definitely great advice. It was a wonderful conversation. I really thank you for taking the time to just chat with me. Thank you so much.

Laura Pacheco

Thank you. It was great. I really appreciate it.

Speaker 3 (38:24):

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