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 guests are Hanna Bjorg Sigurjonsdottir and Jim Rice. Hanna is a disability scholar and one of the pioneers in the field of Parents and Parenting with an Intellectual Disability. Jim is an anthropologist who wanted to study poverty and inequalities and who found himself in Iceland where he met Hanna. Together they work on showcasing the faults in our systems and how power interplays with disability status and parenthood.

I started our conversation by asking them if they came across any acts of resistance against stigma and prejudice from mothers with an intellectual disability in their research.

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

Marjorie Aunos:
As you know, um, Laura Pacheco and myself have been also looking at files and and documents, um, in that we find in cases, and also found that there was either a whole bunch of evidence that was geared to, uh, discredit because of the intellectual disability or not a lot of evidence, and just sort of, you know, using intellectual Disability as a reason to terminate from from the get-go. Um, is there anything that you found in your research that showcases sort of like parents, um, I guess fighting back or resisting all those stigmas and prejudice that we see in those case files?

Hannah (02:13):

Yes. We have seen that from the beginning. I saw the strategies that people or parents were using to try to increase the safety of their family. People did it in various ways. Some did do it just in pregnancy or before the child were there. They actually started to use various methods to collect powerful people or people around them that would have more weight and been more respected and using various methods to increase the likelihood that they could stay in touch as a family. And we have seen it in all our cases and the cases that we are working on today.

What we have found to be, you know, one of the most, most important thing, it's people actually being aware that as person with intellectual disability, you are entitled to support. Some people need, you know, speak, spoke persons with them to help them. Some have been more able to speak for themselves, but it can be extremely difficult. It comes to my mind the research that one of our doctoral students, Sarah, is conducting now. It's a person that I have known for 10 years, 12 years. And she calls us her secret weapons. She continues with her life, but when she needs, when she needs help to have control, more control of her life, she asks us to come to visit to meetings with her or to help her. And I believe that she has, you know, it has been an important part of keeping the family together and getting rid of some workers that they're actually more harmful than helpful in her life.

But we see it, we see sometimes strategies that are not helpful. We see often that parents are trying to serve the system, trying to do the right thing. One of the claim is that a child it's too thin. And the mother is blamed, as we know, the mothers are often blamed for various things. So she started feeding her child with things that are maybe not good for it, like sugar or candy, which is actually a method that are not helpful and not good. But we see that happening. I guess what I'm trying to say is the importance of families to be respected as they are and have this relationship where they are not blamed. Some children, it takes them longer to walk, you know, some are overweight, some are thin, but it's so easy and this families to blame on the parents, and it can actually, the system can harm more than more than help.

JIm (05:56):
The question of resistance is an interesting one, and I think that's also one flaw of our overall research when we're dealing with court case records. Because when you are fighting the system and you hire a lawyer to contest the order for custody deprivation, that is an act of resistance in and of itself, of course. The thing is, we, when we do this kind of analysis, we are seeing cases, each is an act of resistance, but these are cases where the parents have lost. That's why it exists, and that's why we're doing research on it. What we're not aware of are cases where parents sort of quote unquote, voluntarily give up their children to pressure. That, you know, may not require the same kind of court order. So we don't know how many cases that sort of crumble under these kinds of pressures to sort of voluntarily give up their kid.

To tag on what Hanna said, you know, the act, like I said, the act of contesting it is an act of resistance. But we notice in these cases that there is a sort of a requirement for parents to abide by what child protection says in all regard. You know, like if the parent does anything that's contrary to child protection's view of what they should be doing, it is seen as sort of the parents are difficult, they're being stubborn, they're not following, you know, advice from child protection. You know, they call it advice, but it's more like order, I think.

And sometimes it's unnecessary tactic. I mean, when you have to consider the power imbalance here, which is what I do not think that child protection critically considers. I mean, you have parents with intellectual disabilities. They are, you know, existing within a stigmatized category within Icelandic society in general, people with ID or, and disabled people in general.But people with ID in particular, they often do not have great financial resources. You know, some of them are single parents on top of it, and they're up against child protection. They're up against the psychologists who do the parenting assessments. They're up against the lawyers, they're up against the judges, you know, and some of them may not have very strong family connection. So there's that incredible power imbalance that they have to negotiate at the beginning of any of these kinds of cases. And, you know, to engage in acts of resistance is very, very difficult when you know full well the power that's stacked against you, anything that you do could be interpreted negatively. And it often is, becomes a form of another form of evidence.

We are often sort of see these cases, to use the analogy of like a staircase, you know, the case at the bottom is about a notification about noise in the home. Then they get into the home, and then they don't like something about the home, you know, as too messy, as too cluttered. I don't like how you put your kid to bed. And then it becomes about something else, you know? So there's opportunities for resistance in there can become forms of evidence in and of itself. You know, one tactic, you know, parents get frustrated, so they may not want to talk to the CP workers or, you know, they will make notes about, well, they're, they're not, you know. One was what made me really upset was somebody complained that they were not greeted appropriately when they entered the home. I forget if it was a surveillance worker or whatnot. Now think about this. This is a stranger coming into your home against your will. Nobody wants child protection in their life, you know? I can talk about that later. I mean, if they frame themselves as support, that's something else. But they act like the police. They're there to collect information, to make recommendations that need to be supported by the courts. So the parents have to abide by the requirements. And if they say, we want a surveillance worker in the home between these hours and these hours, they have to abide by it. To say no is not an option. It would create more evidence of, you know, the parents are not following their advice or guidelines and so forth. But there was one where she said that she was not greeted appropriately. And I thought, what the hell? Like, you were expecting smiles, coffee and cakes, like, you know, as typical in Icelandic homes, if somebody comes to visit, you will bring out the coffee and the cakes and whatever. This is not that, this is not a social visit. How do you expect the parents to act. They're not as anthropologists would say, reflective. How would you feel if these agents of the state to paraphrase, you know, word from Foucault, if they are in your home against your will, are you going to be smiles and chatting? You know, ideally this is what you should do to get positive reports, but you, I mean, I don't blame these parents. I mean, I would not react. I would probably react the same way. And, but you have to be very, very careful with, you know, what kind of resistance you're doing.

But now that we are sort of working with live cases in that sense, we just try to sort of gently explain to parents, you know, maybe you should not do this. Maybe you should, you know, you have to be polite to them. You have to work with them, you know, they're in your home. It's probably a good idea to tidy up if you can beforehand, you know, answer their questions.

Hann can tell you plenty about where they were given conflicting advice, which is problematic or actually wrong advice about the feeding of children. You know, one parent went and contacted a maternity nurse and was like, no, no, no, no, you don't do that. You know, so, which puts parents an additional difficulty because, you know, you have to consider who's giving the advice. I mean, we know somebody, a former student who was working as a surveillance worker, and she at the time didn't have any children. She was very young. You know, when parents would, you know, would rightly say, well, you know, what do you know about parenting to give me advice about how to parent? You have no children yourself. You're 20 years old.

Marjorie Aunos (11:35):

I love, actually, I loved how you, you said it and you framed it because you are right. Often, you know, we have sort of the data of the research that we've done, um, but we're missing the data that we weren't able to get. And, you know, talking about the act of resistance, it's definitely the acts of resistance of the ones that we found or the case files that we were able to see. But it doesn't tell the whole story.

I, I'm listening to you both, and I hear a lot of advocacy work within your own research. Do you wanna just reflect maybe about that and, and tell us how does advocacy now stand in the current research that you're doing?

Hanna (12:20):

<laugh>? Yes. I think that is, you know, part of being a disability study scholar. Objectively, you know, we want our research to matter. We want our research to be good for people to change things. We would love to affect the system. So it's, you know, it's very, very clear with us that we are not just researchers that are overlooking the field. But often it's so difficult to change things.

Jim (12:59):

We are very much connected to the people. It's not necessarily, you can be an anthropology without being an advocate to that extent, like in disability studies. And disability studies is impossible to do this kind of work without being an advocate in some way.

I've sort of come down to the point of view that the best advocacy work we can do is helping parents and their lawyers and live ongoing cases. Using the knowledge we have of cases that have been decided using the knowledge of the social sciences and the perspectives we have to try to help them. And, in some ways we have been successful. In other cases, not so much. But in one case in particular, the father's lawyers wanted, we were working on an article about this case in particular, and they wanted it published. So they, when it was being appealed to the Supreme Court of Iceland. We had to explain to the lawyers, academia works at a much slower rate than the law, which a lot of people already criticized are being slow. But there's no way we could get a peer reviewed article published that quickly. But we submitted it for publication, which was fine, but they really wanted to have something to refer to. And, you know, I realized that even though I was a bit cynical about the impact of academic research, it can, you know, in the legal context, they can refer to sort of, you know, the status of published articles, something that the judge, lawyers and the judges can look at in this kind of thing.

And, you know, in another case where we were successful, it was about sort of surrounding the parents with, you know, supporter professionals to have a lawyer in, to have, you know, a rights protection officer in to have, you know, these annoying academics from their perspective of child protection in. But if all these people are involved very early in the case, and they, the parent can surround themselves by all these professional advocates, it can't have an impact in that way. So I'm sort of approaching this more on a case by case, kind of more low level advocacy.

Marjorie Aunos (14:59):

How about like, how has all of this sort of understanding and looking at the case file influenced even like the research that you are doing, but the future research that you wanna do? Have you had like ideas of what you plan to do in the future to, to be able to further sort of, you know, research and your advocacy work that you're doing with that?

Hanna (15:27):

Well, Jim has research project going on.

Jim (15:32):

Well, in my, well, <laugh>, I had one that was concluding. It was about looking at cases of immigrants and, uh, disabled parents in a comparative sort of framework. And covid kind of put a, through a wrench into that. So it was mainly more textual than interview based, which is what I wanted. I'm not a fan of Zoom interviewing parents, particularly marginalized parents. It's just, it doesn't work. But because we notice, you know, the immigrant population of Iceland is increasing and they're coming to the increasing attention of trial protection. And some of these cases are as absurd as parents with an ID. And to be honest, they treat some of the parents of immigrant backgrounds as if they do have an intellectual disability. You know, they talk about language difficulties in a way that sort of almost implies it.

And it's one thing I wanted to point out earlier that when we originally were doing this, we wanted to compare non-disabled cases with cases of parents with disabilities focusing on ID and specific. That was easier said than done because, on the one hand, parents with ID, there's other, often other intersecting factors. It could be mental health issues, it could be poverty, there could be some sort of other issues. And parents who are not disabled. I mean, we've seen drug cases where parents had substance abuse issues. Like one case this woman had issues for 20 years or more. Surely in that time she would've developed some kinds of physiological issues, neurological issues, mental health issues. So to say that this case has nothing to do with disability is also probably not true either. So really it boiled down to how the parents are perceived by the system.

So it's often that's whether or not they do have an intellectual disability or they're borderline, or even parents who may be evaluated as having, you know, a low average IQ are still treated as if they have one. So I realize the issue, I'm not so much interested in what their diagnostic category is, but it's really how the system reacts to them. And they often reacted to immigrants, in a similar kind of way. But the larger future I see, again, links to the issue of advocacy, you know. It is not, you know, I could probably pull off an academic career and retire just doing sort of case study work and stuff like this. And I would like to make realistic impacts, you know, on more than a one-to-one kind of case is, you know, satisfying as I can be. You know, I would like to do something larger.

And originally when I did this work with Hanna, it made me realize sort of how little we did know about various kinds of fields. You know, I'm coming at this as an anthropologist, so I'm attracted to certain kinds of things given my sort of background. Hanna's coming to this from disability studies. She's more of the people person than I am. And we work together well for that reason. But in many of these cases, I realized, you know, from a legal perspective, I'm looking at this, what I see as shoddy work thinking, is this legal? Is this right? I don't know. I'm not a lawyer, neither Hanna. So we realize that, you know, we need to work with a lawyer to, in order to just understand, is this best practice, is this legal? Is it, should this, can it operate this way in the Icelandic legal system? So we do have a lawyer on board to work with who has a human rights background, disability studies background. So I can check that box for a future project. I need a social worker. Because I don't know, when we look at this, is this best practice? Is this how the case, you know, is this, how is a parent being supported properly? What resources exist? Do the, is this on display in the case? We want the best outcomes for families, you know, which includes children as well. And we know that there are cases of children who went into rather horrific conditions of foster care. I'm not saying all foster care, but we do need a social worker.

Psychologist, I don't want to speak for outside of Iceland, but within Iceland, there's a real problem there because parenting assessments are done by psychologists, and I'm not disparaging the entire discipline, but they seem to feel that because they have the diagnostic ability to understand, you know, what, how autism is diagnosed, it doesn't mean they know anything about parenting. But for the court's point of view, if you have certain credentials, that's good enough for them. You know, another case where the person had a psychology background had nothing to do with disability. She had some background in disability but had nothing to do with parenting. So there was no real knowledge base there. But it was acceptable to the courts because they had the degree after their name that they recognized. So we locked into a psychologist, a critical psychologist here that we're starting to work with. So very slowly, I think we are hopefully able to build a team.

And so they know where to turn to, you know, that there's a group of people who can support them in a professional sense, but also the kind of work that Hanna Bjorg has done, you know, the simple act of talking to people who believe you, who do not belittle you, who know what the system is like, who've experienced it themselves. The future research would look like that to create some kind of collaborative research project that is also some kind of resource as well tacked onto that and how that's going to be, how it's going to play out, how we can do it. I don't know. That's what I'm sort of thinking about.

Hanna (21:04):

I would like to add one thing. I believe both of us are very interested in that is, you know. Through the years and by, you know, knowing the families and keeping in contact with them, we see families that are teared apart, but you know, to, you know, their narrative or their life story is disrupted, but then they age out of the system, or you know, they come back to their families and it's very difficult. You know, the parents can be full of guilt over not being able to keep their family together. Children can be very, very angry towards the system. It's something that we, I think both of us would love to do. It's to know more about the children now when they are, you know, reaching adulthood too. And, you know, for the years I have been there without exception, each sent, every child has found their family again, you know, in their teenage years. You know, their original family. Some of them keep, you know, good contact with their foster family and have, you know, the benefit of having two families. But there are others that age out of the system as just the children of a system, you know, that don't even have a Christmas card from the various homes that, you know, they have spent there.

Marjorie Aunos (22:44):

I love this because I mean, we're in two different countries. We have colleagues in other countries as well. And yet, you know, we're talking about similar things, even if we're doing research differently. You talked earlier, Jim, you talked about sort of like the working class and sort of like the middle class sort of standards, right? And this is something that we've started sort of discussing and looking at in terms of ableism and what, you know, are those standards that we have in our society that has an impact on how we see other families and how it's sort of like ingrained in us that we sometimes if we don't do that reflective work that you mentioned, you know, it will sort of taint our glasses and our lenses and how we intervene.

You talked also about intersectionality and how like, you know, being immigrant and being sort of with a diagnosis on top of it and like other factors being poor and so forth, adds to sort of that. Which is also something that has come up in research in other countries as well. And then Hanna, when you talked about the children, it's interesting cuz we were talking, Laura and I just recently, and I said, as I was doing this podcast and talking to all of you and all of our colleagues, I felt like there was something missing in terms of like, evidence or data to sort of like, support. Why are we so strongly advocating for these families? And I realized that the one thing that we have been missing that we talked a little bit in earlier research with the Booths, with Australia like Susan Collings and Gwynnyth also talked to children. But that we're missing sort of that voice as well.

So we were talking about looking at talking to children, and as everybody know, I have a physical disability, and I'm a parent. And I find that often people are listening to me. Well, one, because I'm a scholar, so that gives me a certain status, right? That the parents we are working on do not have that status. But also I have a child that is now 12 years old that can express himself and that can say, you know, my mom is just using a wheelchair, get over it, type of thing. And that if we had those voices, I think, that would be really important. And what I liked about what you said also, Hanna, is that, you know, it's the connection. We can sort of place these children in child welfare, but we're disconnecting them from, from their family of origin, but from a family. Because a lot of them are not necessarily being connected to those families either. And when they age out, then what, how are they connecting to other people? And we are human beings are belonging, like it's important mm-hmm. <affirmative>. It's a about making sure that these children are connected to families, to their families.

So I don't know if you wanna respond to all of my rent or like, my long, long question that has multiple sides, but I think, it's very interesting how from different countries we come to the same conclusions.

Hanna (26:14):

But yeah, I think it's very, very important for us to, to look at them, you know, their children and, how, how they connect to families, just as you say. When you were talking, I recall the young man, he was removed from his parents. He was a small time with his grandparents or great-grandparents, but were taken from there because they were too old. And he grew up in various institutions and boarding schools and, summer families. And as he aged out of the system. He was connected to one person and that was his great great grandmother, you remember? Mm-hmm. <affirmative>. Yeah. His, he was so much alone. I have never, I have never in my life met anyone who is this alone because, there was nothing really, there was no, no one in the past, apart from his relative that was there, like 97 years old. Yeah.

Marjorie Aunos (27:28):

Yeah. It's pretty sad when we think of it that,we do have child welfare, for a reason in terms of like, at one point it was necessary, in terms to protect children. But we have to be careful how we try to protect children that sometimes we may create something else. And, maybe we are creating sort of a group of children that are disconnected and lonely when they age out of the system.

And, also we've seen that in Canada, I would say, which has changed some of the policies is that at 18, these kids sort of go from group homes or foster placements and are said, well now you're on your own, so you have to work, pay the bills and find yourself an apartment. And they have never been taught that. And they've never been coached to do that either. And so they are sort of stuck in terms of being vulnerable because they've never done that and they have no support. And so I know that recently in Canada, they've changed a little bit to have sort of support until 21 to be able to try to make that transition into adulthood.

JIm (28:40):

When I see cases also, I see a lot of also positive things. I mean, there are social supports coming from the municipal social welfare services where there are good workers. There are good supports. But once it becomes a child protection case, they change their methods of operation. In Iceland being 18 as an adult is just, it's not gonna happen. They're not even finished the education you would need if you wanted to go to college or university at that stage, you know? And a lot of them have difficult situations. Some of them have diagnosis themselves. The idea that 18 out the door goodbye is just ridiculous. And it makes you wonder, you know, Hanna's followed cases through generations. When you get that kind of perspective, you wonder what's the point? Could this not have this being dealt with in a less harsh manner? Couldn't we have, you know, instead of making it a child protection case, continue to look at support, leave it with the social services, you know, think of different ways that you can help the parents, you know, and that's where knowledge of supporting parents with ID comes in, you know, and the lack thereof in our cases.

And, you know, I just see so many cases that could have just stayed within a municipal social services, but what it boils down to is proper support for these parents, contextually based. And ultimately, you know, I hate this relationship of adversaries, you know, it always seems to be parents against child protection. Why does it have to be adversarial? Well, when you're conducting yourself like the police, it probably will be, if you're conducting yourself like a supportive social worker, it doesn't have to be. Why do, why does it have to be our researchers against child protection? That's not the way I want it to be. I would love to work with them to produce better outcomes because I think that's what we all want ultimately. But I don't know how to bridge this adversarial divide. And I really think it boils down to the kinds of organizational culture that exists within child protection. Somehow. I don't have enough insights into their internal workings to say, but that would be sort of my gut reaction. If we could broach this kind of adversarial divide, then I think we, it would be better for everybody all around.

Marjorie Aunos (30:50):

We could continue talking like this for a long time and we have in the past, and I hope that we continue having those conversations. If there was one thing that you would like to leave us with, what would be sort of your last comment in terms of parenting with an intellectual disabilities, parents with intellectual disabilities and the field that we're working on? Hanna, do you wanna take the last word?

Hanna (31:19):

Yeah, but, <laugh>, you know, actually just one person comes to my mind. You know, Jim and I have been looking a lot on cases where parents lose custody. A mother of four came to my mind now when we were talking. And, she was struggling. She was alone raising these four children, and she went to child welfare to ask for help. And because the children had a father, she could not get the help. And she said, so for me to get help from you, I have to shield him. Am I right <laugh>? And they were surprised, but they said, no, of course you don't have to shield him. But you know what, her humor and her approach to all of this actually, it became a strategy and she got very, very good support. So, you know, it is good to notice that there are some parents that have been, you know, have good stories, but it shouldn't be down to luck. It shouldn't be down to, you know, your humor or to down to luck. But when one of her, one of her first child protection worker died, she, well, she visits her gravestone every year the day before Christmas Eve and puts a candle there. And I asked her about this and she said she always contacted me the day before Christmas Eve to ensure that me and my children were okay for the holidays. So, you know, for so many years she has been doing this. And, we need also to find, you know, some of, you know, they are not many, this example, they are, you know, maybe this example is unique special.

Marjorie Aunos (33:19):

Yeah, to basically build on the positives and hopefully make that become a standard, right.

Hanna (32:29):

In a way. Yeah. I wish, I wish <laugh>.

Marjorie Aunos (32:32):

We all wish, I think. Yeah.

Well, I think what it does is that, you know, there's definitely a lot of work still left to do and there's many different directions and different ways of doing that work. But all to say that we can't retire anytime soon, that's what it <laugh>, that's what it means, <laugh>. So we're, we're stuck with each other and we will be following our careers. And I thank you for today.

JIm (34:02):

Thank you. Thank you, Marjorie. Thank you. Bye. Bye.

New Speaker (34:12):

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