

Marjorie Aunos ([00:06](#)):

We all know that parenting is hard, so how do parents with disabilities do it? With creativity and because we know of the value of interdependence! Come hear about ways experts say we can best empower these families and let's all learn about how parenting can be done differently.

I'm your host Marjorie Aunos. And today my guest is Rachel Mayes. Rachel and I have known each other for close to 25 years. When we started, she was a student of Gwynnyth Llewellyn and I a student of Maurice Feldman. Rachel is one of the most compassionate and kindest persons I know, one that needs to make a difference in the lives of others. She does so in her life and she did also in her research as she studied one thing that not many thought of focusing on: the grief response of parents with disabilities who lost custody of their children. We started our conversation with her sharing articles that came from her PhD research.

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Marjorie Aunos ([01:28](#)):

Two of the articles that you submitted or sort of proposed that we talk about are actually from your PhD research. So I would let you sort of introduce them to, to us, and then we could have sort of a conversation around the content and the research and what that all means.

Rachel ([01:46](#)):

Yeah, sure. So the project was called Becoming a Mother for Women With Intellectual Disabilities. And I followed a number of women, through, it was a qualitative study, and I followed the women through their pregnancies, trying to understand what does becoming a mother mean for women with intellectual disabilities? And at the time, of course, there's a lot of research about how do women become mothers and what does it mean to become a mother? But the voices of women with intellectual disabilities in that discussion and debate were silent. There was, there was no information about them. So, yeah, so I interviewed this women through pregnancy. So the two articles that came out of that PhD that I thought we could chat about today, one is about the mother identity for. So what do these women say about their identity as mothers? And the other one is about their social support networks and how those are negotiated during pregnancy.

Marjorie Aunos ([02:43](#)):

To me, I was very happy that those were two of the articles that you, you chose, because there's like a personal, but also sort of a professional sort of significance to, to both of them. I'm glad also that you mentioned that at the time, even though we had spoken about sort of support, even though there was, you know, different research around programs and validation and best practices and all of that, the voices of the mothers were definitely missing. And I think that that's, you know, why your articles are some of my favorite articles actually.

Rachel ([03:18](#)):

Thank you.

Marjorie Aunos ([03:19](#)):

Because I felt like, you know, I'm actually talking to like, people we're referring to people and we could

see them and we could feel them. And you really went and were able to tap into elements of their experience that nobody had touched upon.

If we go sort of one by one, the one on active negotiation, so looking at sort of how they negotiate their social network. What do you remember of doing that, that part of their research and, and getting that results? And what are those results, if you want to summarize for us?

Rachel (03:58):

Yeah, sure. I think when I started the project, I assumed that becoming a mother and taking on a mother identity would be a very personal, kind of individual, almost internal process. And what I found from talking with these women was that, you know, there was, there was certainly a part of understanding that the baby is real. The baby not just becoming a pregnancy but becoming a real baby. But then there was a distinct point where women started to negotiate who was going to be around and involved. None of the women I spoke to assumed that they would be mothering on their own in the sense that they would be solely responsible for the care of their children. They all assumed and encouraged that other people would be involved. For this group of women, particularly, who are often told, "You shouldn't have had a baby, this pregnancy is a mistake. How on earth are you gonna look after it? You can't even look after it. Look after yourself. You've got a disability." Becoming a mother was quite contested for them, and there was a lot of opposition in their lives. **And this group of women very carefully and actively negotiated the people that they believed would support them, as mothers who would assist them in the care of the child. But most of all who would respect their position as mother.** And the way I defined that, based on their experience, was that they saw themselves as the most important person in their network. That didn't mean that they were solely responsible, as I mentioned. They weren't gonna do all of the caring work, but they wanted to be the center of that support network. And that was what was most important, I think. So where they perceived that that could be threatened, that that support what network might be destabilized, where somebody might say, "you know what, you're not fit to be the most important person in this child's support network. In fact, we are going to, you know, ultimately remove children", which we know happens for women with intellectual disabilities at much higher rates than other groups of vulnerable women. They would try and distance themselves from those people and seek out the support of those who would respect that central role.

So the, for me, that was a, I guess, a big, I guess, a bit of an aha kind of moment. Mm-hmm. <affirmative> to, to understand that social support structures actually had a huge impact in the taking on of the mother identity. I should probably also say I wasn't a mother at the time that I did these interviews, and I used to talk about that with the women as well, say, "look, I don't know, I had no experience in pregnancy or having a baby, or even being, you know, very responsible for a small child." So that I kind of came to it with, I guess we all have preconceived ideas, but I didn't have any ideas from my own experience. So it was, it was interesting to listen to them, in how they, and how they understood it and how they engaged people around them, as key in that process.

Marjorie Aunos (07:12):

Yeah. And see for me, that was the part where, as a professional, as a clinician, I loved reading that article because, a lot of the articles or a lot of the reports that I would read would be about how these women were passive, you know? Mm-hmm. <affirmative>. And this article was sort of saying like, well, hold on a second. They're not that passive. They're actually quite active in how they are structuring and molding whoever is around or will be around their child. And I find that also sort of so interesting in terms of, we've always put the pressure on them saying, "you need to do this on your own. You need to prove you can do this on, on your own." When they were smart. Like, they are smart enough to, and even smarter probably than anybody who said, you're gonna do this on your own, because they knew

that they needed sort of the support. Just like pretty much every parent needs support when they're raising children.

Rachel (08:19):

Yep. Absolutely. It struck me from previous research that colleagues David McConnell and others have done on outcomes from court proceedings. Your family court proceedings where children were, you know, a petition being made for a child to be removed from a parent's care and statements coming out. Like, if she cannot do it on her own, we cannot give custody of this child. And I just remember thinking, that is just ridiculous. And perhaps even more so after I did have my own children, when you realize there's no way one person can do this on their own. The job is too big and too exhausting and too weighty for one to do on their own. I guess being able to recognize how women recognize that and combat a pretty bleak landscape sometimes in the sense that they understand very well that there is resistance to them becoming mothers at all. Yeah.

Marjorie Aunos (09:20):

The second article is "That's Who I Choose to Be." And do you wanna talk about this one and what that was in terms of research and results?

Rachel (09:32):

Yeah, sure. So this article was more specifically about the mother identity. How did women with intellectual disabilities start to conceptualize themselves as mothers? And so we talked a lot about pregnancy and what that was like and things, and understanding women talked about understanding their baby as real. Then they started to consider themselves as, well, what does that mean for me? You know, how does that change me? And how, you know, how does that change, you know, who I am and, and who I might, who I might become or what my life might look like. And I guess this is where we started to see the beginning of that support network. And I called it in the article, the support of an ally. And an ally was somebody who has effectively said to the mother, it's okay that you're pregnant and you should continue your pregnancy.

So many of the women didn't have planned pregnancies. For all of them, there was a decision to continue the pregnancy, so not, not to, not to end the pregnancy for a couple of women, that was a decision that was a legal one, that the pregnancy was too far advanced to consider any other option except for going through with the pregnancy. And so in the face of again, that same resistance to, you know, how you're gonna do this, you shouldn't be having a baby, women sort out an ally who said, it's okay, you're pregnant, you should continue the pregnancy.

I guess who then gave them that some sense of that they would stand by them. In some instances, the ally, particularly when a pregnancy was unplanned, the ally was as devastated as the mother to find out that there was a baby on the way. This was not part of the plan. This is not what we wanted. In some cases, there was abuse involved. So this, you know, there was a baby conceived under really traumatic circumstances, and yet one person in each woman's network kind of stood with them.

Marjorie Aunos (11:31):

Yeah. Pretty powerful.

Rachel (11:33):

Yeah. It was powerful. I think it was powerful for the women in starting to then think through who else might be involved. Not that they were gonna complete all the care or anything like that, but they

might be somebody who was involved in the baby's care after the baby was born. But again, somebody who would respect the mother's central role in that baby's life.

Marjorie Aunos ([11:55](#)):

I think it's pretty much at that time that the article, the "Mother Behind the Mother" was written, if I'm not mistaken. Did you see any links between that article and the ones that, you know, the moms and the stories that you collected for your PhD?

Rachel ([12:12](#)):

I do remember, I think it was Rannveig who did that work, wasn't it? Yeah. And I remember speaking to her about it. Yeah. That, that was fascinating to me because it was, it, it was that idea that there is somebody else involved who's advocating for the mother with the intellectual disability.

Marjorie, you might know the answer to this in some instances, was that mother in Rannveig work, a man. Can you remember, was it always a woman?

Marjorie Aunos ([12:43](#)):

I would say that it was always a woman, but now you are like...

Rachel ([12:47](#)):

I can't remember.

Marjorie Aunos ([12:50](#)):

Can't remember either, because in yours, it was not just women, it could have been sort of a partner.

Rachel ([12:55](#)):

Yeah, yeah, that's right. It might have been a partner as well. But yeah, there, I think, yeah, I do remember chatting to her about that and saying, yeah, there was some really interesting similarities in this sort of forming of an alliance with one other person who provided support at a pretty vulnerable time.

Marjorie Aunos ([13:12](#)):

And again, to be honest, I think that every woman who's going through pregnancy needs to have sort of that person. And that could be the neighbor, that could be their sister, their mother. That could be their partner. That could be, I mean, you know, I think we've all, like, pregnancy is a pretty, like, well, anyways, it was a bit for me where I was like, oh, wow, that's like real, and so now what? Now I need to get my shit together.

Rachel ([13:42](#)):

Yeah<laugh>. Totally. Yep.

Marjorie Aunos ([13:48](#)):

So, we can understand that, you know, it's a bit sort of normalizing that these women wanted or

needed to have sort of that person that was especially in front of a wall, probably sometimes of different workers saying the total opposite. And what have you done? Or like, all the negative messages that they were received. So...

Rachel ([14:09](#)):

I remember a quote from Tim and Wendy Booth in the UK who said that pregnancy is often treated as a mistake, never to be repeated, rather than a source of joy. And I just thought how devastating that can be for a woman who is actually delighted with her pregnancy. But that is the reality that many women with intellectual disabilities face when they become pregnant.

Marjorie Aunos ([14:39](#)):

Yeah. There's no celebration, no baby shows. Mm. Yeah.

Now, from your PhD for someone who didn't wanna do research, you applied to do a postdoc. So do you wanna tell us about that?

Rachel ([14:54](#)):

Yeah, so I think, from the PhD I continued to work in research and then became really interested having done the, some work around the mother identity, really interested in what happened to women when their children were removed from their care, not voluntarily. So when Child Protection Services stepped in and children were compulsorily removed. So that was my postdoc research was interviewing moms who had had children removed. I think by that stage I did have children. So that project, in some ways, was even more harrowing. Yeah.

Marjorie Aunos ([15:34](#)):

What are the things for you that resonate, in this article or in this sort of research that you've done with these moms about what came out of it?

Rachel ([15:44](#)):

I think one of the things that surprised me, and I hadn't really thought about this beforehand, is that this is a surreal experience for these women. I think I kind of imagined that I would find a group of women who had had a child removed, and I did. But what I discovered was that among that small group of women, who I interviewed, they had had multiple children removed. Many, most of them actually. That this was a repeated occurrence. The other thing, I remember when I started thinking, oh, am I gonna find anything other than grief? And we, and there certainly was grief, but in some cases, I also came to understand that the mothers recognized that it was probably the right decision despite the initial grief of losing custody of that child. That it was probably better for them, and it was better for the child.

The other thing that surprised me is that for women who'd had multiple children removed. They didn't necessarily tell the same story for each child. So for some who'd had, you know, multiple children removed, they might have said yes for that particular child. And for me at the time, that was the right decision. But for a subsequent child who was removed, that was not the right decision. In fact, I should still be caring for that child, even if I'm not caring for an older child. That was an eye opener for me, that it was such an individual, not just mother by mother, but mother child dyad by dyad, if that makes sense. Yeah. We can't necessarily extrapolate out from child to child either how this process will play out for the mom.

Marjorie Aunos ([17:32](#)):

Which is, which is very important in my eyes, because often enough when I've read, you know, court reports, it's almost like an automatic. Oh, when child has been removed, thus we need to remove the second one or the third one mm-hmm. <affirmative>. When in fact, basically what these women are saying is that I could see why in this circumstance it was the best decision, yet I wasn't given the chance in the other, you know, pregnancy or birth. And, you know, maybe there was things that were different and the intervention should have been different, <totally>. So I think that that's pretty important to hold onto and to really realize that those decisions need to be made case by case, which means, you know, case in terms of like the child and the mom at the time <Yeah.> Within a particular context.

Rachel ([18:29](#)):

Yeah. Yeah. The other thing that came out that was really important, and again, sort of going back to social networks and things like that. What was important to women was not the necessarily the access that they had to their child, but the support for the access that they had to their child. So some women, it wasn't just a case of everybody saying, oh, I need more access, or I wanna see my child more. How supported they felt by other people around them to have access to their child, to be able to mother in a different way was really important. So there was one woman's story there. These were just some of the hardest interviews I've ever done, I think as a researcher, where this woman had had multiple children removed, and a court had awarded the children to her sister. And she had begged for them not to be cared for by her sister because she had a difficult relationship with her sister. The sister lived in a different state. And in Australia the laws, the jurisdictions are different state to state when it comes to child protection. And she said, she just knew she would never see her children again. That her sister would just sort of take the children, and that would be that. And that was exactly what happened. And she was, she was certainly failed by the child protection system, I think, who then said, well, the children are now in another state, there's not a great deal we can do. Because they had no jurisdiction across borders. She was the most grief stricken, I suppose, of all of the mums that I interviewed. I think she told the story actually that the, she said, the only reason I've seen my children is because her mother had passed away. And so her sister brought the children to the funeral. So that was the only, if my mom hadn't died, I wouldn't have seen my kids in the last 12 months. It was, it was really difficult. And so, for her, clearly she wanted more access to her children. The bigger issue was the support for access and being understood as mom and helped to mother in a different way.

Marjorie Aunos ([20:17](#)):

And see that that was also some, something that was important for me, professionally, because at the time I was a manager. We had established sort of a small clinical program supporting moms with intellectual disabilities. And when I read your, your article, I was even surprised that in our, you know, little program, we hadn't thought of like, yes, we knew all, a lot of the mums that were in our program had lost custody of at least one child. Yet it was sort of like, not necessarily an automatic where we, you know, we asked the question and how do you feel about that? And, you know, like, how can we support you in terms of the grief that you're probably feeling?

And so for me it was sort of like, well, if I am interested in knowing about the lives of these women, yet I didn't think of that, about how they need to renegotiate to some extent sort of their identity, their mothering identity in face of having their children removed, then they're probably not getting it anywhere else. And so we're having sort of a group of women and a group of fathers, cuz I'll include sort of like the family. A group of families who are not supported when something like that happens, which is a big, huge loss.

Rachel ([21:45](#)):

Yeah. And look, there was, it was a loss whether moms felt like it was the right decision or not. There was grief whether they believed that it was better for them and better for their child. That didn't matter, that the grief was, you know, fairly universal. However, they then started to reconstruct themselves as, you know, the mother they were, or the mother they should be. Whether depending on whether or not they felt that they could continue to mother in this different reality where the child was primarily cared for by somebody else, or whether they felt that actually this was the wrong decision entirely, and that I should be the mother, the day-to-day mother, as well as the distant mother, I guess.

Marjorie Aunos ([22:37](#)):

And that's a beautiful, like illustration of resilience, but also actually a post-traumatic growth in a way. Which again, sort of makes me sort of say, or, or reinforce the awe I often feel when I meet, you know, these families and, and these women and these fathers. <Mm.> You know, how beautifully, resilient...re reconstructing. It's difficult. It's take, you know, a long time and they're doing it. So.

Rachel ([23:15](#)):

Yeah. Totally.

Marjorie Aunos ([23:19](#)):

So you are no longer in research, but you're still in a way in the field. If you had sort of an advice or something in terms of like where research or field or where sort of clinical practice should go. Like do you have, based from your experience, any advice or any sort of guide to where the future should go?

Rachel ([23:43](#)):

Hmm. I guess I would encourage researchers just to look broadly. And I know that's something that I think researchers pride themselves on. That's exciting, don't we? We live in a really individualistic sort of society where, you know, at least in, in the developed world, it is, you know, really focused on individual capability and agency and that kind of thing. And I think sometimes we forget that, as a society, we forget that we all need our people. We, nobody, well, very few people live as islands, and our people need people as well, I guess. And, and the people that support us need support. And it, it's exactly the same for people with disabilities. Individualized services are absolutely imperative. I've got no doubt about that. But I think where we need to really start looking is, the broader communities, in which people with disabilities reside and how do we provide support for those communities and the people in them <Yeah.> Starting with their household. <Yeah.>

Marjorie Aunos ([24:53](#)):

And I think that's a very valid guide to the future in looking at communities and maybe sort of going back to how we used to see families, you know, in the past where it was sort of like part of a whole, you know, larger network and sort of how we could reproduce that and not, and forget that it's just, it's not just a one person job and it's, you know, everybody involved.

Rachel ([25:17](#)):

Yeah, yeah. Yeah. That's true. And I think we sometimes, you know, when things like this get brought up people, it might sort of think, oh, we're talking about the 1950s model of mom and dad and the kids, but we're actually defining families and households much more broadly than that. Which is why we're always careful to talk about families as they define themselves. And it may not include mom and dad and

the kids. It may include any number of people who are important to a social network who may, you know, reside in the same house or close by each other. So I think, we are perhaps looking back to the way we used to understand families, but, but families redefined.

Marjorie Aunos ([25:55](#)):

Thank you for your, for your time and for your wisdom and all the work that you've done.

Rachel ([26:00](#)):

Marjorie, thanks so much. Thank you for inviting me to be part of this and for having the vision to get it going. I'm really excited about this whole series. I think it's fantastic.

New Speaker ([26:12](#)):

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