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 Gwynnyth Llewellyn. Gwynnyth is a well-respected scholar who has done incredible things in the field of parenting with disabilities. She is a great communicator, and I can't wait for you to hear how she carefully chose how she conducted each study and on which topic always focused on making sure the voices of parents which shine through. We started our conversation by talking about the professional articles she chose to highlight in this podcast. Enjoy. And don't forget for more information about where to find the full recording and additional resources. Check out the show notes. I'm so thrilled to have you with me today for this conversation. So thank you.

Gwynnyth Llewellyn (01:25):

Thank you, Marjorie

Marjorie Aunos (01:26):

<laugh>. If we start from the beginning, looking at some of the articles that you chose for today, the first one is actually on social support. And I found that a very fascinated, because I remember that at the time everything was very parent training focused. And I felt like when you published this paper, you were putting the focus on something else that was just, you know, different than just looking at it through a clinical eye. So do you want to tell us about that paper and research around it?

Gwynnyth Llewellyn (02:04):

Sure. In my doctorate, I purposely chose to understand in depth, the lives of parents, because there was dad there as well with intellectual disability, to try to as best I could clearly not being a parent with a disability and particularly an intellectual disability to understand their lives from their point of view. And one of the aspects of their lives that was clearly critically important was social support. And my friendship and my colleague then too, Tim Booth, he and I talked about this a lot because both of us had begun by really saying what is happening in these parents' lives and what is it that may make their lives a little easier if I can put it like that. And I'd learn from designing this game, "Safe Parenting". And the parents playing this game, in a supported environment in a family community center one day a week, and how much it meant to them. The actual support of being with each other, as well as in that supportive environment.

So much so that one of the mothers actually had to go to the hospital for a few days. And the other parents said, well, we're still going to play. And they all turned up in the local hospital in the general medical ward. And there was a furor from the staff saying, you can't do this. And they said, well, she's coming back to the center with us. If she's, if we're not allowed to stay. And the game was a board game <laugh> they sat with the board game on her bed and played together. This teaches us as scholars. What is it that matters in people's lives? These are the circumstances that we need to pay attention to. What is it that matters to people? What is it that helps them feel fulfilled? So, that's why social support became for me a focus. I was not so interested at all in what seemed to me to be a little bit of a blame game, a defect finding game.

It didn't suit my view of the world. My view of the world is very optimistic knowing that everybody given an opportunity can blossom. And so I focused on social support. What was really critical about that paper is that it was published in a journal, a high ranking journal, which is important because other scholars read that it may not be so important to practitioners or child welfare professionals, but it's important for scholars. And it's important for two reasons. It spreads the knowledge to other people and other people then start to think maybe there is something worth doing here, but it also spreads the knowledge that helps to get funding, to continue developing that knowledge. So the article is important for many reasons, not least that we are able because it was a larger sample of mothers. They weren't all from what we would call a clinical population.

They were mothers, including all the ones I knew from the safe parenting game days who lived in the community. They weren't de-institutionalized people with intellectual disability, but some of them had really quite severe difficulties. So I needed to understand that too. How had they managed to keep going in the face of discrimination and people thinking they couldn't possibly be parents. And that study opened many people's eyes to it because we came to understood that if you're a single parent life was going to be more difficult. Sure. You might get support from services, developmental disability services or family services, but your network as it were, was going to be primarily professionals and good as professionals are, they're not friends. They're not someone who you can just have a laugh with, go out and socialize with, talk nonsense with sit and watch telly with. They're professionals

and they move on. But if you lived with a partner, you were likely to have quite a broad network of support. Both from your own family, the family of the partner, probably as well as yourself for the mother and a dispersed network, because there would be other people in those families who would also support you, but they may not be geographically close to you. And then the third group was the mothers who actually still lived with their parents. So they'd never left the family home. And often the grandmother was doing some of the raising of the child or children. And those mothers were very alone. Sure, they had good support from say their mother and the mother of father or brothers and sisters, but they didn't again have peers or friends or someone just to hang out with, share the stories of being a mother or a father together. So to me, it was a critical moment when we published that paper. And literally people came out of the woodwork from then on to share their stories of other people they knew. Other mothers, other fathers, and how they were living their lives. It did open a floodgate of interest in the lives of parents with intellectual disability.

Marjorie Aunos (09:00):

Thank you for those stories. I love that. The next paper that you submitted to me was about home safety. So do you wanna tell us a little bit about that one?

Gwynnyth Llewellyn (09:14):

Yeah. This was my attempt with my colleague David McConnell, who had also been an author on the previous paper on social support. This was my attempt to say, if we really want to continue this whole line of interventions to support parents, typically mothers, but also parents, fathers too, with intellectual disability; we better do it in a way that we know it actually works. Now that's provocative because of course we had by then quite a body of knowledge from people who I call my colleagues and I hope they would also see me as a friend, Sandy, Tim Cho, and Maurice Feldman. But most of that research was either single case study or with smaller groups of parents who came from clinical situations. So their parents were already identified as having such a difficulty that they're in a setting. And I felt strongly for many years that we needed to broaden our interest to understand better about all parents with disabilities, including parents with intellectual disabilities in the context within which they live.

So the continuing and continuous theme through everything that I've done is about context. Understand the context, understand if you like the ecology, understand what's in the environment, because if you can open your eyes and really look and listen to what is local, then you have a much better understanding of why people act in the way that they do. So we needed to use the design where we could randomize the parents to the intervention. They weren't parents only from clinical services. They were parents who were living in the community, who people said they may benefit, and they're interested to do it. And it might have come from a family member or it might have come from a church group. It did not. These parents did not necessarily come from a clinical service and a randomized control trial allows you. It's the called the gold standard of interventions. Typically used, of course, for things like pharmaceuticals and so on. But perfectly possible to do in what we might think of as a more social setting because of the way that you randomize, how people begin the intervention and where you take the data points.

So that was the first randomized trial to be published. Anyway, in the international literature about interventions for parents with intellectual disability, and I'm forever grateful to Sandy, Tim Cho for being very open and sharing with the program that he developed at the University of California at Los Angeles. We adapted that for the Australian situation, and I'm very grateful to Maurice Feldman for everything that he'd taught me about all of the interventions that he'd been using at that stage. In what was then a quite clinical setting in the Surry Place Center in Toronto. So all of that knowledge and their support brought that randomized control track into being, and that's what we did developing the materials for both the home and safety components of parenting for parents with young children.

Marjorie Aunos (13:40):

Okay. So we have an article and a book chapter that you sent me. One of them was really to look at how parents with intellectual disabilities sort of compare with other parents and taking in pretty much all the larger data sets, studies that were written up until then. And then your book chapter to me has a little personal connotation just because I became paraplegic 10 years ago. So I had already been in the field for a long time. I was mom to 16 months old Thomas. And so all of a sudden I became a mom with a spinal cord injury. And as I'm going through my process, you in terms of your research nterests started to bring in different population of parents with different disabilities. And that's what that chapter is about. So could you tell us more in terms of why you chose those two and if you have stories about them, that would be awesome.

Gwynnyth Llewellyn (14:47):

So around, I think it would've been mid 1990s. I'd been doing a lot of advocating about parents with intellectual disability. And I thought <laugh> totally inaccurately that the research that we'd done demonstrating that so much of their lives were circumstances beyond their control. Much of it was due to social structures, to inequities in the system or inequalities in the system, which created inequities for these parents. And I thought that knowledge that these difficulties were what was critical in the lives of parents with disabilities, but particularly for parents or in a very specific way for parents with intellectual disability, that that knowledge would open people's eyes. And I'd come to realize that knowledge isn't enough, that knowledge of people's circumstances by itself isn't enough. And my colleague, Eric Emerson in the UK had come to the same conclusion. Not about parents with intellectual disability, but about intellectual disability per se, that the stigma and the discrimination, the stereotypes, the assumptions about people with intellectual disability was so strongly rooted in our cultures, that it was hard for people to believe when people did well, when they succeeded in life.

When they, in my case, they were parents and managing very well. It was, we needed a different way and I've always been taken by <laugh> two particular sayings. One, you can trace back to Mark Gold, who was very early American, psychologist working with people with intellectual disability. He developed a whole system of support and it was called "Try Another Way", simply think differently. Try another way. The second is about what's often called divergent thinking and convergent thinking. In convergent thinking, you can continue to dig the hole in the same place, but you are actually not digging much deeper or learning much more. divergent thinking says, go dig the hole in another place. So Eric and I together started digging the hole in another place, trying another way. And I pay absolute tribute to his skills to think at a very high level in statistical analysis to do this.

That is not my strength. My strength is being able to think divergently and think differently about the situation. So together we started looking at what are the lives of parents with intellectual disability? How do they look when you compare them to the lives of parents living in similar neighborhoods with similar other things happening in their lives? How do they look? Are they the same? Are they different? Is their parenting any different? Do their children do as well or better or worse. And asking that in relation to parents without disabilities, and then later asking that in relation to parents with other disabilities. So that allowed us to start to see what is it that is happening again in the ecology, in the lives of this particular group of parents. That means that there are circumstances that people become concerned about. Because that's really why we are talking today because people are concerned about parents with intellectual disability and in particular their children.

So that's what we started doing. So I think it was, we started that in the late nineties and we continue to do it, not only with parents with intellectual disability, but with children and young people with disability in low and middle income countries right around the world. So we have lots of publications which try to understand ecology and context. Why is it that it is, so is the question we're asking, why do their lives look different? How different are they and what can we do about it? And the reason that we ask what we can do about this when their lives are different, they are more disadvantaged. They are more discriminated against. They do. It is more likely for parents with intellectual disability to have a lower education level, live in unsafe neighborhoods, less, not only economic resources, financial resources, but less social resources as well.

And often to have mental health difficulties through the stressful environments in which they live. So all of those things together, all are amenable to change. So if we can understand the extent of the difficulties in the environments of parents with intellectual disability, we can begin to envisage a different outcome. We can begin to envisage what is it that needs to be done to change these contexts? So people have access. These, what are social inequalities is what is it that needs to be done so that we can change these contexts? So these parents have the best start to not just parents who live in very safe and very nice neighborhoods, not just parents who have access to lots of resources. How is it everybody gets a fair go? So that's the beginning of how we started all of our studies on what are really comparative population studies.

They require that there are large data sets, which means it's either the whole population. Think for example, of a census or countries run a census. And in that census, if the data is collected on disability, you can compare the lives of people with disabilities, to the lives of people without disabilities. Think also of administrative data, child protection data. That's very large data sets of child protection data on parents, on their children, on out of home care, on all of the orders. Again, you can start to compare our things different for parents with intellectual disability compared to parents without intellectual disability. So that 2015, I think it is paper. We took all of the literature then, which had focused on using these large data sets and comparisons between parents with and without intellectual disability. And again, that paper had quite an impact in, again, people coming out of the woodwork and saying, I think we can do this with data sets that we have in our country.

And we would then better understand how, for example, there was very little research using those sort of data sets in the us at that at that time. So now we have a very big growth of people interested to use all sorts of national and state based population and administrative data sets in the us and in many other countries as well. So I personally feel very pleased about that because criticism often comes that this is a special group and they need something special. There's a whole field around providing specialist support to people with intellectual disability. And I've always argued that it's the person first. And then it's thinking about their environment, their context, and then what would be supportive to them. And yes, in some instance, it may need to be specialized support, but in many instances, the support can be provided in a very natural and local way.

And I'm reminded here, Marjorie of a woman who I met in Canada, actually at a place, the name which escapes me, but outside, uh, Toronto. And it was a people first conference. So it was run by people with intellectual disability, four people with intellectual disability. There are over 2000 people there. I went along as an assistant to two parents who I knew very well by that stage. A mom and dad who had at that time two and much later a third child and were managing with supports from family and friends and neighborhood. And I met a young woman, a Canadian, and she had this beautiful little child and she got up and talked and she told the story of how this beautiful little child was her fifth child, but the only child who lived with her, the only child.

So it was a very moving story. And afterwards I chatted to her over coffee and to her partner. And she talked to me about what she thought made the difference that when this little baby was born and even before the baby was born, there was a neighbor, an older woman who lived two doors down from her. And she had taken an interest in her. And when the baby was born, the baby wasn't removed. Like her other children had been removed either at birth, or very soon after she was allowed to bring the baby home. And that woman, she never moved into the house, nothing like that. But she provided the support from two doors down that met that this woman with this child was able to be the mother that she wanted to be. So again, it comes down to context. And if we don't understand this and understand that parents, mothers with intellectual disability typically are more likely to have a less supportive context, then we automatically assume what we see in what they do or don't do that. It's their problem, their fault, rather than the environment has created a particular mil in which it's almost impossible to do otherwise. So we need to start thinking about how do we change these societal, cultural, physical, financial factors, which make the lives of parents with intellectual disability often. So challenging

Marjorie Aunos (28:35):

It's, again, sort of fascinating to me how one story could just move you to tears that story about this young woman that you were talking about in her fifth child. I I've seen many of those moms in my career as a psychologist, but every time it moves me, because I feel like the system has failed them. And yeah, what I find beautiful in all of those stories that you're bringing forward is that in a way, and maybe I'm putting words into your mouth, but the way I've, I was listening to you. It's an advocate that became, um, someone who use academia to be able to, to give voice to these parents. And to me, that's what you, you are basically. And you've used research and different methodology and the beautiful talent that you have of telling stories to basically move things forward, not so much for a career, not so much for, you know, uh, colleagues of yours or, but for those parents and their children for those families to be, uh, together. And for that, I thank you for inspiring me yet again, you know, for, for doing everything that you, you do, that's pretty beautiful. It will lead us to what comes next or what should we do? Where should the research, where should our field as a whole go in your opinion.

Gwynnyth Llewellyn (30:15):

It's a very big question. I mean, predicting the future is probably a fools game. <laugh> there are several themes. I think that are important here. They're a little random, and I'm sure people will take from them. What they will. The first is, the title does not make a person and regrettably, when we talk about parents with disabilities and particularly parents with intellectual disability, the title in other people's minds becomes the person. There's an assumption, a presumption that the person fulfills the title. And a very good friend of mine. In fact, the dad <laugh>, I was his assistant at that conference in Toronto all those years ago. He says, never assume because assumptions make an ass of you and me. Never assume. So be very wary of titles, be very wary of labels of terms. A second really important point, I think is that where our field is at now is that we are starting to understand much better what you might call the life circumstances of mothers and fathers with intellectual disability that have literally through, and I say, quite seriously, no fault of their own.

The social, the financial, the physical, the cultural, the attitudinal environment has placed them in circumstances with a title that makes them "other" to those of us who are much more fortunate. So our job in my view, in our field is to get rid of that, to work on ourselves and our view that somehow they are "other". And if we understand that disability is part of the human condition, that individuals who are worthy of respect, because they are a fellow human being, we come to them with a very different perspective. And that perspective is about them as a person in their local context, their neighborhood, their family, all of the things that have made them, who they are. Just like you and I have been talking about what has made me in the context of my career and my work in this area.

We need to come to them in that context. And when we have a better understanding of that, as well as a better understanding of how you can actually break through those barriers of inequality, we are more likely to give parents with intellectual disability, a better chance at life. What else do we need to know though, to be able to do that well? Well, I think there's all sorts of things. My third theme is have friends in powerful places. <laugh>, it's a very important thing. I wouldn't have been able to carry out in fact, that randomized controlled trial. As I said, the first one published in this field. Except that the director general of the department responsible at that time for, Aging and Disability. When I took this idea to her, she said, "we should do that." Why did she say that? And she found the money.

Why did she say that? Because her background was as a nurse and a psychologist working in institutional care for people with intellectual disability. And she knew intuitively from that, that there were people who could be good parents. How did she know that? How did she know it intuitively? And do we know this is the case? Empirically, let me firstly, address how she knew it intuitively. Because as a person, she approached each individual living there, no matter what their circumstances were that had brought them there, no matter how they behaved in that environment as a person in their own, right. Who needed to be understood as a person in their own right. Not as a person living in residential care, there's a very big difference. They were individuals to her. So she understood context. She understood individuality. The second thing, is there evidence to support her intuition?

Yes, there is. And it's from a very old study, a very famous study by Skeels and Dye and what those researchers did. And they didn't do it from a perspective of, can women with intellectual disability be good mothers. They didn't start from that, but they were part of the early pioneering work on, is it possible to increase IQ by providing stimulating environments? Think of it as them, as the fathers, if you like of the early intervention, early stimulation, all of the practices we now take for granted. Absolutely take for granted that children thrive in stimulating, loving, nurturing environments. Back in the late

1930s, early 1940s. That was not really understood, not in the research literature. I'm sure it was understood in homes, but not in the research literature. And it was literally an experiment in an instititution where they had babies and infants in one ward and where the women who lived in that institution with intellectual disability, women, themselves with intellectual disability institutionalized because of their intellectual disability, each of them was assigned to one of the children in that ward.

And over an 18 month period, the researchers took data on whether those children changed. Their development, of course changed enormously. They had a nurturing, interested, loving carer. And those nurturing, interested, loving carers were institutionalized women with intellectual disability. So I'll finish there because that, to me speaks to what needs to happen in our field is the continuing growth and opening up of the minds of the researchers and the workers in the field to understanding that it's the local context, it's the environment. It's, it's the person, it's the forces literally that are impacting on the person. When we understand that and work to change or modify or ameliorate, some of those forces, then we have a chance of supporting parents with intellectual disability and particularly mothers who are very discriminated against to live less discriminated lives and to live fulfilling lives in our community.

Marjorie Aunos (39:14):

Thank you so much. I have to say, you know, every time I speak with you, every time I listen to you, I feel like a renewed sense of like beauty in the world. I see you as one of the most beautiful people I've ever met in my life. There are so many other personal stories that I could share about how you have influenced my life. And today it was very telling how you have influenced the lives of many. I hope that everybody who listens to this podcast feel as inspired as in awe of who you are. And I am so happy that, you know, I was a little bit part of the gift that you gave us today. And I thank you greatly for that. Thank you so much.

Gwynnyth Llewellyn (40:11):

Oh, thank you, Marjorie. It's been a real pleasure. It's always a pleasure.

New Speaker (40:18):

This podcast was supported in part by a grant from the Minnesota Department of Human Services, Children and Family Services Division.