# Episode 1: Once Upon a Time...

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 today. I will let you know a little bit more about me and why doing this podcast was important to me. Let me take you on a journey as a parent, a researcher, and a long time advocate of parenting done differently.

In the next year. You will hear me talk to different professionals, scholars, parents, sometimes children of parents with disabilities. And I'm really excited that you are going to come on this journey with me today. I thought that we would start by letting you get to know me a little bit more before I get to introduce you all those fantastic people. And so I will follow the same sort of format of the interviews that I've done with everyone, with myself. So it's like I'm interviewing myself, but without asking the questions. So the first part that you will hear when I share with the scholars and the fantastic people that I will be interviewing, there's three parts to the interview. And so the first part is, sort of like how they started in the field, what led them to studying or supporting or advocating for parents with disabilities in the first place.

The second part of the interview is more in terms of research. So what types of research they've conducted, but really because some of them are very well established in the world of research. They have tons of studies that they've done already we've selected, or they've selected three of their papers. And so we're talking about these three papers. And then the third phase is really looking at the future. And if they have any advice in terms of the younger generations, what they should be looking for or looking at. And how they should be conducting research. And most importantly, if they could talk or speak to professionals in the child welfare system, what they would say to them.

So this is pretty much the same format that I'm gonna follow today for myself. So in terms of the first part I will tell you stories about three moms that were very significant in my life. I believe that thanks to them, it led me or me meeting them, led me to becoming a scholar and a clinician and working with parents with intellectual disabilities in the first place. So the first mom that I wanna introduce you, I call her Julie. So Julie has two children and I was working with her daughter at camp. So I was a shadow, what they call a shadow. So basically a one-on-one educator. It was a quote unquote normalized camp or mainstream camp. And her daughter needed a little bit of help in terms of integrating and being included in the camp. And so that was my role basically.

And I was working with her daughter and someone you know, within the first couple of days, sort of said, if you really wanna understand this young girl that you're shadowing you should meet her mom. It would tell you a lot about sort of the communication that you need to hav with the family, with the mom, so that you know, this young girl can, can be integrated and sort of follow the rules at camp. So that's what I did. I called the mom and I said, oh, I would like to meet you since I'm gonna be spending the summer with your daughter. And when I got to Julie's apartment, she, you know, welcomed me with open arms. It was a time where it was sort of supper time. So it was after camp. It was, it was a busy time cuz the kids had just come back from camp. Julie was trying to sort of juggle, preparing supper, but in the same time preparing lunches for the next day. And so I'm here sort like in middle of it, but I'm so impressed because Julie's sort of like juggling with the two kids, keeping them busy while she's sort of cooking while she's preparing the lunches and she's doing such an incredible job. I was so impressed and I thought, my God, these women who like do it all on their own are just pretty impressive.

But what I also saw is that, you know, she didn't have a lot of means and supper time was as healthy as she could, based on the money that she could get. Which was like sort of disability pension, really, and a little bit of money because she had two kids on her own. Like there wasn't a lot of vegetables or fresh fruits, but yet she was really trying to have like a balanced meal for her kids. And so I saw sort of poverty more than disability that creates disparities for these families. It wasn't her disability. She knew exactly what needed to be done. It's just that sometimes she didn't have the means. But she was just like very impressive. And when I met Julie, I thought, this is what I'm gonna do for the rest of my life. I'm gonna work with these parents because they deserve a chance.

And unfortunately society is not giving them a chance. And so somebody needs to speak up, and make sure that we see them as people. Because I think that sometimes we don't and I know that when, you know, at camp they had said to me, you need to meet the mom. I knew it wasn't because I needed to meet the mom. They wanted to show that mom had a disability and they wanted me to know that. And I think that, that really touched me in terms of how disability was all she was in the eyes of certain people when really she's so much more and her kids were so much more. So that was Julie. That same summer so maybe a couple of weeks after I was asked to spend some time with the young girl. And I say, young girl and I shouldn't, I should say young woman.

She was 20 years old. And the reason why they had asked me to spend a few days with her is because they had taken her to the United States to get an operation so that she wouldn't have, or be able to have kids anymore. And I call her Eve. That was, I don't know, I'm still like in shock when I talk about it, because I couldn't believe that her parents in a way had made the decision for her that she couldn't or wouldn't, or shouldn't be a mom ever. And she knew that she was going for an operation. When I spoke with her, she didn't really know why, but that was, that was it. It was done. And yeah, to see that sometimes we take away the choice of people without ever considering their choices, their voices, what they think, their dreams, their aspirations. I think that's something that really touched me. And so having those two sort of women within a couple of weeks where I see this mom doing, you know, quite amazing and doing the best that she can for her kids and then having like a young woman taking her opportunity of becoming a mom, if she wants, was very striking for me. And from then on, I knew, I mean, my future was set because this was something that was dear to my heart.

And so what I did is as any sort of like top student that I was, I went to books and I went to journal articles and I tried to find out as much information as I could on mothering parenting with an intellectual disabilities. And what I found was a few studies, not many, a few, we're talking. I was maybe like, I think it was before the two thousands, Ooh, maybe like 1995 or something like that. And there were a few studies and I found them and I read them. And what I realized is that certain names kept coming back and those names were Feldman and were Llewellyn, and were Tim Chuck and were Booth and Booth. And so I was intrigued because obviously these scholars were making a living or were, you know, dedicating their research on working with moms with intellectual disabilities.

And I say, mom, because it's mostly moms. But we're working hard at having dads in research now, but those names kept coming back. And so one name Maurice Feldman, I realized was from Queens University. Which is in Kingston. I live in Montreal, that's about three hours drive. And I said to myself, that's it. If I wanna be doing research in this field, I better learn from the best. And one of the best, one of the most prolific researcher in this field lives three hours away from me, that's it. I have to meet him and I have to ask him and convince him to work with me and to supervise my thesis. And so that's what I did. I took a car, I went to Kingston, I met Maurice Feldman. And then that was it. I was sort of like, that was another brick in my road or another brick in my foundation of my house that I was putting together.

And when I spoke to him, he agreed to be my supervisor. And then he talked to me about a conference that he was going to where he was gonna meet up with Gwynnyth Llewellyn and Sandy Tim Chuck. And he said, do you wanna come? And I was like, oh yeah, because those were two of the other names that I had been reading, their work and I was super excited, but I was so excited that when I got there, I couldn't speak. There was like not one word that could come out of my mouth. I was so starstruck. I think it was like meeting, I don't know, Brad Pitt or any like amazing like Hollywood star that you've watched their movies, you know, and sort of grown with them in their career.

And so for me, it was like meeting those Hollywood stars and it was quite, I was just listening and taking it in cuz they were pretty impressive. And for me that was incredible. I will speak to you now about my third mom. And my third mom who influenced me, I call her Star because that's what she is. She's a star. So Star is basically a woman that I met on a day. It was like, I had just gotten my license as a psychologist. Like just, just like I'm talking two days. And a social worker with whom I work in the rehabilitation center sort of said, you know, Star really needs some help. Her child is followed by child welfare and they are basically going for permanency planning, which means that she was at risk of losing custody of her son forever pretty much.

And so the social worker said, you know, you have an expertise because of your thesis in working with these moms, I would like you to come and maybe do something and help as a psychologist. So that's what I did. So I met Star and it was like in an afternoon. I'm in her living room. She has like one couch. So she lets me sit on the couch. She's taking like a chair in the kitchen and then we're chitchatting. And at first Star is like very reserved and she doesn't like speak like not one word. And I don't know, I just made jokes and I like played around and I sort of like, I was basically like having a chit chat with, you know, someone that I had just met. And I think she liked the fact that I was just unassuming, I guess, or not sort of imposing my diploma or my profession on her.

And so she kept like smiling a little bit. And then after, you know, I don't know, a few minutes, she started speaking to me and opening up and as we were talking, it was maybe like half an hour an hour. We heard a knock on the door and she knew that it was child welfare that was coming to assess sort of how she does the evening routine. And she said, it's them, but I don't wanna be alone. I would like you to stay. Can you stay? And so of course I said, yes. I saw how nervous she was just at the perspective of opening that door and facing the workers. So they came, there was two people, two social workers who came in, they had a clipboard, a pen. And basically when one asked a question or asked about Star doing or performing a routine or part of the routine, the other one would take notes like frantically.

And, you know, I had just been a psychologist, but I had been an intern for a few years. And I was like, oh, this is really not the way that you can establish a relationship with a parent. Especially a parent that you want to sort of like be able to assess and see what they can do, because if you have to put them at ease, you have to sort of, you know, have that relationship or that trust. And, I've never seen that before I had, I've never seen that since. Thank God, but it was very striking in terms of like how these two social workers were definitely clueless. So it's not a reflection on all social workers, but it's definitely a reflection on them. They were judgey, they were, you know, sort of like passing comments. And sometimes it's not even like in the words that we say it's in the attitude that we have.

And certainly for me, these women were like passing judgment by saying like, you know, like how someone can sigh and sort of, I don't know, you know exactly what they're thinking and they're not thinking something positive for sure. What's amazing for me in the story of Star is that her and I started working that day together. A week later I was in court basically telling the judge what I had seen and how Star was very comfortable with me performing anything or being just as she would be normally. And how child welfare or these two workers were very scary. Even for me, I thought it was like very intimidating. And, you know, the judge asked that a new social worker be assigned. That one came in and right away made the whole difference. Cuz he looked at Star right in the eyes, introduced himself, said, you know, I'm so happy I'm gonna be working with you.

Please let me know if there's anything you need me to do. And by his whole demeanor in the way that he spoke to her, most importantly, the way that he looked straight at her, not at me, not at the, you know, rehabilitation social worker, he was really working with her and we were helping their team, you know, in terms of their parenting. And so that made the whole difference and Star opened up right away with him and was able to keep her son, which was like an incredible, incredible outcome in this case. So those are my three moms that, or two moms and one young woman who influenced my early career. This is, you know, the first part, the second part of the interview, as I mentioned earlier, is basically talking about three research studies or three papers that I wrote or co-wrote.

And I have to say that I'm being the host. I'm sort of very lucky because a lot of the people that you'll hear about are actually my colleagues, my research colleagues. And so a lot of the papers that I've written, I've co-written with them. And so I know all of them, you know, what they're going to be talking about. So I was able to basically choose whatever articles they're not talking about. And I feel like my, my whole, you know, career is going to be, presented to you through the year. So the first paper I wanna talk to you about is actually my thesis paper, which is, you know, the research that I've conducted between meeting Julie and Eve and meeting Star. So by the time I had met Star, I had already completed or I just needed to write my thesis, but I had completed the, study per se.

And so this study was pretty incredible because there was no research done in Quebec at the time on parents with intellectual disabilities. And so I was pretty much the first one to conduct research with this population. And I was able to find 50 mothers, which again was also at the time, something that was quite incredible because finding large samples of parents with intellectual disabilities was quite a challenge just by itself. So across my province, across my region, I found 50 mothers and I interviewed them all and pretty much spent two interviews of about two hours each. So with each of these moms, I spent about four hours, and I traveled everywhere. And so some were like in, in Montreal. So a big city, others were in smaller villages all over Quebec, the province I live. So that's what happened.

And from this, you know, these interviews, I basically had several papers written. The one that I really wanna talk about is the paper where I took Maurice Feldman's. And you'll hear about that when Maurice speaks. And that's like, I think in a couple of weeks that you'll hear that he had conceptualized a model that sort of explained or looked at all the variables that could have impact parenting. I remember clearly the first time that he, showed me the model and like lots of boxes and, and arrows going everywhere. And it was a hypothetical model based on some theories that already existed and based on his practical or his clinical work. And so from those boxes, basically there were variables like social support, you know, how does social support basically impact positive, consistent negative type of parenting? There was also sort of like the whole idea of health. The parent's health, so physical health, but also mental health and how could that influence parenting?

And then there was another box at the bottom that was more in terms of like social disparities, but socioeconomic status in a way. And how that influences sort of mental health, let's say, how does it influence parenting? As well, the parents' childhood experiences might also impact mental or physical health. So that was another box that was there. And then of course there was like the box of the children and the box of the children was basically like, how many children do they have? And, you know, do the children have any disability themselves, or any difficulties at school that could also sort of make parenting a little bit more difficult? So those were like different variables. And basically it was really looking at how those variables impact parenting and how parenting is delivered by parents with intellectual disabilities. We didn't look at IQ, because a lot of studies already had pretty much determined that IQ per se had no impact on parenting.

It's not like a lack of intelligence that would impact parenting. It's really sort of all those other variables around, out of the 50 moms that I had met, we took 32 of them who still had custody of their children. And we basically put their information on those variables together to try to see if there was any relationships that could lead to explaining the impact on parenting. And basically what we saw is that mental health was definitely something that, seemed to impact the type of parenting skills or style that these moms would have parenting stress. So they all had really high levels of parenting stress. And we also saw that parenting stress had an impact on the parenting style that they delivered. So pretty much sort of less consistent and less positive parenting style was associated with parenting stress. We also saw that physical health seemed to be not as good when the children were younger, but as the children were older.

So there was not such a need of carrying them, picking them up and so forth. Physical health seemed to be doing better. And so we did find that certain elements in terms of even support or like poverty definitely also had an impact on mental health, which had an impact on parenting style. So it was the first, pretty much study that looked with data on those different variables and how they play out. So that's the first one that I wanted to speak to you about, cuz I'm pretty, pretty proud of you know, this study and, and how it was conducted. And again, it's sort of influenced me in my career. So the second study I wanna speak about, it's a study that I've done with one of my most treasured collaborator, and friend Laura Pacheco. You'll hear about Laura in a few months, I believe. So with Laura, we work together clinically.

So on a lot of the cases of, of parents with intellectual disabilities. And then we've always tried to conduct research from the samples that we would have from the parents that we met at work. And this one was interesting because it was this study was done a year after I had my car accident. And so I was paraplegic and I think there was like a drive for me to like I really wanted people to know that I was still here. That I was still sort of capable of doing stuff. So I really like dove back into work right after my accident. And one of the things that I've done with Laura was take a number of files of parents that we've worked with and basically looked at the content of those files and looked at the variables from this model, written by Spath and colleagues. And look at the collaboration between rehabilitation services and child welfare and to see if the type of collaboration these two agencies would have together would have an impact on the outcomes for, for these families.

And basically we use sort of that questionnaire or developed a questionnaire from that model. And we looked at the number of times that workers would speak to one another, the length of the conversation. We looked at elements in terms of the mandates of the agencies, the objectives that each worker had. So we took like the intervention plan and look at at the objectives. And we really looked at those two elements from those two agencies and put them together. You'll see in the show notes, I'll leave the reference for the spa and colleagues, uh, article as well. So you have that. And basically we looked at those factors that would be associated with family preservation or reification, and the factors that were associated with these two elements. So keeping families together was creativity, was leadership and having a strong advocate. So those were like three points in collaboration that was very important in creativity.

We can sort of imagine that because we are now creating new ways, maybe of intervening, new ways of working together, we might, you know, sort of see creativity or innovation in terms of the types of services that we offer specifically for the family based on their specific needs. So that seemed to work to keep families together when we do that. The strong advocate is basically having someone who like ensures that the voice of the parents is heard. Sometimes it is not heard. Sometimes it is hard for parents with intellectual disabilities who have been discriminated against all their lives because you know, they have a disability. So even in school, maybe bullied, it's hard to then sort of like learn to speak up for, for themselves. And so having a strong advocate is really sort of helpful in making them aware that their voice matter and that their decision, their dreams aspiration, you know, should be taken into consideration.

So a strong advocate is definitely something that helps in terms of collaborative framework. And then leadership. A leadership is basically having our bosses to serve believe that we should be doing things differently, that we should, you know, be doing things more creatively. And if we have sort of bosses that believe that, then I think it allows any kinds of workers to be open to new things, to be open to new solutions and to working together. And so that's what this paper found, which is like incredible. And I think we can only go places and we can only truly support parents with intellectual disabilities or disabilities when we actually work together. And so that's why it's so important to me. The third paper is a paper that will be published very soon. It has been accepted and I'm very ecstatic. And it's a paper that I've done with colleagues in Australia and then here in Canada. And this paper looks at my journey sort of adapting and accepting my disability while being a single mom.

And it's also using research of moms with intellectual disabilities and moms with disabilities and sort of putting that in perspective with my own story. You know, moms who have a disability often face very strong biased attitudes against their capacity to parent. And I felt those biases very strongly. And I felt them yes from certain people, certainly from people like when I go to the park, in the public and so forth. But the worst was feeling it from myself. It took me years to realize how hard I had been on myself or was on myself because I had imagined, even though I was working in the field. So even though I had met all of these moms and parents with intellectual disabilities and believed in their capacity to parent, it was like my conceptualization of how I should parent, you know, would only work if I was an able bodied person.

And so it didn't match, so that image of me being able to run after my kid in the park or be everywhere. You know, like how parents are just like taxi drivers sometimes, you know, and bringing kids like to all of these activities. And I couldn't do that anymore cuz my body just like I have to log it everywhere. I have to bring my body everywhere. And so my attitude towards myself was very negative and that's called Internalized Ableism. And when I realized that I was basically putting a lot of pressure in trying to be this overachiever, overproductive mom, who's like super fast, who can do everything physically who can teach them how to like kick a ball. When I realized that I couldn't be that, it was hard. And then I realized that I needed to conceptualize parenting differently for myself. That I could be a good mom doing table activities.

I could be a good mom by bringing him to the museum. I could be a good mom by witnessing him, sort of do all of those physical activities or, you know, what, why don't I do those physical activities with him too? I've done, you know, swimming and kayak, you know, and there's like many different things that now I can do if I have the proper equipment. And so it was really about sort of conceptualizing my parenting differently. And so that article is about that and I'm very proud of it. So I welcome anything. Now the third part, as you will hear in the upcoming episodes, the last part is really about sort of the future that those scholars, clinicians, parents, children sort of envision. In my case, what I see for the future is a movement. I really definitely feel the momentum building right now.

And I see parents with disabilities, all disabilities joining together in several endeavors. For example, you have a book called, We've Got This and you'll have the reference. You definitely have to read that book. It's 25 stories, 25 families who have all kinds of disabilities. And so right now the book We've Got This is there's a version from Australia. The editor Eliza hall from Australia is currently working right now on the book from, with UK and US and Canada's, families. And this book should be coming up early 2023, so soon. And Eliza will be interviewed by me because she has spoken to all of these families. And I think that she has a wealth of knowledge to be able to share that with you guys.

There's other books like Celebration of Family, which is again, sort of a collection of stories about parents with all kinds of disabilities and that's from the US.

There's another book called Maternity Rolls. And then there's my book called Mom on Wheels. So all of these parents basically wanted representation and made sure that we could link together and create a movement by sharing our voices and having our voices together. And that led me to producing an event called Amplifying Voices of Parents with Disabilities, where 10 to 12 speakers who are parents with a disability were speaking about their experience. This year was just amazing. It was parents who were trailblazers, who did incredible things like the book, a blog anyways, it's just great. You have to go and see it. It's also in the link. What I see also researchers bridging the gaps of knowledge together. So in the last few years, you know, scholars who have been focused on looking and researching parenting or parents with intellectual disabilities are now looking at different kinds of disabilities and putting like all of those voices together as well.

And why do they do that? Well, because we've realized that the disability in itself doesn't really matter. We all face discrimination and disparities, and that is what we have in common. And if we look at that piece, that element, then we can sort of lead the research to being useful and potentially sort of making a difference in services and supports that are offered. I've seen also mainstream media sort of like talk about parents with disabilities and there's many different articles that were written in the last I would say decade, a few interviews, different things. Again, I could link you up, which is amazing. Community organizations coming together, even public services. So in different countries we have different health systems. They work differently. Obviously all of them are talking about parenting with disabilities and potentially this will lead to, you know, services being modified and more inclusive, really more accessible.

What we do need now though, is to really do have a promise from governments, from each of our governments, to making sure that those services are adopted. And I will end with the last question. If I could say one thing to child welfare workers, what would it be? The first thing I would say is your work is important. What you do is important, it's necessary. It's protecting children and we all should be protecting children. Child welfare agencies were organized or created, you know, in the late 1800's early 1900's to do just that. And at that time it was like some children were in horrific conditions. Unfortunately we still have children who are in horrific conditions and definitely require support. And to be safeguarded from whomever is not treating them right. The thing though is that we need to all evolve with the times or understand or be open to new possibilities.

I mean for a long time, people with disabilities could not have children. Why? Because they were sterilized against their consent or without their consent. And so, you know, it was not just a possibility cuz they couldn't. And anybody who had a physical disability while often had medical issues as well and, and which prevented them from living long enough maybe to have kids. It's not the case anymore. We live happily, with our disability, we are proud to be sort of like trailblazers and we're proud to be creative and so solution focused and so strong and resilient. And so it's really about sort of opening our hearts to those possibilities. The children who are in need of protection are not our children. Our children are being raised to be creative solution focused just like us. I hope that you get what you need through this podcast. And I hope that you stay open-hearted in the possibilities of parenting done differently.

New Speaker (39:10):

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