EPISODE 14 ELLA CALLOW PART 1

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.

And today my guest is … 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.*** We started our conversation with me sharing the impact Ella has had on ***me*** after I became a parent with a disability myself. Enjoy!

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

Marjorie (00:01:09):

I'm very excited to have Ella Callow, uh, here with us today because every time I've met Ella, she impressed me by the respect that she has for every parent. And to me that was very meaningful because in my line of work, certainly respect and dignity was important. And so recognizing that in someone else was equally sort of beautiful, I guess in a way. But it was even more important to me when I became a parent with a disability. And the kindness and the compassion and the hope that Ella gave me was very extremely meaningful. And I will forever be thankful to her for that. So thank you Ella, for accepting to be here with me today to talk about parenting and disability and I'm very excited about the time that we're gonna spend together.

Ella (00:02:06):

Well thank you so much. That was, that's lovely to hear. And I really appreciate those kind of words. I'm very happy to be here. Yeah.

Marjorie (00:02:15):

Excellent. So at first I wanted to know a little bit more about how or what led you to doing this kind of work and working with parents

Ella (00:02:25):

Yeah, thank you. It's interesting because my background and my area of interest really was on Indian Child Welfare Act law. I focused on, I majored in social welfare and Native American Studies undergraduate. I come out of the native community and I was really interested in law school, in Indian Child Welfare Act law. For people who might not know those, that was a large piece of remedial legislation passed in the United States in the 1970s to try to address and remedy the wholesale removal of native, indigenous tribal children in the United States that had occurred through targeted federal programs and just generally through child welfare in the US over decades and decades. And I really wasn't focused too much on disability generally.

I did grow up in a family with a grandfather who was significantly hearing impaired. He had lost his hearing in World War II. And so I had grown up as a child with a disabled adult that I utterly adored. And there was six of us grandkids, we all adored him. But I didn't really think about disability or parenting with a disability until I finished law school. And I wanted to spend a few years getting training in a firm. And so I had done. That was my third year and I was looking for a different position, something back doing the type of work I wanted to do social justice work with law. And I saw an advertisement from Through The Looking Glass, which was a very old independent living movement grassroots NGO in Berkeley that focused on a non-pathologizing family interventions and support for disabled parents and children, families where there're both often and they were looking for an attorney to join them and create a legal program. They were designated at that time and funded as the National Center for Parents with Disabilities and their children.

(00:05:07):

And so that was interesting to me. It was a situation of doing some research and going, Oh well I might not know the words but I can hum atune to this. I understand the idea of taking a people and exploiting and excluding and segregating them and then denying them the right to familial integrity, taking their children or preventing them from having children from the native context. And realized that many of the same dynamics were in place in the native for the disabled community. And so I came in and I started a legal program that did three things generally. (1) One was that we provided free legal technical assistance to parents and parenting relatives with disabilities across the nation when they were facing loss of custody based, in least in part on their disability in any of the systems that remove children. So either the private family court system, the public dependency court system, or the guardianship system where you can lose a custody of your child to a guardianship.

(00:06:25):

And the other thing that we, things that we did were (2) to provide technical assistance to stakeholders seeking to create legislation or policy in their state to protect these families. And (3) the third was to conduct research into the systems where this dynamic was taking place, so the child welfare system and the dependency court system where the legal side is managed of child welfare cases. So in doing that work, it all sort becomes enmeshed and that you're using the research to support the legislation and policy. You're talking to parents to figure out what needs to be researched. You're providing technical assistance to parents by making sure everyone's aware of legislation and policy that exists that could be helpful or useful or not. So we published many articles and created many guides for parents and their counsel when they had counsel, we gathered a data on, so we could find trends in what happened with parents. And we really focused on the intersectional nature of the population. Child welfare particularly is a poor people system and you find many groups that have been negatively racialized as well as pathologized in other ways. Very few people that hold what Wolf would call socially vitalized roles in our society. So we really wanted to hear from those who are multiply, excluded from the opportunity to have families in the United States.

Marjorie (00:08:16):

A big job.

Ella (00:08:20):

Yeah. It kind of just kept snowballing getting bigger and bigger. I began there in 2004 and the reason that they had wanted my position and this program that we developed where I was a legal director was because, as I said Through the Looking Glass, was a grassroots old school, Berkeley Independent Living Movement program. A lot of the same people that had worked in developing the first CIL and had been in the same group of people as Judith Heumann and Ed Roberts and integrating schools and other spaces. And they really were a place that disabled people went to look for help. So they began after the institutionalization when disabled people then had both the social opportunity and the physical capacity cause they weren't just being outright sterilized or institutionalized. When they had the opportunity to become parents. Then the other side of that eugenics coin of having prevented them from being parents was all of these laws that developed to remove children on the basis of disability along with the other typical factors which are not identity factors, which are usually behavioral factors.

(00:09:39):

And so they were overwhelmed because they were just constantly getting calls from all over the country. People were going, “They're taking my kids, you have to help me. They're taking my kids, you have to help me.” They had worked with the National Independent Living Center chapter in Idaho to do a project to create what is still the most comprehensive legislation protecting parents with disabilities in their kids. And the reason that came about in Idaho was because they were doing listening sessions that Independent Living Centers do listening sessions in their states and asking what are the biggest issues we should be taking up in the next year? And over and over people said, “They're taking our children, we have to do something to help us.” So they had gone from being kind of overwhelmed, providing individualized technical assistance and support about what clinical services are appropriate in these circumstances, what are the policies, misconceptions or myths about these parents and their children and things like that to being asked to contribute to creating legislation and policy on a statewide level and realize that they needed to have someone at the legal background to own those. And then we just really had deficits in the narrative around, well, how many of these parents are there now? How many in the systems that we're looking at, how much of that system is comprised of this population of families? You couldn't really talk about it, validly without answering some of those questions. And so we knew we'd have to do extensive research as well.

Marjorie (00:11:26):

<affirmative>, I love in your story how one it started grassroots. So it's really sort of coming from parents themselves <Yeah>. Saying, No, we need help with this. And to have an organization to say, Yes, we're gonna tackle this and we're gonna create this position. We're gonna find somebody who's socially justice driven <affirmative> with the legal background to be able to tackle this. And I find that very beautiful in terms of how all of this came about. Very powerful actually.

Ella (00:11:59):

Yeah, it was interesting too because the organization itself contained many parents with disabilities and many people that owned and lived multiple identities. Many LGBTQIA, parents with disabilities working in this field. So Corbett O’Toole and her partner were closely associated with it. And her partner of many years worked there. Judith Rogers who wrote The Disabled Woman's Guide to Pregnancy (and Birth) and was herself a wheelchair using parent, was there as an employee and for 30 years or something, one of the founders of it. The founder herself, Megan, she was married to a man Howard KirshBaum, who himself had MS and went through the experience of being diagnosed with MS and having his MS progress throughout the time that they were parents. So while they were both therapists and a lot of what they had started the agency to do is to provide non pathologizing family systems, child development based interventions with families.

(00:13:33):

Very Bay Area, very San Francisco state, early childhood development, all of that stuff from the seventies and eighties. While that had been their focus, it also became a personal thing for them because he was a person with MS.

And so lots of people of color working there, lots of queer people working there and disabled people working there. So my experience working in the disability community was never a disability rights for disabled people with ux. It was always disability justice and it was always grassroots and people and run by disabled people and their families. So it was different. As I went out into the world, I found out how different that was. I didn't know that I'm from this area too. So you know, grow up with everybody's movements. And I'm from the Bay Area, so we grew up with the Black Power movement and the Feminist movement and the Gay movement and the Disability movement. And I was used to seeing kids being zoomed around on their parents' wheelchairs and seeing people whose parents were blind or were deaf. But I didn't realize how political and how politicized it was and what that represented as a response to this hegemony of eugenitism in America until I went into the field as a professional.

Marjorie (00:14:55):

Wow. There's so many things. It's mind blowing right now. You're giving me sort of a history lesson, which I'm so thankful and grateful <laugh>

Because I'm like, and you're naming names that I know and some of them I've read their work, but you're giving me another layer as to who they were, are as people and what led them to probably doing the work that they did, that I've read, that I cited, that I sort see as mentors in a way. But you're giving me that extra layer, which is incredible.

And I was getting also emotional because after my accident, becoming a mom on wheels was not necessarily something that I wanted to, that I asked for obviously. And I was looking for those people that came before me who were parents who could have told me: "Yeah, you can do it. Yeah, it's feasible. You just have to be a little creative."

Ella (00:16:07):

Yeah, like I know that one of the things that I really loved that we did while we were there, cause all kinds of trippy, interesting projects happened at that place. And one of them was a guide for blind parents that was done by done by blind mom who had actually been a blind mom of twins and of that's mind blowing twins themselves, parenting twins is mind blowing. But we go, Wow, how do you do that? But she had all of these stories and tips and tricks and how twos and things that were from blind parents in the community. And once you get involved in the community, you know that blind parents like the blind community, there's just tons and tons and tons of blind parented families. But I thought that was so amazing because I was like, God, if I was a new blind mom, that would've been my Bible. But I think there's a real need for collections just of what was your experience? What was that like for parents who are either parenting, even if they've had their disability, their whole lives entering that parenting world, or for people who are newly disabled as parents? I think that that's a real need. I hope somebody has somebody does that. <Yeah.>

I'll say the one book that I think goes there to a degree of people are interested is there's a book called Mothers with Disabilities that was published about, I don't know, six years ago or something, and I did a chapter of it and Paul Preston, Dr. Paul Preston who, who's a coda and cultural, cultural anthropology and focused on parents with deafness, parenting with deafness. He did a chapter and talking about research they had done showing using very conservative measures of child wellbeing for young adults and showing that children of disabled parents fair just as well as anyone else when using that measure. But that's a great book that looks at it. I'm always, I forget sometimes that there are other stories in that book because I do legal and my article was I think Motherhood and Madness in the American courts or something and it was looking at court cases, but there are other stories in there as well.

(00:18:33):

But there's a need for so much more and that because my work involves all disabilities, because coming at it from an attorney, I'm looking at, well, what does the Americans with Disabilities Act protect? And if you're protected by the Americans Disabilities Act, then you fell within the scope of my work. I was really able to hear from many different communities about the challenges and to see how the experience of parenting was different when you have a visible versus an invisible disability, what your vulnerability to social judgment is and how you can more quickly end up in Systems that incarcerate children, like child welfare systems, when you have apparent disabilities and what those experiences are. If you have a disability that's more highly pathologized than others, mental illness being more pathologized say, than someone who has vision impairment. There are differences in how those communities experience parenting. And then when you include race and ethnicity, gender issues, issues of gender identity and sexuality, you know you can really have you just see that it's this incredibly human area with this incredible range of diversity in the experience of these parents and what they mean, what they experience both positively and negatively.

Marjorie (00:20:02):

It's not just your personal experience, this is actually some of the research that you've done that actually sort of gives you that knowledge. And two articles that you suggest that we talk about today actually talk about of Intersectionality and the Indian Child Welfare Act, if I'm correct. And then talks about the prevalence and everything that you talked about having more parents with psychiatric illness or diagnosed as such in Child Welfare. So do you wanna talk a little bit about the research and tying in what you've been saying?

Ella (00:20:40):

Yeah. Yeah, I think I'll start talking a little about prevalence if that's okay. But the prevalence question. So in order to get any action, especially in countries like ours, those large countries, you really have to be able to say the 'why should I care piece?' And sadly, especially when your work is for pathologized, non-valorized communities, you need to be able to talk about numbers and impact on systems. And so one of the main things that we did was look at a couple of different, we took a couple of different methodologies to try to establish some sort of baseline around how much are Child Welfare systems comprised of parents with disabilities and their kids. We wanted to know that because I felt that similar to our American penal system, that what we would find is that these were largely disability serving institutions. That in the same way that research had come out in the 2000 teens, early 2000 teens talking about these exceedingly high, over half of the populations in our prison systems were people with mental health involvement that we would find high levels of disability in these systems of Child Welfare systems. But we didn't have really a way to prove that. There had been one study in Boston right after the passage of the ADA to try to establish prevalence. And they had gone and looked through a randomly selected number of Child Welfare files looking for evidence that families are disabled and then extrapolated from that. And this had also been undertaken by Booth and Booth in England. So we thought, okay, we wanna do that, we really wanna be looking at some actual files.

(00:22:40):

And then we took the National Child Abuse data set, the NCA data set, which is just a large data set around child abuse and neglect in the United States. And they collect a multitude of demographics about the children and it's collected from each state and each state is bringing it up from localities where they have designated child welfare entities to do this work. And so we wanted to look at that and see what we could find about if there was disability and caretakers. And we found it in both far more than anyone expected really. So for the Child Welfare case reviews, which are extremely difficult to do because Child Welfare pieces and their filings don't fall under foyer or open government acts, sunshine laws, things like that, it's very difficult. You have to get agreements from child welfare to give you access to their files.

(00:23:33):

You have to go there typically to as far as I know, always to review them. So we chose the largest urban system, Los Angeles, a small rural system in Texas and then a suburban center in Minnesota to get a range of geographies and population, demographic, scopes and populations. It was interesting in the beginning asking Los Angeles, how many people do you think you'll have? And oh, I don't think we have hardly any. And then I remember someone going, 'Oh wait, do you think like…' and I think they used a term delayed or something, meaning intellectual disability or developmental disability. 'Do you mean those people too?' I said, 'Yeah.' And they go, 'Oh honey, that's every other case.' And I thought, okay, so it's somewhere between nothing and every other case, this is gonna be interesting. So we requested that we gave them an explanation of what we were doing and went down and went through the cases and went through, I think, oh gosh, I forget how many 150 case files, Some of the case files had eight or nine, 10 files within it. It was several of us over many, many, many days. Many days.

And what we were looking for was if there was a formal designation of the parent as disabled. So either it was pled by the system that the parent was disabled and it was a basis for removal or concern. There was a doctor, there was doctor's documentation, medical documentation, or first responder or medical documentation. So people being what we call 51 50 in California, taken in for psychiatric observation.

And so we were really looking for as formal as we could find. And then we replicated that at each place. And in Los Angeles, I think it was well over 30% of the population just formally identified. We don't even know how many people have it, but it wasn't the main stay of their case to the point that it was pled or there was documentation on it.

(00:25:28):

And I have to note that one of my areas of deepest focus is on either the intersection of Indian Child Welfare Act and disability, because native people, as in most colonized nations, including Canada, have the highest levels of disability. They did not provide us with their equal court documents and they also did not give us their Death Court documents. They didn't even tell us they had a Deaf Court until we began. So that doesn't include Deaf families and it doesn't include Native people. I was very frustrated with that, because they knew that our model would've required those and wanted those. So that's even lower than we expect probably really is.

In Texas, similarly, very high numbers, and I think around the same amount. In Minnesota, the entity that we were working with happened to have, I think a grant at the time for them to do Mental Health Screening when parents enter their system. Cause you have to realize that they don't screen for this. They don't collect data on disability unless it's problematic, unless it's problematized, they're not collecting it.

(00:26:44):

Which is interesting from a bioinformatics point of view of ‘what do you wanna know?’ Because if people have a disability in the United States and you're a public system, you must provide them ADA, right? So why would you wanna know that if your concern was austerity and the provision of services on a cost-based basis, you're trying to keep them so they don't collect this. But in Minnesota they have this grant to do Mental Health Screening and it was over 60% where there was Mental Health Screening. So we can imagine that if there was a proper valid intake, asking people, and screening people that we'd see much higher numbers even than we saw in LA and Texas.

<Yeah.> So that was the first one and we did that research and published it in late 2000 teens, but we had the data before publishing for a couple years and were using it and it was extremely helpful to move legislation and policy in a few places.

(00:27:31):

Of course, my work was National because our funding was National, but as the way I met you, is that we also did International work hooking up with researchers that were doing the same type of work through IASSIDD, International Association for Scientific Study of Intellectual Disability. And also, I worked with the Nordic Network on Disability Research (NNDR). So, it was good to be able to talk about, what does our population look like, what are the numbers we're seeing when we're going to talk with people in other countries in order to try to figure out what types of interventions would be useful.

<Yeah.> So that was really the first step was, for us, early on, is going, we know we need some numbers.

Marjorie (00:28:36):

Yeah. It's interesting because we all say we need numbers and we all say despite the few numbers that we already have, we keep needing sort of more numbers because it's sort of like we need to justify all the time sort of why we're doing this work and why services or the system actually, cause it's not really about services. I think it's larger than that. It's systemic reorganisation around how we're just supporting families as a general.

Ella (00:28:56):

Yeah. I mean if you want, as we want to see the creation of capacity to serve these populations, you have to show that there's a certain size of the population. And this is a huge problem that we have is that even if, say, I was working with a, say for instance, I had a case as a young black mother of cerebral palsy who was a walking king user in Georgia and they had just provided nothing for her. And she luckily had a really good counsel that came in then and started shaking things up and they were trying to prevent the move to the termination of parental rights stage saying she hasn't received services. She needs to receive services. All that she was receiving was an older white social worker who would bring her child to her home from the foster parents' home. when they were foster do parents, they wanted to adopt this child and the social worker would sit and play with the child at the house in front of the mom. Really did not even involve mom.

(00:30:02):

So we go back to court and really this attorney did a great job of zealously representing this mother and child, and the court agreed with us and even let me testify in a very unique move regarding the Law, which is not usually something that I would be allowed to testify about under a very old Georgia Law, something to do with a bank robbery I think. But the State ended up saying, 'Okay, we agree, your honor. You're saying that we need to provide services, but those services don't exist in our county and this isn't California, this isn't the Bay Area. We don't have this and you can't order us to provide things we don't have.' And that argument is made successfully all over. So it becomes this round robin thing of parents with disabilities lose their kids all the time in court. People aren't giving them services, nobody understands these cases.

(00:37:01):

So the services are not developed. We have excellent models and things like domestic violence where there's the VWA Act, the Violence Against Women's Act, the United States. Because domestic violence impacts children and because the system needs to be educated on it. There are summer for social workers offered year after year after year to educate them on this issue. And there are entities that have sprung up to provide counseling for families where domestic violence is an issue that are funded by the Child Welfare systems because they understand it's an issue. So they are trained on it all the time.

If you fund it, they come. If you start funding for Parenting Wvaluations that are best practice, if you start funding for people to learn peer-reviewed intervention like Maurice Feldman's interventions for Parents with Intellectual Disability. Some of the interventions out of Canada on the East coast around Parents with Mental Health involvement, things that were developed at places like good looking glass of Occupational Therapists trained to work with parents with physical disabilities and sensory disabilities, blindness, deafness. Then if you fund those things will develop that. They'll take those trainings, they'll learn that methodology, they'll start providing the service. But we haven't gotten there yet. We really haven't.

Marjorie (00:32:37):

Yeah. Yeah, there's a lot of steps to be taken on that road. Certainly.

Ella (00:32:43):

Yeah. I would say that in 2012, the National Council on Disability came to us and asked us to write a report for them. They advise the, in the United States National Council on Disabilities, an independent entity, that advises the Executive, the President and Congress on issues of importance to disabled people in the community nationally. And at the time, Ari Ne'eman was on NCD and Ari and I had worked around parents with autism and custody issues. He began the autistic self-advocacy network as a very young person. He was really sort, prodigious in his work around that, very young. And we really felt that we needed a report coming out of NCD to bring this to the attention at the national level.

And so it was edited by Robin Powell and myself and Dr. Paul Preston and a number of other people contributed chapters to this. I think I probably did the majority of the framing of issues for that. And we included this whole history, as well as what was happening now, special issues in the Native community, issues of reproductive technology and access, looking at best practices nationally and internationally. Talked to many of folks like you, and others, Australia and all over. And your recommendations of course.

(00:34:26):

So it was really 2012 when that was published. That a lot of this work in America began on a national level being framed in as an issue and a population to talk about parents with disabilities. And we're only right now at 10 years since then, right. So I wouldn't expect to see that nationwide, we have amazing services available, but I'm disconcerted by the lack of progress. We've known that these things are needed, been making these arguments now for 10 years. And I really don't know of any Child Welfare systems that are building these resources in their community, as a matter of compliance with the law. I did participate, I've acted as a litigation consultant for the Department of Justice Civil Rights Division in my past. And one of the things that I worked with them on was looking at, they had a matter opened with the state of Massachusetts around their Child Welfare system and treatment of Parents with Disabilities.

(00:35:30):

And it stemmed from the Gordon case, which was a case of a mom with intellectual disability that had her child removed. And ultimately it was determined that had been in violation of the ADA in section 504. And after that case in 2015, the Department of Justice issued Guidelines saying the ADA applies to Child Welfare proceedings and it applies all the way through termination of parental rights. That had been a matter of, we had split circuits on that issue. And the Department of Justice in America has what we call Chevron deference, meaning they have authority to interpret ultimately they're the entity that interprets the ADA. And so to have them finally say, 'yes, it applies at all stages' was huge. And they then brought an investigation to the whole state of Massachusetts after the boarding case that finally settled in 2020. And its landmark. It's the first State where there is a settlement saying we violated the rights of disabled parents in our system and we will remediate our System Statewide under the direction our agreement. This agreement with the Department of Justice. So I'm really hoping that we'll see developments in Massachusetts around creating these services, providing training for social workers, public defenders, county councils, dependency court judges, all of the people who are stakeholders, professional stakeholders in their systems.

Marjorie (37:03):
This, listeners, is where the first part of my conversation with Ella Callow ends. But there's much more ahead. In our next episode, we'll discuss the intersection of disability, poverty and First Nations' rights. We also talk about the use of IQ in custody battles, the pseudo-science around it and how it is being misuse. I hope you'll tune in.

New Speaker (37:30):
This podcast was supported in part by a grant from the Minnesota Department of Human Services, Children and Family Services Division.