

Marjorie Aunos ([00:03](#)):

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 Liz Lightfoot. Liz is the director and a Professor at the ASU School of Social Work. Her research centers on disability policy and services, with a focus on the intersections of disability with child welfare, disparities, and abuse. Her research has been used in the creation of national policies involving disability.

After talking about Dr Lightfoot's beginnings and her involvement in the groundbreaking report *Rocking the Cradle*, we spoke of the kind of research we are pulled to do.

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

Liz Lightfoot (01:24):

I was trying to figure out what would be interesting to talk about. And so I, I'm not gonna talk about the older, the older research which led to *Rocking the Cradle* because that's well known. So I'll talk about some that I particularly interesting and some of their smaller studies and bigger studies. So first one, I'll talk about is one that I thought was really a unique study that we did in Minnesota. We published it five years ago, so I think we did it a coup, you know, a year or two before that. And this I did with Traci LaLiberte and Mane Cho, who's a doctoral student who's, who has worked with me on a number of projects. What we'd done is we'd, we were trying to do a case record review where we would go into the cases of parents who'd had their rights terminated parents with disabilities, so had their rights terminated through the child welfare system. And how we identified them was kind of unique. So instead of identifying them to the child welfare system, and the child welfare system in the United States is notoriously bad at even recording whether a parent has a disability or not.

So what we thought we would do is we would look to see how, um, parents were listed as having a disability when they were in the education system. Cuz in our education system, they're required to identify disabilities. That's not perfect either, but it's sure a whole lot better, um, than in the child welfare system. So, so we found, so these were young parents, parents, young parents, and we were able to match their records and to look at parent, parents who'd had their rights terminated, and we looked to see who had been identified when they were in the school system as having a disability. And then we pulled those records out. And that doesn't sound like a big deal, but it was very complicating getting all the permissions from everybody, the counties to look at the data and whatnot.

But then we went through and looked through the details of these case records to see how disability was identified, what kind of supports they were pro people were provided, what the compliance was with the parents with the treatment plan, how they were included in the treatment plan, and so on and so on. there's a whole lot that came out of this study but was very interested to me is first of all is that maybe about a quarter of the parents weren't even identified by child welfare even as having a disability. So they just didn't know there was nothing in the case file. So these parents, not only were they not getting any kind of modification to services or supports or tailored services or anything, the child welfare system didn't even know that they had a disability, which that was, I guess it is not shocking, but shocking at the same time. Like, I'm not surprised, but it's still horrible. So how can we even provide supports if we are so bad at even knowing who we're working with? And that leads in, people with invisible disabilities might be called, you know, lazy or, you know, they're not complying because they don't, or haven't been, been told information the way that that's successful to them or

haven't been provided the support. So whatever they needed to understand what's going on. So that was one thing that was interesting. Other thing that was interesting, very few people did get modifications to this and they weren't very, they weren't very tailored to people. So I think there were some case workers who naturally were providing, you know, repetition of information and doing a good job, but it wasn't at the average. So most people weren't provided modifications at all, and it wasn't documented in their case file. So they weren't taking any systematic look at the cases and saying, okay, even if it wasn't best practice, just the law, like we're required under title two of the Americans with Disabilities Act. And, you know, now we've got guidances from the Department of Justice and the Department of Health and Human Services to provide individually tailored services to parents with disabilities. It then wasn't really mentioned in most of the case records. And then the final finding that was the most disturbing was something that we do in child protection. As you look to, they develop a plan, you know, a parenting plan that people are supposed to comply with, and then the parent is supposed to comply with this plan. And we found in the study that almost it was, it was an extraordinarily high completion rate of their plan.

So these parents were dedicated to doing exactly what they were supposed to do to get their children back, I mean, get their children back. I think it was, I don't, I think it was close to 90% of was completion rate. All of these parents lost their kids. Wow. So even though the parents are doing exactly what was told, the system still decided that they couldn't keep their children. And I find that a huge injustice to these parents. The parents are trying, they're working with the child protection workers to try to do everything they can. And I think it's just a failure of the system. So the system decided what they needed to do, the parents did it, and they still took their kids away. So I thought that this study really, you know, almost should be required.

Marjorie Aunos ([07:01](#)):

Yeah. I remember that this study actually. And I remember Traci talking about it in a conference and it was so groundbreaking. I think it really shook the whole community because you were able to get data one larger set of datas when we had, you know, done studies on smaller sets. You know, linking those two databases to get that information was just brilliant in terms of the method. So it was not only sort of groundbreaking in the results that you got, or the outcome that you got, but also in terms of how you did it to get there. And I think it really inspired many other researchers.

Liz Lightfoot ([07:53](#)):

You know, it's sort of sad that we have to link these two systems together because the systems aren't linked already. =They should already be linked. But it wasn't, but what was interesting I think is. I mean there's a so much good research going on with parents with disabilities and I have so much of it. And it really, it's not in the United States, in Canada and Australia and England and Scandinavia, you know, the United States is far behind what you all are doing in other places. We know parents are slipping through the cracks, but we actually could say, aha. See. Here's, here's evidence <laugh>, they're slipping through the cracks. So that was kind of, I mean, it wasn't, I don't know. It was, it was sad, I guess. We're not providing better services.

Marjorie Aunos ([08:37](#)):

Yeah. So that was your first article. Yeah. What would be the second?

Liz Lightfoot ([08:42](#)):

So the second one I was thinking about is a study that I did recently. I had some great doctoral students at the University of Minnesota. We were sort of doing this large database look. So it was kind of interesting that I found, when I was first starting into this field, as I kept trying to figure out what our prevalence was. And I'd hear these statistics that would say 40 to 80% of parents with intellectual disabilities lose their kids. And I'd like, where is that data? Where, and I'd dive down and I would track,

it's nowhere. I think people were making that up. I could not find that anywhere. I <laugh> the, the late, the earliest place I found it referenced to was on a, was in a VHS tape.

And I haven't been able to go back further. And so I've done a couple of different studies of it. We did a study earlier where we're looking to see how many kids in foster care have a parent with a disability? We found that about a fifth of them at least, the data's not so great, but at least a fifth of them have a parent with a disability that's huge. You know, so we should be training all foster parents, all child welfare workers. I'm working with parents with disabilities. Cause the fifth of the kids in foster care in the US have a parent with some kind of disability. <Same in Canada.>

Yeah. Yeah. And that's only the ones we're identifying. That's right. And if we know that there's a number that are slipping through. So that was so, but, but this, so then I'm trying to get into more de like where is this happening? And this is what we've done in disparities in child welfare in the United States. Where, where, what are the points, where we're seeing the disparities show up the most? Are there certain points? Is it when they're hidden when they're being referred to child welfare? Is it substantiation of maltreatment? Is it removal from home? Is, you know, all of the, is it termination of parental rights? And so that's, that's what I've been trying.

We've done a couple of different studies. So the study I'm gonna talk about, which I thought was kind of interesting, was looking at referral into child welfare. And this is just for parents with intellectual and developmental disabilities. So in the field of child welfare, and I've heard this in working, you know, talking with parents with disabilities and other folks that we think maybe some of it is that people with disabilities have so many mandated reporters in their life. They've got the sur, and so people call it the surveillance bias, where they've got people coming in and out of their home to, you know, personal care attendance or they're going to physical therapy or all of these kinds of things.

So maybe it's that, one of the reasons that they're getting involved in child welfare more often is because they've got people who are in their house every day. I don't have people coming in my house every day. Nobody's coming in my house. And they couldn't see what I'm doing with my kids, who are now grown. But when they were kids <laugh>. But if I had somebody coming into my house every day, they could say I was neglecting. They could, you know, they, all of these sorts of things. This is not even taking into account bias, but just the surveillance, extra surveillance.

So we did a study of referral source. So we looked at the national dataset of child welfare. And we only picked out the states that reported the data. So there's some states we have to exclude cuz they don't even look at parents with disabilities. But of the states that collect information on whether a parent has a disability, we look to see how are they getting into the child welfare system. Is it different than other parents? And it is. So we found that, for parents with intellectual disabilities, and we actually looked at parents with just all parents with disabilities too. So parents, all parents with disabilities, parents with intellectual disabilities, and then parents without disabilities that they're much more likely to be referred by a social service worker than parents without disabilities. So that is very interesting cuz that's exactly what the surveillance bias says. Education is still the number one. And that makes sense too, because kids are going to school and teachers will report. But for parents with disabilities, social service workers is much higher than would be expected for their referral rates.

For other folks, when we're talking about surveillance bias, particularly they're looking at people who are living in poverty, they haven't found evidence for that. But it looks like there is evidence for parents with disabilities that they are getting into the system in a different way.

The other part of this study is we look to see how often it's substantiated. So they get referred to child welfare and then how often is substantiated. Now for parents with disabilities, if they get in the child welfare system, it doesn't matter how they're referred it, they're much more likely to be substantiated. And I imagine that bias is playing a big part of this though. You know, that's a hypothesis. Cause I'm just having the data out, but I'm guessing that's part of it. But what's interesting is that if they're referred by a social service provider, they're much more likely to be substantiated.

So this pathway of getting referred by a social service worker more often, and then the social service worker's report is more likely to be substantiated, leaves parents with disabilities much more likely to be substantiated.

So this is like getting into the nitty gritty of things, but I think this is like gives us, if we're trying to think about how to improve the child welfare system, sort of understanding, you know, if people understand where referral sources are coming from and what the biases might be that can help us train them to be aware of that rather than just sort of giving this generic.

Marjorie Aunos ([14:32](#)):

We've seen research in looking at parenting capacity assessment that actually sort of demonstrated that the notion of the expert, quote unquote, made the difference often in cases, because the experts. So that means any worker, and that could be just like a front case, like a frontline worker. Yep. Or it could go to a, you know, a psychiatrist or psychologist that's called for their expertise. Whatever they say or they think or their analysis is often sort of weighs more in the balance, than even sort of the voices of the parents, which often are not even present. They're invisible, they don't exist.

Liz Lightfoot ([15:15](#)):

That's right.

Marjorie Aunos ([15:17](#)):

So it's interesting to see in terms of your research, how it, it fits with other types of research with different methodology, but you come out with the similar.

Liz Lightfoot ([15:25](#)):

Yeah, it's a very, very similar idea though. I do have to say it doesn't even matter who's referring. They still <laugh>, you know, like it's still higher. But this idea of the expert and it's like the whole medical model slapped in your face about, who, you know, the experts will decide what is <laugh>, you know, if they've said, if they've referred it must be true. And it puts the mandated reporters in this type, you know box too because, social workers and others who are mandated reporter.

I just went to a mandated reporter training a few days ago. And, you know, essentially the message we're given is any doubt whatsoever. Report. And what if you think it's not gonna work out, well you still have to report, you know. So you're trained to report even if you might not think it's you, you just have a hunch, right. And that can lead to these horrible ramifications for tearing families apart. So I feel bad for the mandated reporters in some way too because I don't think people are necessarily doing it cause they want to tear families apart, but that's what might happen.

Marjorie Aunos ([16:39](#)):

Yeah. And I'll just mention also that in our conversation, for someone who thinks or who doesn't know all the research that do exist. There are evidence, from intervention type of research that showcase that parents with disabilities are good parents, they're capable. And so it's not like we're saying, you know, we don't believe what the reporters are saying. It's just we know that the parents do have the capacity to parent. <Right> And so it's putting those two together that leads the conclusion in terms of the

Liz Lightfoot ([17:12](#)):

Right, right. And really I, you know, there's parents with disabilities who are horrible parents and there's parents without disabilities who are horrible parents and the disability is not the factor. <laugh>. <Yes.> So it has to be based on behavior. And that's been kind of my whole focus is like our, you know. We can't be doing this based on assumptions or real, like we think how could this parent ever parent a kid? You know, that's not how we're supposed to be doing our assessments. <laugh> It, you know, is it they

actually neglecting their child? Not do we think they will necessarily neglect their child? So Absolutely. Absolutely. But I think these biases are so strong that they lead to horrible disparities for parents with disabilities.

Marjorie Aunos ([18:01](#)):

Yeah. So thank you. What is your third one?

Liz Lightfoot ([18:05](#)):

Okay, so the third one, you know, the previous two and a lot of my work had been related to sort of documenting problems, you know, <laugh>. What are the, you know. I really wanted to give tools to people especially social workers. So cuz I'm in the social work, so child welfare workers or people working in disability services to evidence-based practice, to working with parents with disabilities. Understanding that we have very few funding streams to fund this. So there's a few, some states have these, have some pilot projects where they are providing funding for parents with disabilities to parent their kids. But primarily our funding gives individuals, <laugh> money to take care of themselves. You know, so there you can't generally get a personal care assistant to help you dress your child, you can to help you dress yourself.

So anyways, we don't have funding stream. So I was trying to figure out something that could be integrated into child welfare practice that was positive. And so we, this is with a doctoral student and I, she's now a professor at St. Catherine's University, Sharon DeZelar. And I developed this parent-centered planning model, which is very similar to person-centered planning. It's borrowed from person-centered planning. We thought this would be a simple intervention that we could use that child welfare workers or others could use, when they're working with a parent with a disability.

And essentially the idea is to recenter the focus away from what a parent can or can't do independently to, what supports the parent and family need and what their goals are for their family and what sort of supports we can gather around the parent to parent their child, whatever it may be. And, so it's very simple. And we are trying to do this sort of as a brief model because we knew there wasn't funding attached to this. So we developed this sort of brief intervention and tested it out.

And so we tested it with parents with disabilities in Minnesota. And these were parents with intellectual and developmental disabilities. And we held, and we called them parent centered planning meetings where we would bring the parent and whoever they decided were their support people, usually their families, sometimes friends, sometimes paid workers, even though that's not what they're supposed to do, but that's for some people, that's who their close supports are and had them go through a planning process. And, parents loved it. And for a lot of time it was the only time they've ever actually sat down and talked about parenting their kids in a way that was positive. And the sort of impetus behind doing this is to pay for anything preventative in child welfare, in the United States, it has to be an evidence-based practice. And so it has to be tested. So that's what we are trying to develop a, like no cost brief intervention that would be evidence-based that then they could use to their child welfare funding to pay for.

So I've got several articles on it. The one article sort of explains the whole process of doing it. We found that parents did meet and they made goals. We then followed up with them later and they actually had taken the steps to, towards meeting their goals. And they had developed stronger supports. Some of them had reduced their support circles a little bit, but that's because they realized that some people might not actually providing them support. So they got better support systems for parenting. <Amazing.>

This was really fun. This was also a super time consuming project. But I, we, you know, we now have, we have, we made a manual so anyone can download it and use it and it hopefully people can, you know, if they're looking for something they can take off the shelf to, you know, if they're in child welfare and they can take it off the shelf, it's very simple, simple to implement. We tried to make it something so it didn't take a whole lot of extra. <Yeah.> Work or trading.

Marjorie Aunos ([22:36](#)):

That's amazing. I'm a clinician at heart, you know, so Right. Hearing about how research can be used and lead to a resource that's useful for clinicians, I think is, it's, it's the best kind of research, for me just because I know how when you're working on the frontline, you're like, you're just craving for all those resources or tools that you could use in different situations, and this would be definitely beautiful. It will be in the show notes actually sort of the link so that people can download it.

Liz Lightfoot ([23:07](#)):

This is a very much of a social work intervention where we're looking at developing the supports. Like there's just no emphasis at all on training, the <laugh> training the parents. And there, I mean, there's great, and we have lots. That's where our evidence is. We've got lots of, and I know you've been involved in a lot of these evidence-based practices and with Maurice and, you know, in training parents and improving parenting practices. So we wanted to do one that was based on the context. And there's a few of them that, you know, Gwynnyth Llewellyn has done some in Australia and there's a few of them, but there's not too many, that focused on this. So that was why we were doing this one. We're like, well let's do a social work version of this.

Marjorie Aunos ([23:38](#)):

That's beautiful. I think it anyways, you know, when we work with people, it's not just people we work with like system around that person. And so totally. So even if I'm a psychologist, I do look at the context.

Liz Lightfoot ([23:52](#)):

I know you do. Yeah. <laugh>

Marjorie Aunos ([23:54](#)):

Because I've learned, I mean, there's so many social workers that I've worked with, right? It's like, it really opened my eyes in terms of like, it's not just one person. It's like, you know, the neighbor that helps out, it's the pharmacist that, you know, you ask questions when your son is sick. It's, you know, a whole bunch of people around. It's the school and the teachers and, you know, and so totally the system has.

Liz Lightfoot ([24:17](#)):

So I think it's all important. So that's why when you were talking about the community of researchers, that's what I think is so lovely, is that we've got people, especially in this field. We've got people from different perspectives and different backgrounds and training. We're thinking about this different ways and the, and the activists too. And all of us are activists in our own way, but there's different, you know, different just different approaches and perspectives to what we think is, you know, what we think we're, we're interested in focusing on. And all of that helps.

Marjorie Aunos ([24:50](#)):

Yeah, definitely. So let's move to a different sort of looking at the future.

Liz Lightfoot ([24:53](#)):

Yeah.

Marjorie Aunos ([24:54](#)):

What do you think, you know, the research community and the social work community or child welfare community would need to, to sort of like go into which direction right? For the future?

Liz Lightfoot ([25:09](#)):

Well, I'll tell you what I've been, you know, from doing this for a while. What I think, at least in my particular area, that really working on changing the practice, the child welfare practices to support parents with disability. And it's been happening a little bit. They, we've had federal guidances and whatnot. So I think there's a little more awareness to this, but I think we need to, you know, institute training for child welfare workers on working with parents with disabilities and not just like, this is how you talk to a parent with this, but like understanding the biases that are built into the system and the historic discrimination and oppression that has led to this. And our biases in society as well. To really understand this as a social justice issue.

We understand this about, about disparities, racial disparities in the United States. The Native Americans, you know, similar in Canada. <Yeah.> You know, where, you know, we took kids and put them in boarding schools. Well it's different, but it's a similar sort of discrimination that's occurred for a hundred years, related to parents with disabilities in chapel for more than that. But we had eugenics laws and then we had these horrible State laws that still exist. So I think we need to do this massive overhaul.

And so what I'm doing is through the National Research Center and Parents with Disabilities, which is at Brandeis. That's the one that Susan Parish started. Monica Mitra is the PI on that. I've got a project that's starting up next year, <laugh>. I did it to start. So I'm like, at the latter part of the grant where I'm developing a national training for parents with disabilities. I mean, not for parents with disabilities, for child welfare workers working with parents with disabilities. So it's geared toward the child welfare workers and we're gonna be testing this and then we're hope, we'll, we will be able to implement this nationally.

We've been talking to the folks in some of the National Agencies and they really want this too. You know, the Department of Justice and Office of Civil Rights, they're, you know, they're paying attention to parents with disabilities now. <Yeah.> And that's new <laugh>, that's new. So in the United States we've made a lot of progress. So we're catching up to Canada. We're catching up to Australia. I think is starting to become awareness issues. So when I tell people what I'm doing now, people, you know, people get it. I say, do you know they can, they can take kids away just cuz a parent has a disability and they think that's a bad thing. And I don't know if 30 years ago they would say so. <Yeah.> So I think we've made some progress. Yeah.

Marjorie Aunos ([27:59](#)):

So the future is looking good.

Liz Lightfoot ([28:01](#)):

I, well, I don't, that's, I have to say that to keep me <laugh> <Yes.>, to keep me going.

It's still bad things happening every day to people. So I, you know, but I wanna think that we can. I can only keep doing this, so I think we can improve.

Marjorie Aunos ([28:22](#)):

Yes. So here's my last question. okay. For our conversation, if you were able to talk to child welfare workers and social workers, what is the one thing you would like them to remember about our conversation today or about your work that you've done?

Liz Lightfoot ([28:33](#)):

I think like the main, the main issue is that parents with disabilities should be treated just like other parents. And if you're working with a parent who's been referred to you, <laugh>, to child welfare that focus on their parenting and what you can do to support their parenting rather than focusing on their disability. I mean, you wanna provide disability appropriate supports, but just because a parent has a

disability has nothing to do with whether they're gonna be a good parent or not. It might be that you're not providing them enough supports. But it has nothing to do with whether they're gonna be a good parent or not. And that's like the ultimate goal.

Marjorie Aunos ([29:13](#)):

<laugh>, yes. Thank you. Thank you so much.

Liz Lightfoot ([29:18](#)):

And thank you so much for chatting with me. It's been fun.

New Speaker (29:23):

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