

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 here 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 David McConnell. David and I met as students of Gwyneth Llewellyn

and Maurice Feldman, pioneer researchers in the field of parenting with disabilities at a time when this field was not a very popular topic. David is a thoughtful researcher who always kept the stories of the parents. He met close to heart, those stories drive his research to this day. I began our conversation by asking David how he got started in the field enjoy. And don't forget for more information about where to find the full recording and additional resources. Check out the show notes. So David, could you let us know like how you started, if there's a parent in particular that you met that inspired you?

David McConnell ([01:28](#)):

Sure. So I'm an occupational therapist and I trained at the University of Sydney and that is where I met Gwyneth Llewellyn. Gwyneth supervised my, honors thesis. It was actually about children and, but after graduation, I worked for a couple of years and, got a phone call from Gwyneth, asking me if I'd be interested in coming back and really working alongside her on a project, exploring the support and service needs of parents with intellectual disability. And I was certainly interested in research, did not know the field at all. But that project quite literally took me out of the office, and into the homes of families all around my home state of New South Wales. And, you know, I do remember the first parent that I met and he really set me straight on a lot of things really.

But I don't want to single any one parent out really. I mean, that was really quite an extraordinary experience. I was certainly impacted by their stories. The sense of absolute privilege you feel when people open up their lives to you? I think was truly extraordinary. Um, and I was struck really by the grit and craft that these parents showed really under some very difficult circumstances. And there were two really observations that came from that study for me that really laid the, I guess, the groundwork for my research program and you know, research career really. One is, I was struck by just how many parents were living with the ever present fear that the welfare would come and take their children. So that was one observation. Um, and the other observation was that so many of these parents were terribly isolated socially. Um, and I dare say lonely. Um, so those two observations you know, worry or concern about the welfare coming to take their children and secondly, the social isolation that those, so many of those parents seem to experience. Those two things kind of stuck with me and led to further questions. And so the research.

Speaker 1 ([04:11](#)):

Yeah, it's interesting because now I could see, so your trajectory, right. Because I really do see those two themes coming back again and again, in terms of your research, but also in conversations that we've had with colleagues or, or with each other. So, I could really sense how, how that must have, you know, impacted you a lot. I remember when I started my thesis and I would talk about, about it with like people around me and I would say, oh, I'm doing this research on parents with intellectual disabilities. The first reaction was often sort of what they do exist. Like as if you know, something coming out of a, I don't know, a magic book or something. Yes. Do you remember, like, what was it like for you when you first started in the field in terms of talking to maybe child welfare workers or people around you?

Speaker 2 ([05:04](#)):

Look, I remember in the early days, showing up at conferences to, you know, to share findings from our research and there being one or two people in the room, and one of those people had, you know, made the mistake <laugh> of going to the wrong room, right there, there was not much curiosity because I don't think there was any great awareness that, you know, adults with intellectual disability form relationships had kids there just wasn't that kind of level of awareness, but I can, all, what I can also say is, you know, in, I don't know, is that 25, 30 years of, of research in the field, my mother still doesn't believe that there are appearance with intellectual disability <laugh> or, or that they can thrive with, you know, appropriate supports. So, you know, expectations can be, uh, a tremendous barrier, I think, to engaging people in conversation in this area.

Speaker 1 ([06:12](#)):

Yeah. And it's interesting that you talk about your mother, cuz my mother, I introduced her to some of the clients I worked with, so she met them, but every time she would come back and sort of say, oh, but she doesn't have an intellectual disability. And I was like, yeah, I'm pretty sure she does. And she was like, you know, couldn't believe it. Well, no, she she's so capable. She can do all these things. What do you mean? And so it's interesting, you know, how the perception or the, you know, biases that we have and we all have them can really lead to, to a conception or conceptualization of, of something that's foreign to us and how that can impact and affect, you know, everything we do, even in terms of understanding somebody else's story. Yes. So we'll move into, sort of some of the research that you've done.

But I will share a little secret, the first one, which is the disability and decision making in Australian Care Proceeding, that was published in 2002. So, you know, we're talking 20 years ago after all these years, I hadn't even read it. <laugh> like it was seriously. And I read it and I was like, damn, that was good. That's like, there's a lot of really important formation. How could I missed it? I basically, you know, learned something new in my field after working in this field for so many years. So apologies for not knowing that you had written this beautiful piece and I will let you talk about it so that everybody knows what we're talking about,

Speaker 2 ([07:52](#)):

The papers I wrote early in my career. And I selected those to share with you Marjorie because I thought, you know, they gave a good indication of the direction that my research would take really, you know, really reflecting, I guess, you know, my longstanding concerns about disability based discrimination and child welfare. And also, you know, the marginalization and social isolation of these families in the community. Um, but this paper, it was, um, one of the outcomes of, of my doctoral research and, uh, it was based on a critical ethnographic study. Um, so I spent, um, a couple of years reviewing, uh, court records, interviewing the lawyers involved in, uh, in child protection matters, interviewing all the magistrates in new south Wales who, uh, decided these matters, um, and, uh, literally conducting countless group interviews with, with child, youth protection workers, really trying to understand something about, um, you know, uh, something about the process and how decisions were made.

Um, and what, and, you know, a number of things came out of that study really. Um, I wanted to understand what influenced decisions, um, and outcomes and, and certainly, you know, uh, uh, our raw data showed that, that, you know, um, these, these kids were much more likely than, than others to, to be removed and, and placed outta home. I wanted to understand why, um, and through those interviews, it allowed me to get, get some insight into the process. Um, and also some surprises, well, a

lot of surprises. Um, so the research really revealed how, I guess, you know, stereotypical assumptions influenced decision making, um, how outcomes depended on, you know, on, perceived parent compliance, and also the availability of services, all these things and other factors, influenced outcomes, but what it also revealed, I think, and perhaps controversially is how outcomes were decided, not just based on considerations of what was in the child's best interest, but they were also driven by what I called system imperatives.

Right. So, you know, I was witness to lots of hallway negotiations between lawyers in the courthouse. The magistrates were very clear to me that if every case was contested, like if every parent wanted to contest the decisions or order requested by, you know, the child protection authority, if every case went to a contested hearing, the whole system would, would, uh, would collapse. So to keep the system alive and going, there was lots of emphasis on, on negotiating outcomes in the back rooms. So there was a lot of give and take, you know, if you have the parent, you know, concede that their child was at significant risk of harm, then you know, then we'll consider providing more contact, um, once the order is made or something like that. So there was kind of a trade off sort of happening in, in the back room, which I think would surprise many people. Yeah, certainly certainly offered, um, you know, um, some insights. So this, this paper really kind of documents the findings of, um, of that study, the, the, you know, that, that study had both a, a quantitative dimension, right. Looking at prevalence and outcomes. Um, but it also had, you know, an in-depth qualitative kind of ethnographic dimension of exploring in context in the courthouse, in, you know, child protection agencies, you know, in the hallways, how decisions were made and, and, and what influenced those decisions.

Speaker 1 ([11:50](#)):

Yeah. I was gonna say that one thing that really surprised me, but didn't at the same time, cuz I've seen other research talk about, this is the lack of, of like representation of the voices, the power difference, how expert opinion was more important, how the lawyers would negotiate, but amongst themselves and you know, we didn't really know where the parents stood or what they thought about it. It was more sort of like a chess game in a way, uh, between lawyers. It was sort of like the expert and not, not the parents. And it was always also sort of like the availability of somebody better than, you know, um, they would be put against sort of the possibility of staying home with their biological parents.

Speaker 2 ([12:36](#)):

Yeah. That that's right. And that could vary from agency to agency like the availability of a suitable, alternative caregiver, like a suitable foster family, um, you know, those resources available to child protection, authorities varied from area to area or district to district. So whether it, if a child was restored home or not partly reflected the, the, you know, availability of, out of home care resources.

Speaker 1 ([13:00](#)):

So the other two articles, um, that you brought forward, one talked about sort of the adverse outcome in pregnancy and birth outcome, uh, which I think is also sort of very important aspect of, of the research and information in terms of when even we work with these families and then the other one on social support. So I would let you, um, sort of talk about those two.

Speaker 2 ([13:26](#)):

Sure. Um, so I, I selected the paper on pregnancy app on, on pregnancy birth outcomes for recent, um, after our, that initial support and service needs study, which was back in the early nineties, we followed that up with, uh, a, a trial of a home program, health healthy and safer home based learning program

for, for, for parents. So this is in the early days when, you know, the question was, you know, um, how can we effectively support and, and teach parenting skills? Um, you know, when parents have, you know, a need to learn those skills, um, and in the context of, of trialing healthy and safe, we gather a lot of data, including data on, on children and their development. And in analyzing that data, I noticed that those kids who, you know, were, I guess, demonstrating some delay in, in one or more areas of development, those kids also tended to have, you know, let's say a, a challenging pregnancy birth early years, history, um, many had been born low birth weight, and preterm, which got me wondering, got me wondering for a couple of reasons.

One is that I had, I was observing in the courts at the time and, and in the context of, of child protection cases, the developmental delay was often used as kind of Primal facia evidence of neglect. So I got to thinking, you know, is this developmental delay that's being attributed to neglect? Could it actually have as much or more to do with what was happening before birth or early on? So we followed that study up with, with you know, kind of an investigation of pregnancy birth outcomes. Uh, it was situated in Southwest Sydney, um, and we literally screened pregnant moms as they were coming in for antinatal care. And we did over several months, I think there were, uh, eight, 900 moms that we screened. Um, and sure enough, that study found that difficulties during pregnancy were more prevalent that, uh, these kids were, um, substantially more likely to be born preterm, um, or low birth weight. And of course there have been several, um, more robust studies I'd have to say several more robust studies conducted in, you know, certainly beginning in Sweden, but more recently in Canada and the US which has kind of confirmed those early findings, the results are entirely consistent, confirmed, but, and extended those findings. So I just, i wanted to tell that story about how one, cuz I think it's a nice illustration, how findings from one study lead to more questions, which then lead to further research and so on.

Speaker 1 ([16:15](#)):

And I'm glad that you mentioned the more recent studies, because that was definitely my observation when I saw that you chose this one and it's sort of, yeah, sort of the first one who talked about this issue, but yet even though you had 57, I think moms you know, that had an intellectual disabilities in that one, whatever you found was, is now found in population based data sets where, you know, we're talking about hundreds of moms with intellectual disabilities. So it's quite, it's quite impressive to sort of see the evolution of research.

Speaker 2 ([16:51](#)):

Yeah. Yes, yes. And I think we still have a long way to go in terms of understanding or explaining really the poor pregnancy and birth outcomes. We know it is in one way or another, we don't understand the cause or pathways, but I think we understand that it is an effect of, of social exclusion of marginalization. Um, but understanding the pathways, um, that's, you know, that's, that's certainly this a need for further research to help us understand how we can better support women during pregnancy. Really. Yeah. Um, so the, the third paper I shared with you Marjorie was a study, I think it was titled Strengthening, uh, the Social Relationships of Mothers with Learning difficulties. It was a study that was embedded within Australia's Healthy Start Strategy, which was world first national strategy to build systems capacity to support these parents and their kids to promote a healthy start to life for these kids.

Um, so the focus was on really, you know, focus was on systems as part of this national strategy. We, we developed something, we call the Australian Supported Learning Program and it is inspired really by work of Wendy and Tim Booth in the UK. Um, but we developed this program, um, that really utilizes principles and processes of participatory action research to bring, um, moms together in small

groups to really look at, um, their experience and to look at how they can connect and participate more in the community, you know, and, and addressed, you know, some of the, the, the isolation, um, in their lives. So to come together and together, understand what the barriers might be, and to come up with solutions to act on those solutions, come back together to reflect on their experiences, uh, in the community and so on.

So, yeah, so I wanted to share that because I think, there's been so much emphasis, and valuable research focusing on parenting skills and parenting education. Um, I think it's one study among, you know, a relatively small number of studies that have really tried to focus on, you know, the social ecology of these families, um, and their, and their lives. So I wanted to share that too. Um, and of course we have collaborated since on a, a pilot of that program in Canada, and I think there's, there's, uh, I would really like to see us build on that.

Speaker 1 ([19:29](#)):

Well, actually, that was one of the questions that I was gonna ask you, because, you know, the, your research showed that,

and since then we have many evidence that shows how isolated these parents are most of the time. Yeah. Um, and how sometimes part of the adversities were definitely the buffer that the social support can offer and give is not there. So the stress level and, and the anxiety and, and finding resources makes it, you know, it's harder for them because they don't have that support.

Speaker 2 ([20:02](#)):

I think one thing we do need to do is differentiate the role of social support yes. As potentially a stress buffer. But to understand that that is, you know, that's different from loneliness or how loneliness can, you know, impact parents. You know, we understand that loneliness is a significant stressor, you know, and we understand that people who are lonely see the world as a more threatening place and act accordingly. Um, so our social relationships matter, you know, and of course we learn through our interactions and relationships with others. So being isolated is, you know, the, the social isolation experience by many of these families, I think, is a priority.

Speaker 1 ([20:42](#)):

You also, in talking about this program, you also mentioned Tim and Wendy Booth. Um, could you tell us who they are and, you know, the time that you spend with them in UK?

Speaker 2 ([20:54](#)):

Sure. Tim and Wendy Booth invited me to the University of Sheffield, um, as a visiting scholar and for us to work together and, and to kind of replicate and extend some of the work we've done in the courts, um, and the child protection system in, in New South Wales. Um, so we've spent, I think it was six, seven months together. I mean, that was an incredibly, you know, productive, uh, time together. It really was Tim and Wendy Booth were among the pioneers of research in this field, their work, uh, their book Parenting Under Pressure. And, uh, the later book Growing Up with Parents with Learning Difficulties, I think they're two of the seminal work. Uh, seminal works in this field. I would argue their primary contribution, I think is in, I guess, challenging the clinical gaze that really dominated the field, the questions at that time.

Uh, so we're going back to the eighties early nineties, the question that that time were, could these parents be competent, um, or be through training, be made to be competent right. In their

parenting. And of course that work was really important in showing that, well, actually, you know, we can't really generalize much. Um, we can't, you know, we, we can't predict, uh, you know, our parents', um, skills based on, you know, the label, um, that work was really important, but where Tim and Wendy came along is challenging that clinical gaze and, and, and saying, you know, we want to listen to and understand the lived experiences and perspectives of parents with intellectual disability themselves. Um, now there were others who in the field who were, you know, who were beginning to do that, but I think Tim and Wendy, you know, most compellingly challenged that clinical gaze really enabled us to listen, uh, to parents their stories, um, to understand their stories in a larger historical and social context.

So I think they were critical in, you know, really supporting a contextual rather than a, you know, pathology based or de deficiency based perspective. Um, so they challenged the clinical gauge. They challenged that individual deficiency orientation, um, that was dominant at the time. And I would suggest is still dominant. And I think, and maybe I'm jumping the gun here Marjorie, but I think one article, most of their work, Tim took the lead on as, as first author, while, while Wendy did most of the field work, this paper, Wendy was first author and it it's an called Accentuate the Positive, and it was published in 1993. Um, I think everybody should read it. I think all our professionals working children, youth protection should read it. It contrast two ways of reading the same situation. So it, the articles based around Molly Austin's story among with intellectual disability and, uh, Wendy and, and Tim kind of apply that, you know, clinical gaze, that individual deficiency perspective, um, to the case and highlight what I think for many of us might be kind of familiar tropes.

Um, and then they, uh, they contrast that with what we might say is a, a strengths based perspective. And I think it's, it's powerful and revealing how the epistemic frame, right? Like the, the, the lens that we bring to any case can really determine what it is that we see or what's possible in, in any situation. And I think when I read that paper, it was the first time I'd really deeply contemplated how, you know, the lens or frame that I brought to a, a case could so impact, you know, what it is that I perceived did that, does that make sense?

Speaker 1 ([24:45](#)):

Yeah. And, um, I remember reading it when I was preparing for my thesis. Um, but now the way that you've talked about it, I feel like I need to go back and reread it and, uh, really put a focus. And of course, we'll, we'll add that to the list of, um, your articles so that people can track it down and, and be able to read it as well. We're gonna now sort of go towards the end. So, uh, in terms at the end, but it's the beginning, the beginning of the future, uh, where do you think we should go in terms of research, but also clinical work in working with parents with disabilities?

Speaker 2 ([25:22](#)):

Wow. That's a big question. Right. Um, and there's so many things I'd like to say, but I I'll just try and focus on one idea for this. Um, I was just thinking about this on the car, on the way in here this morning. Really look, I think, uh, well, broadly speaking, I think we focused a lot on the capacity of parents, um, you know, and how through education and support we can, you know, strengthen or enhance their capacity in the parenting role. We've focused a lot on that and not enough on how we address deficiencies within the health and social care system. And that's a huge question, right? How do we do away with discriminatory practices? How do we institutionalize new practices that are non-discriminatory and accommodate difference really? And that I think means, you know, really shifting, you know, uh, attitudes and, and the perspectives at a really deep level.



Um, so that that's broadly speaking, I guess, more specifically, you know, I think our research has been very effective in challenging the assumption of incapacity. I think research, you know, there's four, 500 articles in the field and the most consistent finding is that is that these families are diverse, you know, with respect to parenting skills and, and, uh, parenting success. Um, so I think research in the field has challenged the assumption of incapacity, um, and it's brought some attention to life history and social ecology. There's some understanding today, I think of how the, you know, the abuse and trauma experience by too many, people with intellectual disability, how that can have an impact, but also, you know, the strength of social relationships and the enduring poverty and, or too often poor health experience by many families.

So I think there's a, a much more sophisticated understanding of, you know, the social ecology of parents and parenting with intellectual disability. A concern that I have is, sure we've challenged the assumption of incapacity, but I think we've really questioned the basis upon which attributions of incapacity are made. Right. So unconsciously, I think we hold the idea of the traditional, , in our mind's eye, a frankly white, urban middle class, I think we hold that, that idea, uh, in our mind's eye and, and we expect, you know, mothers to be, you know, natural, devoted caregivers. We expect them to be independent and self-sufficient, um, and so on. In other words, we continue to define parenting as the work that parents do in bringing up their kids. So the question then is, is whether the parent has the capacity to perform this work, um, and the way this plays out in the health and social care system in the courts.

And so on is, is that the test, and we I've heard this from, from, uh, decision makers. The test has to be whether the parent can stand alone, right? The test is whether the parent can stand alone. This is problematic on what's of different levels. I think, you know, I would call this that ideological, right? Um, so one reason I think I would suggest that it, it it's problematic. I would suggest that, uh, the reason why so many children are taken from their parents and families is veiled by this ideology. The main reason I would argue that so many kids are removed is that we're either, um, or we simply lack the resources needed to effectively support them. Right. So I would suggest the question isn't and never was about capacity. The question is really about support and our willingness or ability to provide it.

Um, so I've talked before about, you know, I think you and I have had conversation. I said, you know, I imagine a child looking at the records of court proceedings, right. Looking to understand or searching for the reasons why they were taken from their moms and dads. I would like that child to read the record and find that they were taken from their parents because we, as a community were either unwilling or unable to support their mom and dad. I think we don't get there to that point until we challenge that individualistic lens through which we look at these families as both as practitioners, but also as researchers. And I would argue that it's researchers we've done that too. Mm-hmm <affirmative> right. I think that parenting education work and research is really critical, but on its own, it can potentially just reinforce this notion that parenting is what you know, that that capacity to parent is really locked up inside the individual.

Um, so I think we need to be self critical in that sense. But another reason why I think that ideological individualism is really problematic is I think it limits what is thinkable in terms of solutions, right? It limits our creativity. What if, for example, we define parenting not as the work that parents do, right? But rather as the work that many are involved in, in bringing up a child, right. If we viewed it as a social, rather than a solo activity, what, then I would argue that historically, and cross-culturally, this is pretty much how children have been brought up <laugh>, but, but two things flow from that, right? Two things flow from that. Firstly, the question for child welfare workers is not whether the parent is capable. The question becomes whether the child's needs are being met within the network of social relationships, in which they're embedded.

Um, and with that basic insight, I think we can begin to imagine and research creative solutions. Right. I think it's been hard for us to think creatively in terms of how do we support these parents, children, and families, because we were approaching it with that individualistic lens. But if we think more ecologically, I guess you could put it. And I think it would enable us to imagine, for example, different kinds of shared care arrangements and to research that, but also to understand, to look for how that is happening right now. Right. We know there are a lot of families headed by parents with intellectual disability who do not come into contact with a child protection system. Right. We know that and many are, are really thriving. Well, you know, they're getting by in the context of their, you know, their social networks and so on.

Right. Um, so I think we need to appreciate how parents and children are, you know, are doing family together in context, but it also, you know, as practitioners, we need to be thinking about that often rich, you know, thick tapestry of relationships, that surround these kids. Yeah. So to very extent, I think, you know, most kids are brought up under shared care arrangements. So it's really important to emphasize that when we talk about a need for shared care, we're not identifying a lack of capacity, right. So it's a think for example, about how most parents, would utilize child care services. This is a shared care arrangement. It's just not viewed as such. Right. We also see that double standard played out in the courts just to go back to a central theme, right. Where you know, if a parent with an intellectual disabilities child is, you know, if you know, if that child's in daycare, you know, their, the question is sometimes raised about, well, who's caring for this child, but that same question would never be asked of the lawyer, you know, whose child is in daycare.

Right. So, so that double standard plays out, but it's coming to appreciate that, that interdependence is the norm. And what are the implications of that? What are the consequences of that shift in thinking for how we relate to support these parents and families? I think that's key.

Speaker 1 ([33:41](#)):

And I love how you, you place that in terms of like, let's try to think creatively, you know, and try to look at something that we're not seeing right now. Cuz we're standing in one position, let's try to move and see it from a different angle.

Speaker 2 ([33:54](#)):

Yeah. Well put

Speaker 1 ([33:56](#)):

And maybe one or two minutes. Can you tell me if there was one thing that you would say to a child care, or child welfare worker about this work, why would it be,

Speaker 2 ([34:08](#)):

No shortcuts. And, but that, I mean, a shortcut is getting a label or diagnosis, of intellectual disability in relation to, or suspected intellectual disability in relation to a parent or making inferences, you know, based on that label. So no, no shortcuts. I think, you know, the label should really play no role in decision making that there is a really need to a approach families and see, you know, how they're doing in the context of, their lives. You know, that's one thing. And I think part of that is recognition of the need to address some of the environmental adversity that's impacts on these families. Sometimes I suspect workers may interpret poverty as, you know, evidence of incapacity as opposed to a factor that



could potentially underlie or be a root cause of difficulties that are, you know, a family may be experiencing. So yes, no shortcuts, a central message.

Speaker 1 ([35:20](#)):

It's funny because when you were talking about labels, it made me think of your article with Strike

Speaker 2 ([35:25](#)):

With Robert.

Speaker 1 ([35:27](#)):

Yes. And so when it was like labels are for jars or something, that I retained, that's how I, I retained it anyways. So

Speaker 2 ([35:35](#)):

Yes, I recommended accentuate the positive as something that, uh, that it's, it's really accessible. Um, but potentially transformative to, um, for workers who may have not read it before. Um, that that's one and I guess another one that I would recommend is "Look at me, listen to me, I have something important to say," . It's an article that was first or authored by Robert Strike, um, who is a father with intellectual disability. And Robert, I think very powerfully kind of lays out some principles that ought to inform, you know, our interactions with parents, with intellectual disability.

Speaker 1 ([36:13](#)):

Thank you so much, David, for, for all of this, you certainly took me on a voyage, on a journey and you brought some really interesting points in terms of having, you know, that different lens or that different, you know, director's cut in terms of like looking at the situation differently from different points of view. So I thank you so much.

Speaker 2 ([36:35](#)):

Lovely to talk with you.

Speaker 1 ([36:37](#)):

Lovely to talk to you.

Speaker 3 ([36:41](#)):

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