EPISODE 15 ELLA CALLOW PART 2

Marjorie (00:05):
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. Today, we are continuing with my conversation with Ella Callow. Ella Callow. Ella is a lawyer who has always advocated for the rights of marginalized groups. She believes everyone has the capacity for self-determination and defends people's rights to be empowered and live their lives as they see fit. In this part of our conversation, Ella and I began our discussion examining the Intersection of Disability and First nations' rights. Enjoy!

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

Marjorie (00:01:13):

So you mentioned a few times about indigenous and the Indian Child Welfare Act. <Yeah.> So, do you wanna talk about the second of document that you submitted.

Ella (00:01:20):

Definitely, Thank you. Yeah. So I was offered an opportunity by what I think of very admiringly as an old school poverty law, Poverty rights journal, the Clearinghouse Review, to do a piece, sort of my choosing. And one of the Editors had attended an Event where I was speaking, I believe that's how we met. And I wanted to do something specifically on the intersection of Indigenous Communities and Disability, particularly in legal context, the intersection of the Indian Child Welfare Act of the Americans with Disabilities Act. So I had always been focused, as I said on Indian Child Welfare Act. My mother's family who I was raised with here in California, my grandparents grew up in Oklahoma, my grandfather on the Cherokee Reservation. I have the greatest affinity and sense of belonging with that community and in the Bay Area native community.

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I've always been very active. I feel like there's such synchronicity between what these populations experienced as far as Society determining, particularly at the beginning of the 20th century, that these are populations that were inconvenient, and that other than being exploited for money, there was just no recognition of their humanity at all. And, I do work looking at the history of incarceration of Native people in two Institutions, that, one that was particularly only for Indian people, the Canton Asylum for Insane, in South Dakota and the Morningside Asylum, in Oregon state, which was not specifically for Native people, but it took specifically those who were institutionalized from Alaska, because Alaska did not have its own infrastructure of carceral spaces for disabled people. And it ended up taking a significant disparate number of indigenous Alaskans into its system for many decades. So that was an area of interest to me of how disability was leveraged as yet another mechanism for exploiting and oppressing indigenous people.

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And then on the other hand, there was this synchronicity in sterilizing of the populations. Indian people were sterilized routinely without their consent, both in institutions and out of institutions, through the 1970s. Disabled people obviously were sterilized as a matter of National policy, institutionalized and sterilized or either one, either together or either one, through the 1970s. And I know people say what's still happening there, space is still happening, including our penal system. And I agree, I'm just saying what was formally on the books started to go away in the seventies. And so, I really felt like there was this synergistic suffering that had happened around being denied children and then the removal of children. So Native people are the only people in the United States that were subjected to a Federal Adoption Policy, specifically targeted at removing their children. Quite similar to the empiric colonialistic efforts undertaken in Australia and in Canada, and just taken on the basis of poverty or their family structure, not being to the liking of white middle class people, racism, a particular hatred of native people.

And then disabled people are the only people on the books where your identity, can be used as a basis for removal. So, you can't remove children based on their parents' race, or religion, or gender, or sexual orientation anymore. But there are many States and more when I began this work, that say specifically if the parent has a disability, usually intellectual disability or a mental health disability, and people 'go, Oh, but it says if it's creating problems for the child'. The problem is that there's sort of a tacit agreement often in courts that it's simply in and of itself constitutes a danger, the sort of predictive neglect model. And that's what we found the other article I sent you, talking about IQ where they're like, 'Oh, the IQ is X, then clearly this parent can't be capable.'. So, I really wanted to do something on those populations together.

(00:06:14):

What I found was that in many instances, disability in a parent or parenting extended family member is used as an end run around the Indian Child Welfare Act. So, the in Child Welfare Act actually has very strong protections, very good, well thought out protections, things like Native children should be placed with kin first. Beyond that, their band or tribe. Beyond that, a member of an Indian Nation before they're placed outside of their communities. That's in theory, that's fabulous. Native children, native children's cases, equal cases, should have cultural experts who testify if the parenting or the parenting structure is an element of the state's case, that there's some, that they're pathologizing, something we do with the parenting or parenting culture to make sure that it's not just a cultural difference, but actually something that is negative or path pathological for children. That's wonderful. But what I found was that there are cases where you could see that the argument was basically, 'well yes, typically it would require that we go through…' and also you're supposed to have beyond reasonable efforts, active efforts.

(00:07:34):

'So yes, we know usually we'd have to have active efforts, but we all know the issue is mom's bipolar, so what are you gonna do?'. Or once we accidentally got cc'd on an email between social workers in a case where grandma wanted custody of a child as that next kinship member, and they didn't want grandma to have a child and one was saying, 'Well doesn't any Child Welfare, we have to place with kin if possible.' And the other one said: 'Well not if grandma's disabled, she have arthritis.' So finding ways to circumvent a protection or situations where we don't need a cultural expert. This isn't about culture, it's about disability. Completely avoiding the fact that first of all, there may be a different conceptualization of disability <affirmative> , right, and that almost never do they actually have the capacity or the expertise to even be talking about the disability either.

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So that was one of the things that I wanted to write about and include there. The other was to talk about strategies that may be available to citizens of Tribal Nations because equal applies where the child is a citizen or is eligible for citizenship in a Tribal Nation. So, talking about some strategies that may exist there. So, in the case where it's an equal case, in those cases, the parents can appeal a decision, the outcome of emotion or something up to the federal court can test it with the federal court without having to go through the usual exhaustion of State remedy, or can do it at all where in some cases you can't at all go to the Federal level, the State is in control of that domain of law. So there is some things that are available and I wanted practitioners to be thinking about, be aware of that.

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Some of our doctrines around how you can appeal a matter would be different in equal cases.

I've been amazed at the fact that I, I've, I've been contacted by people in Agencies in Washington DC going: 'We're trying to look into this issue of Indian children and parental disability. And somebody sent us, I know a scanned in PDF of some article, but we don't know where it's from, do you know?'. And I'm like, 'Yeah, that's mine.' <laugh>. Like there's not much out there about this. And yet there's been significant interests over the years. So, I really do hope that this generation of Native attorneys and Native social workers will focus on this issue. I know that right now I'm really excited because there's a woman named Kimberly Cluff, who worked with the California Indian Legal Services for many, many, many years and is looking at disability in Native children and whether or not the State is providing, through their county services, county agencies, proper services of those children that are Tribal citizens in California.

(00:10:28):

And working with a huge consortium of Tribal communities focused on this and the California government. And she's working with a young woman who's an indigenous woman. And I would love, and we talked about how parental disability, if the child's disabled and the parent's disabled, they also need to be able to work with the parents with disabilities, make sure things are accessible for them to help their children get services. And those are the kind of things that give me hope that we can start building more into the community. Native communities also are incredibly well focused on the wellbeing of their communities. So like the Cherokee Nation, Oklahoma has probably the most state of the art extensive medical facility and medical training facility of any Tribal Nation. Just completed last year I believe. And that's somewhere you could teach doctors about this issue, teach occupational therapists about this issue.

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And they create their own programs to intervene around parents with mental health involvement and other vulnerable parents. In Navajo Nation, they did a project with Johns Hopkins and I think it's called Strong Spirit Program. And originally it was really focused on teenage parents, but it is best practice for disabled parents. It addresses and use, it uses modalities and interventions that we have seen are beneficial for disabled parents too. So, there's a lot of creativity and opportunity happening in Indian country around this. And I'm hoping it'll become more and more explicitly included in the teaching and the interventions that happen.

Marjorie (00:12:17):

And I'll definitely ask you all those references so that we could put it in the Oh yeah. Show notes so that we could

Ella (00:12:24):

Share. Absolutely. People, Yeah, I just finished for the first time being an editor of a journal edition. I've been on the other end of trying to get things accepted so many times. So it's funny to be an editor finally. And I did that along with two colleagues and Juliet Larkin and a woman named Susan Birch from Middlebury College. And the whole issue was called Disability and Indigeneity. And it's through Disability Studies Quarterly. It was a special edition and it's open to access. People can just, you know, sign in with an account the first time and you can go on it. And it has this incredible collection of writings from mostly indigenous people discussing the concept of disability and indigeneity and in their own communities and in history and in looking at historical legal documents and looking at cultural matters. And we really wanted it to be accessible to all sorts of readers. And so, it includes first person stories and also photo essays and poetry along with traditional academic articles, research, academic articles. And I encourage people to check that out because the voices of these people will take you a million times deeper than I could go on a podcast.

Marjorie (00:13:48):

Wow, amazing. I can't wait because as you know, that's also sort of an interest where I feel like we need to be of service <Yeah.> you know.

Ella (00:14:01):

Yeah, In Canada. Definitely.

Marjorie (00:14:02):

This is fantastic. That's gonna be an awesome resource. Thank you for doing that and for spearheading.

Ella (00:14:09):

Absolutely. It was thrilling. It was absolutely thrilling. Yeah, sure. I loved it.

Marjorie (00:14:14):

So the third document that you submitted is one, I believe that you've done with Maurice Feldman. <Yeah.> On IQ. So do you wanna talk about this one?

Ella (00:56:23):

Yeah, absolutely. It was to Munazza Tahir, and Maurice Feldman and myself. And this was an article where we really wanted… It was interesting for me because my work is typically pretty sweeping in scope. As I said, it's any type of disability. I'm looking at parents, I'm also looking at parenting caretakers. I was working nationally by mandate under my grant, but also worked internationally, and worked with people in Mexico and all over. And this one we really narrowed the scope down and said let's look at just parents with intellectual disability, developmental disability, in the American court systems, in just the dependency court system. Because also I work across court systems. And see how this pseudoscience of relying on IQ to sort of ritually predict parenting capacity is manifesting. If it's manifesting, how often is it manifesting? And what we did was to look, we did bullying searches of legal data to extract over, I think we have 45 cases at the appellate level, to see how frequently this issue of 'we can tell you if they'll be able to parent based on IQ' or included it as part of the offerings to the court to terminate parental rights occurred in the trial court and how often it was upheld in the appellate court.

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So I'll say to begin that there are many states in the United States where you do not have the right to counsel for appeals. So we don't know, this is not determinative obviously, because there may be many more parents that experience this use of their IQ being weaponized against them in Child Welfare proceedings, that are never able to appeal because they don't have a right to appellate counsel and they can't proceed alone. They're not gonna proceed proper on their own into appellate level cases. So that being said, what we found was that over 80% of the cases, this IQ was pled where a parent had intellectual disability identified as having intellectual disability and over 80% of the time it was upheld in the appellate courts. This is particularly concerning because we have peer reviewed consistent, long term data, showing that IQ is not predictive of parenting capacity.

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We know that many, many other elements are far more determinative. You're talking about whether parents are isolated, whether parents have appropriate supports, whether they receive an intervention that is best practice or peer reviewed, whether that parent has trauma in their life that's been addressed or not, whether there's alcohol or drug addiction or domestic violence happening. Anyone who's worked in the field, and because I actually worked with parents and their counsels, hundreds and hundreds and hundreds and hundreds of cases over many years. You know all those things are what create problems. Parental IQ in and of itself, we know from the research is not determinative and yet a courts just eat it up. And it is really easy to weaponize against these parents. We saw in the research of these cases things that I had seen in the work in real time with parents, which are things like courts.

(00:18:17):

So I've, one case particular that really troubles me still to this day was a mom. And she was actually a native mom. She was a Tribal member and she had intellectual disability, and she and her child were in a supported living facility that was actually really good in model. It was kind of an apartment complex, but they had people there that would check, see how everybody's doing, there to help if anything goes on. And she had personal aids that would come and assist with her and her daughter. She worked at a local Walmart, but they were just really hot to remove her kid because, and this was <laugh> first, that it wasn't normal for children to grow up with staff coming and going. Which I found very amusing growing up around the tech upper class of the Bay Area where staff comes and goes about every month of the year. And that the mom wouldn't be able, 'yeah, she was fine now when the kid was a preschooler or kindergartner, but she wouldn't be able to help her with math by the time she hit eight or nine.'

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And I was like, nor can I. Nor will I never be able to help anyone with math? Cause I was terrible at math. But that focus on her IQ and what it predicted she would or wouldn't be able to do as a child got older around schoolwork specifically was just a huge hang up. They were so determined that this mom's IQ would be a barrier. They began pursuing, having the child connected to her birth father, who the mother had, did not like and did not trust and had not had around the child, began having visitations. Mom told them that the child was coming home upset. Didn't wanna send her, she was wetting the bed. Now they still insisted, right? Cuz they wanted to reunify this kid and her dad cause he didn't have intellectual disability. Kid came home, didn't wanna take baths. Finally, it ends up father was sexually abusing the child, father was arrested, but mother at this point, the institutional betrayal and her damn good parenting instincts drove her to take the kid and run and she left. And who knows, we have no idea what happened to her. I had connected her to a native law or law resource center, but they don't know where she went either.

But that's why it matters is that the entire progression of pursuing services of whether children are removed or not, whether reasonable services are provided or not, whether reunification happens or not, whether termination happens or not, can be strongly driven by reliance on one variable. I mean, it wouldn't even meet the standards to be considered in our courts as scientific evidence. And yet no one raises this. That's not raised that I've ever seen in court proceedings that this is pseudoscientific and shouldn't be allowed into the record. It's not relevant.

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And so yeah, it's very concerning and that it was only, I think we did that article in 2016, maybe 2017. So this is very recent. It's very parents with intellectual disabilities, as I said, are most often called out in the codes, Child Welfare codes as a parental, an aspect of the parent that can be a basis for removal or for termination of parental rights along with mental health. And there are other issues that are similar for people with mental health to this issue of relying on IQ, specifically in California and New York and some other states that consider themselves so liberal and progressive, have the most horrible on parenting disability. You can have two psychologists assess a parent with a mental health issue. If they determine that the parent won't benefit from services, no services may be provided. Right? So there is something similar to this, but I feel like that's what IQ does.

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I feel like when they plead IQ, it's almost like, 'okay, case over, right?' Yeah, 'the doctors have established the number and that's it.'. I was on the SAGE reservation a few years ago training, I would provide free trainings to any Tribe whose social services office wanted it. And they had, many Tribes have their own social service departments, like social workers and they also have their own courts. And in case anyone's wondering, the reason why the ADA we're even talking about the ADA and Child Welfare Act, because ADA doesn't apply to Tribes is because most of the cases don't take place in Tribal Court. Most Native people do live off reservation and their cases where they should be going to Tribal Courts often and instead they're adjudicated in the State's courts. So anyway, but I was at <inaudible>

and talking with social workers there about parents with intellectual disability, and asking them how is it considered, how is this disability considered around parenting?

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And their answer was so wonderful, these professional social workers women, but also culturally emerged in their immersed in their Osage culture. And they said, especially with the traditional families, if they just tell the family what the child needs, that the family sort of wraps itself around the parent and child. And they will make sure that whatever needs to happen happens. And that I've spoken with disability advocate, another disability advocate specifically, who is in Oklahoma and has disabled children herself. And she talked about that, about the way that the community wraps themselves, she used that same term, wraps themselves around the family. And I think that that is so interesting because a lot of the research is even people like David (McConnell) talking about the need for this, a system of support and people around and how chilling and undermining isolation is to people with intellectual disability. I think everyone needs that.

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And that is why, again, I think especially with intellectual disability, we would do really well to look to Tribal communities and ask them: ‘what do you do? What do your social workers do? What do your courts do?’ They do it better in many instances because the underlying conceptualization of disability is not that there's something pathological and negative about you. It's an aspect of who you are. And there are a variety of interpretations about what that means or why that is, in different communities. But I feel like inherently they do some things better than us and we really need to be looking to them and asking advice on how to improve our systems.

Marjorie (00:25:46):

And it's great that you're mentioning this because it's a great segue to the next question, which was, what should the field, or in this field, what should we do for the future?

Ella (00:25:58):

Right? Yeah, that's always the question. And there are lots of recommendations in the Rocking the Cradle (NDC) that are still valid, and unfortunately have not all been done. But I will say that I think it begins with training. It begins with, we have to accept that as Nations, because of eugenics. We isolated and segregated these people away for over 50 years. And it takes Society a while to relearn, not to learn. Cause they were part of our societies until then. And there were always some people with disabilities parenting. But as a large population, we have to relearn to think about them again and to integrate them again when we're talking about families and parenting. And so I, I have degrees in social welfare and Native American studies and law. I never received any information on parents with disabilities. And my Social Welfare Program is the number one in the United States. And the Social Welfare Program at UC Berkeley, it was a people's program.

(00:26:59):

It was trying to create people that would go out and work for the wellbeing of families. I don't think any social worker wakes up in the morning and goes, I wanna go screw over families today. That's just not, I don't believe that people are driven by an inherent desire to do badly at this. But we don't train anyone, we don't teach that, right? This needs to be a part of the training in Social Welfare programs, in Law programs, this should be part and parcel of what people are taught. And then when they go into their professional communities, it needs to be part of the continuing education that they receive. Particularly in Child Welfare and dependency courts, but also in the guardianship courts and the family or divorce courts we call them. Because those are places where we are still making what feel like life and death decisions for families.

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In Child Welfare of course it's that much more intense because we are legally terminating the relationship between parents and children ultimately, potentially. And we have to start talking about these families and these systems.

I think we have to own the fact that disability is an inherent experience of the poor. It is so common among very poor people, being poor may maybe not as much as Canada I can't speak to other contexts, but in America where you have no guarantee of housing or education or healthcare, the likelihood of developing disability if you are very poor is exceedingly high. And so, when we're dealing with impoverished systems, as in the Child Welfare independency system, it's a matter of Justice and fairness that we acknowledge we have disabled. Huge of that population and we need to account for that. And with communities that are highly overrepresented in our systems, specifically our black and indigenous communities, we need to account for how that is driving them, the overrepresentation of those communities in our system.

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Unfortunately, I see people on both sides of arguments around racial overrepresentation in these Child Welfare, ignoring the disability aspect and how it can drive involvement in that system. And so, whether you think it's from due to Structural Racism or inherent harm that's been done to the community that's created dysfunctional coping mechanisms, whatever your position is, nobody's talking about the disability in and of itself is a driver of ending up in that seven doing poorly.

So I'd really like to see education, I'd like to see training. I'd like to see people acknowledge that we have a responsibility to address this because we've created a lot of the disability in the poverty community and the poor community.

I would very much like to see the Department of Justice require training and that funding be tied to developing resources, in your county. So, if counties are gonna receive monies from the State and from the federal government to do Child Welfare, they must show that they're funding the development of peer reviewed and best practice intervention services, specifically in creating interventions that are peer reviewed, like Dr. Feldman's for people with intellectual disability. Some of the Australian models for intervention in parent with in families or parents who have mental health and in training. Occupational therapists, that was the other group I was gonna say, occupational therapists, social workers, and lawyers all need to be trained about this. But in creating OT training, funding and creating capacity for OTs to learn how to work with parents with physical disabilities, including blindness and deafness to parent their children.

I think that those would go huge way towards ensuring the safety and wellbeing of children. And you know, I'll admit like adults are nice, but my real driver is kids. I just don't ever want to see a child removed from their family and put into a carceral space, simply because people guessed or assumed that the child couldn't be cared for by a disabled person safely.

We know that when kids go into foster care and dependency systems in our country and in other countries, their risk for harm, for sexual abuse, for physical abuse or mental abuse, and even for death, skyrockets. And no social worker, lawyer is gonna tell you: ‘Oh, foster care's great. That's definitely a great place for kids. It's wonderful. I'd recommend it in a case.’ It seemed typically as a last resort. But with disability, because people are working off of myths and assumptions and sort of tacit agreements about the pathology of disability, they jump to that to removing kids. And once you remove them, take them out, it's hard to get them back with a disability.

Yes. So my real focus is on the wellbeing of children. I don't want children to be put in riskier situations simply because someone's guessing at whether or not there's risk in their home situation. So I think all those recommendations go toward that.

Marjorie (00:32:11):

We're gonna be busy for until our retirement

Ella (00:32:17):

For sure. Oh yeah, absolutely. <laugh>,

Marjorie (00:32:23):

If there was one thing that you could tell childcare workers, what would it be?

Ella (00:32:28):

Oh, if there's one thing I could tell 'em… You can't truly know how parents with disabilities or caretakers with disabilities and their children mutually adopt to one another. How parents learn to do all the things that you go, ‘How would you ever do that safely if you are blind or deaf or whatever’. How could we ever create support or an emergency plan, if you have this mental health issue about you. You can’t understand that how creative parents are and what they will do to ensure they can care for their children. And also, you can't understand unless you've looked at the research, how babies and little children mutually adapt with their parents, and how babies of a parent who maybe has small motor functioning show patience and a lack of distress when their diapering takes five minutes and an infant whose parent doesn't have that disability will start to become distressed after a minute and a half.

Parents and children. You can't know that inside internal, the way that works of ‘I will figure out and do anything for you.’ And the child just, it's their norm. It's the water they swim in. So, Stay humble. Don't assume that you can tell from outside what the reality is of that relationship.

One of my very fondest memories is being about two years old and my grandmother telling me: ‘Go get your papa. I need your papa for something.’ And my grandfather, who was deaf from World War II, won Purple Heart, the bronze star got his ears blown up by a Nazi grenade. It was a sniper. I ran into him. And I remember being so little, I had to kind of climb his legs to get up on the sofa where he was. And holding his face and saying: ‘Grammy needs you’. Because my grandfather read lips. And so I knew, by two years old, that if I needed to tell Papa something, then I needed to climb up to get to Papa and hold his face and tell him. And I remember him just cracking up because it was so funny that this little tiny child got how to communicate, but I had mutually adapted.

So under, Stay humble. Do the reading. Read the research. Bring in the right people, before you assume that you can understand what the risk is or what the bond is. You might be happily surprised by what the reality of that family is.

Marjorie (00:34:53):

On that note, I just wanna thank you so much for this enlightening and empowering conversation. It was just a very beautiful moment, and I loved every second bit. So thank you so much.

Ella (00:35:11):

Thank you.

New Speaker (35:13):

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