Marjorie Aunos (00:02):

So we've got that. All right. So then the next two steps, I'm gonna clap three times. This is to sync your phone with my phone. Mm-hmm <affirmative> um, so I'm gonna do that. And then once I've clapped three times, we're gonna plug in our, um, headphones and that's when we're gonna be able to start speaking does that make sense. Okay.

Susan Collings (00:22):

Okay. Yeah.

Marjorie (00:30):

Okay. So now we could plug in our headphones

Susan Collings (00:48):

Can you hear me?

Marjorie (00:49):

Yes. Very well, actually.

Susan Collings (00:52):

Likewise,

Marjorie (00:54):

You can hear me.

Susan Collings (00:56):

Yep. Good.

Marjorie (00:59):

Okay, perfect. So you're all good.

Susan Collings (01:13):

I'm all good.

Marjorie (01:14):

Perfect. So I'm gonna start, it's my little story of how we met and then we'll start.

Susan (01:22):

Okay.

Marjorie (01:27):

Susan and I met in Vienna out of all places. Um, it was a big international conference IASSIDD part of the parenting SIRG, uh, meetings were discussions. And of course the drinks after the discussions, uh, that we would have at the conference and Susan and I met at that, uh, at that point and I guess that's where we were able to serve chit chat and it was a pretty special, um, trip, I think for Susan, because she was just about or had just about graduated with her PhD and she was presenting the result that she'll be discussing, um, that we're gonna be discussing today. So I'm really, really happy to have you Susan come and join and have a little chat with me about, um, that time, which was, I don't know how many years ago do you remember?

Susan Collings (02:21):

I do. I think it was 2014. Yes. 2014 Marjorie. So eight years ago. Yes, exactly. Exactly. Now in the middle of the year, July and that, yeah.

Marjorie (02:34):

Wow. Oh, well that means that I was already in a wheelchair.

Susan Collings (02:38):

Yes.

Marjorie (02:38):

Yeah. I have forgotten about that part. So see, I'm like telling a story and I'm imagining myself like standing up, which is like, still baffles me how I could do that. And my brain could still see me, you know, standing up after all those years.

Susan Collings (02:51):

And in fact, we had met at the, um, IASSIDD two years before, I think two years before in Halifax. But, or actually 2010 mate, no, 2012 12. Yeah. Um, but I think that was a bit of a whirlwind for you.

Marjorie (03:04):

It was, it was like my first, uh, my first trip after the accident. So that was, uh, pretty, uh, pretty big for me, for sure. So tell me, Susan, um, how did you end up working in the field of parenting, uh, parents and parenting with intellectual disability?

Susan Collings (03:23):

Um, and thank you so much for having me Marjorie, it's a delight to talk to you as always. Um, so I, as many of the, um, research community, um, from Australia, I, uh, I came to this research through, um, a now Emerita Professor Gwynneth Llewelyn um, who has been, um, sort of a, a driving, you know, leading force in Australia in, in sort of highlighting, um, the, the issues and, and highlighting the need for research for many, um, decades now. Um, and so I was, uh, I just had my third child and I was, uh, moving from professional roles, community work, um, as a case worker into a research role, I'd done a master's of public health. And I had got a job to work on Healthy Start and to work on, um, work for one of large NGOs. That was part of that.

And through that met Gwynneth and the team at the, um, University of Sydney. And, um, and my role was, I was, I was actually employed at the NGO and doing research for a project they ran, um, that was offering sort of group based support and case work support to parents with intellectual disability, through that, um, evaluation that I did at their project. I got to know the team in Gwynneth and started doing my PhD. I also came to it with some lived experience. I have a sister with a, um, um, an intellectual disability. Um, she's not a mother, but she would've loved to have been a mother, but I think like a lot of people, um, who, who have, um, lived experience of disability, we are passionate, I guess, um, about, um, hearing those stories and, and, and advocating, I suppose, research to practice and research, to advocate for, um, inclusion, um, you know, genuine inclusion of people with disability and in my case, particularly intellectual disability. Um, yeah, so that would've been, uh, I started my PhD, I think in my, my, my little, my youngest was two, so 2009.

Marjorie (05:47):

Oh. And like you said, I mean, um, people will have by now, uh, heard Gwynneth, um, talk or like conversation with me. Um, and so they know a little bit about Healthy Start. David McConnell also mentioned, um, you know, about sort this program. So you said that you worked with Healthy Start within healthy start.

Susan Collings (06:09):

Yeah. Yeah. So, um, um, one side side of my PhD, I, um, I was involved with healthy start, um, as part of my PhD because there, because my PhD was interested in children or parents with intellectual disability. Um, and, and obviously in Healthy Start was about, um, improving the, the capacity of the workforce to work with parents. And they, and I think Gwynneth was very aware that there had been very little research at that time that was focused on children, um, and in particular, um, and what we worked together on and what my, what my work with healthy start and my PhD was actually about bringing the, the voices of children and young people, um, with that lived experience to, to, um, bear on this, on the field of parenting. Um, so to hear from children about being raised by parents with intellectual disability.

Marjorie (07:08):

Yes. And that's actually like a great segue because we're talking about Healthy Starts or your PhD, and two of the, um, three documents that you submitted for today's talk were about your PhD. So do you wanna go into more, you know, details what your PhD was exactly what you looked at and the kinds of results you got?

Susan Collings (07:30):

So, so one of the, um, one of the publications that I, that I shared was a chapter for my PhD, which was a literature review, um, of what we knew. So it was obviously, um, an important piece of work for me to, to ground myself in understanding what we knew so far and how, how that knowledge had informed, um, not just research moving forward, but, but what, um, how, um, how practitioners understood the needs of children living in these families, um, you know, headed by a parent with intellectual disability. It was, um, it was a really good experience to do that because what I came to understand from that was that we generally had thought about children, um, as being at risk. So we, we really didn't have a lot of, um, um, evidence for children who did well. Um, and I think this is the case with this field.

And we, and we know this, that we tend to, um, where, where parents show up their parents who are, um, struggling with a lot of intersectional issues related to, um, disadvantage, um, not just disability and that was playing out in the research of our children. So that was seen as an at risk group. Um, and I guess that framed really, um, importantly, um, my thinking about this group of children and, and the silencing of any stories that were about, resilience. That were about strength and family, um, you know, families that were working well and were doing well. Uh, so I guess really wanting to, um, in some ways challenge the idea that it's inevitable that children will, will be, um, doing badly. And, and we're talking about developmentally, we're talking about out of home care placement, um, and a range of sort of problems socially.

Um, so trying to sort of see, well, what happens if we, um, talk to a group of children about their lives, um, to try to understand how they see their lives, um, at the point of being children. So I was, I was talking to children who were, what we would call primary school aged here in Australia. So middle school probably, um, in the Norman hemisphere, um, there were children from about the age of seven to 12, um, that middle childhood stage. Um, so I guess in terms of asking about my, um, my, my project, my, my thesis, um, project, uh, I really needed to think about how to engage children in conversations about their lives that were in ways that were kind of age and stage appropriate. Um, so I started delving into, and this has been, I guess, a really a really great, um, learning for me and was really influenced the research I do now started thinking about how can you, how can you engage people to talk about things where you're not just relying on them, the words they say, you're giving them other tools to speak to their experience.

So I had children, um, I used photo voice, which many people might, may have may know about, um, where you use sort of photo elicitation. So you use photos, you either take photos, or you share photos as part of the research process, um, um, to introduce yourself and your world, um, and explain how you see, um, your world. We also did the, um, the young people, children that I talked to did, um, did some drawing, we used sort of eco maps, I guess you could call them looking at them in, in the context of their relationships. And I was really in interested in ecological systems theory. Um, so seeing the child, not just in their home, but seeing how they see themselves in other relationships that are important in their life. Um, yeah. So, uh, so I, I did that and I, I, I used those sorts of methods as well as obviously having conversations and discussions with children. Um, yeah. So, yeah,

SMarjorie (11:48):

So that's very interesting, cuz like you say, I mean a lot of people, uh, would do research with children, but maybe not think about sort of alternative methods of gathering that information. Um, and I kind of like, you know, using photos in terms of like, how do you introduce, you know, or your world and who you are as a, as a person, or as a family basically. So I think that, that was definitely very clever. How many, um, how many kids did you, were you able to find and interview and, and how did those methods, were you

Susan Collings (12:22):

Yeah, that's a really good point question. Um, really hard to recruit children for this study. Um, despite me having all of the advantages that came with having good relationships with NGOs, myself, through being, um, in having been working in the NGO sector, plus having all of the relationships that came with Healthy Start Seven. So it was a very, very small study, which was actually a strength of the study because it could go very deep. We were able to go very deep. Um, and I talked to some of the children up to four times, um, which was really important because, um, you know, you, there was a lot of rapport building in that. Uh, I also was really fortunate to be able to be introduced to children through my own, um, professional networks. So not just relying on agencies. Um, I also did talk about gate keeping and, and, and this is no disrespect meant to, um, professionals and case workers understand, you know, there is there are competing demands and researchers not always the main game, especially research where it's not with the person they're working with, which is usually the parent.

So you have, you have some sense of, oh, do I really wanna, um, you know, I do, I really wanna ask the parent to, to have their child take part in this study and, and will the parent feel comfortable? So there was some barriers there and I think they are well known barriers and I, I, I actually suspect we've got better over the last decade at embedding ourselves as researchers more closely in the work of our partners in, um, in practice so that we can have those relationships, um, strengthened and enable us to talk to, um, children and families who maybe otherwise are less visible in research and, and less willing to be part of research. Um, so yes, it was a, a, a small study.

Marjorie (14:34):

But I think, you know, it's the depth of knowledge like you mentioned. And I think that that's, um, you know, definitely the benefit and the, the added bonus of your study. And so if you were to, to talk about sort of like what came out of the study or what results, what would you say, uh, were the most striking or the, the ones that spoke to you the most?

Susan Collings (14:56):

Yeah. Um, so I think what really, um, sh through, across, um, across that, you know, all the children's stories was, um, the importance of their, their, um, really the strength of their relationships with their mothers. So they were all children and mothers with intellectual disability. Um, and, and none of them had been in out of home care. So, um, it was a very select sort of sample too. They were being raised in the community by their mothers. Um, and, and the, and the, the big, um, I guess the thing that was really noticeable was who their mother had in their life to support them from the child's perspective. So, you know, we didn't directly talk about their mom, their mom's disability. We talked about their family, we talked about the people in their lives and the other adults. So they got to say, and they got to talk about how those adults supported them, how those adults supported their family.

And, and what was really clear was when mothers had support that flowed onto their children, their children, um, felt supported and felt, um, connected to community connected to school. Those, those, um, there were bridges built between their, their, their home life and their other, um, parts of their social worlds. Um, and what was really striking was I think, um, for me, was, it, it, it, it was the quality of that relationship and the benefits that were coming to the child. So how much the other adult, um, supported their mother and also how much that support was directed to the child. Um, so it was about what they were interested in. It wasn't just about parenting skills. It wasn't just about somebody working with their mom. It was about what that person brought to them and, and, and how they supported their life, connecting them with, um, uh, uh, activities in the community with other people, with making sure they could, they could get to sports, um, get to their sport, or, um, you know, be part of the other normal things.

The kids did like birthday parties and, and so on. And, and that, that didn't have to be a family member. I think that was really striking it, it could be a family member. Um, it could be indeed the father of that, that, that the children, but it didn't have to be, it, it could, it just needed to be somebody that as Bronfenbrenner says, you know, really, really cared about that kid was mad about that kid. Um, so somebody who really, um, was focused on, on, um, on what, you know, on resourcing, if you like, or on supporting that child's, um, development and their interests, um, including service providers. And I think, um, sometimes we underestimate the role that, um, a service that's, especially one that's around for a long time can have, you know, often we have short term services, um, and that's, that's, um, problematic because children's relationships, you know, children need support to develop those relationships. They can't, you can't really do that in a 12 month or two year service. Yeah.

Marjorie (18:30):

I'm, there's a few things like I'm listening to you and there's a few like ideas that just pop, uh, in my head first. I think that definitely one, one, uh, added value to your research was definitely that it's focusing on strength, you know, and it wasn't about sort of, um, the families that we often hear in the research papers and, um, that we have thus far, which is often sort of a group that comes from child welfare or is followed, or has been followed in child welfare, which tells us like the families that are, maybe are struggling a little bit more in your case, it was sort of families that were still together. Um, you know, the kids were not placed. And so that definitely shows in terms of what does it look like when it it's, you know, those families are doing well and what elements of that could contribute to them doing well and thriving as a family.

And I think that definitely that's, you know, something that's very important and I hope that people will be reading, um, your article, especially for that reason to sort of have that positive image that we often do not have. Um, so that was one. And then you also talked about sort of, you know, that, that support, that it could be people that support the mother yet. It's really about supporting the whole family, which includes the children and certainly, um, some discussions and interest that, um, that I have, and that I've talked to, uh, Dr. Spencer Margaret Spencer, about, and the, both of us is looking at co-parenting arrangements, but co-parenting when you sort of look at everybody, all those adults that are around each of the children and how, you know, their relationship play out. Um, and you know, how, how does that work within the family in terms of, um, showing for, for benefits and support with the children?

So I thought that that was interesting also that in research, you mentioned sort that in that, you know, a community around children or around families is that important. And I will, and, and I know that it's more about hearing you than hearing me, but I will say that the other part that I found fascinating is how you mentioned, um, about service providers and how we usually have like short term, you know, um, service provider engagement, when in truth for, for children that might be, you know, somewhat detrimental. And we are doing basically, um, you know, ill favor to them because we are basically, you know, throwing people that come in and leave very rapidly. Uh, so I think that that's something to, to consider or think about, I think when we offer services to, uh, to these children, um, and their family.

Susan Collings (21:24):

Yeah.

Marjorie (21:25):

I don't know if you wanted to add something in terms of like my reflections on that, or should we go on, because you also mentioned how, you know, your thesis research sort of, um, gave you some knowledge to do other research, which you're currently doing.

Susan Collings (21:42):

Yeah. I would echo definitely everything you say and that, and that family focused approach, um, where we don't we're too often. And, um, and again, this is systems thinking it's not necessarily about any individual practitioner, but systems tend to segment, you know, we, we like to segment, this is the client and this is the client and in the case, and I, I know as you said, um, Margaret Spencer talks a lot about this, you know, and we see this in the work that Margaret and I do together, this segmenting of all the, the parents are, you know, the child's our client, not the parent. And, and we see this a lot in child welfare. And in fact, you know, but we're also hearing the stories of when it works, it works because we are taking a family focused approach. Um, and, and we know from the research that the, that parents need sustained support parents with intellectual disability, um, so do their children, you know, so I think that that is the, the message, you know, this, this is about, um, embedding and supporting as needs change and not, and not seeing this as a quick fix, you can get in there and we'll just, you know, address that problem.

So the child's isolated because the mother is socially isolated, we'lll, connect the members and things, then we'll leave. That's not how these, these things work to help children thrive, as you say. Yeah.

Marjorie (23:06):

Yeah. That's a very good point. So tell me now about sort of the types of research that you were conducting. Yeah. And which led to the third article.

Susan Collings (23:17):

So, so I am, I am doing, um, more research around looking at, um, how, um, child welfare and also, um, our, our National Disability Insurance Scheme are working or not working for parents with intellectual disability and their children. I'm, I'm doing some research around, around that at the moment. Um, but what I've been a, and that is, um, uh, I don't have an article to share, but what I've been doing over the last decade really is looking at how to co-design research with, um, people with lived experience. Um, and that's both lived experience of disability, um, and, or, um, lived experience of, um, the child welfare system, um, including as a, as a parent, as a carer, as a young person who was in care, um, and really trying to, um, find new ways to involve people with that lived experience, not just as research participants, but really as research leaders and co and partners.

Um, co-researchers um, and so the, the third article I shared is based on a project, um, that we did, I, I did, um, with colleagues at the Research Center for Children and Families at the University of Sydney. And we were looking to understand how young people with the care background saw this concept of permanency and understood it. Um, it's a very, it's a very, um, kind of nebulous and imprecise and quite conceptual, um, term. And, um, and we are finding in Australia, it's, it's leading policy in child protection. Um, and, and this is, this is not new for, I think our, you know, our North American and, um, certainly, um, um, colleagues in the United Kingdom permanency planning has been a feature of, of, um, the system for a long time, but it's newer to Australia to think about this. We did have children staying in foster care for really long periods of time.

We had low rates of permanency through guardianship and adoption and low rates of really low appallingly, low rates of restoration, particularly affecting our First Nations, um, families. So, um, so this is really started to drive policy reform, legislative reform over the last sort of six or seven years in New South Wales and, and in Australia. So we really wanted to say, well, actually, what do we know about what young people say about this? And there, there was some research from, um, England in particular, some, um, some studies in England that talked to children, but most research had either done surveys or had talked to adults, carers, um, or children who were then adults. Um, and we wanted understand what it was like when you adjusted justed left care, what you thought the system should understand about children who were in care and their permanency needs.

So we used photo voice, and I thought this was a nice segue for the PhD that I, um, study that we've been talking about. We used photo voice, and we, and it was very much a participatory, um, process of engagement with, um, 11 young people over. We did it over two years. One of them was during COVID. So it was virtual, um, where we sort of discussed, um, um, in big groups, the sort of concepts of permanency and, and started to get some shared understanding, um, with young people. Um, and then they took photographs and, um, we just got a publication, um, under review at the moment, um, look at talking about, and what was really interesting this time. We did actually analyze their photographs, which I didn't do for my PhD, and really not only did the, were the words they were, um, using.

So, um, different to the way that permanency was spoken about in the literature and also in policy where the focus was on residential permanency, legal permanency, these are the important things. In fact, it was all about relationships. It was all about connections to people. And it was those really intangible things that, that the young people reflected on. We had some amazing, um, symbols, um, lots about nature, which never came up in the research, but this was about immersion in nature nature as a, as a, as a, as a stabilizing force, even if things were unstable in your own life that you, that you, um, going and looking at a sunset or a sunrise helped you feel a sense of, um, connection to, um, something beyond yourself connection, um, to, um, a future to a, to a hopeful future, lots of images of the ocean and, and discussion about water and continuity and flow.

So really a lot of symbolism and some beautiful images of what signified feeling home. So one young man who, um, took a photograph of cookies, um, and he said, what I remember is my foster mom making cookies with me. And that smell was, you know, it's so evocative of home. I felt like I belonged there because we did, we had this shared activity together, and that was home for me. Um, and, and another couple of people talked about being given a pet, and that was, didn't matter that someone said, you've got a legal order that says you belong here. You, this is your address. Now you live here when they were given a pet their own pet, that meant they were there to stay. So you can see how the meanings that, um, they attached to permanency were really, um, evocative and very visual, like, and, and it wouldn't have been the same had they just spoke this wasn't the stuff that came up in the discussion. It was when they had taken the photographs and brought them back, that they started to really gain some depth of thinking about, about, um, what they, what, what, what this, what they brought to this understanding of, um, of how, how, um, you come to feel a sense of stability and safety when you're a kid in foster care. Yeah.

Marjorie (29:55):

That is so powerful. Um, and I was listening to, to you talk about sort of those photos and how, you know, it really sort of brought, um, data, I guess, that you wouldn't have gotten any other way. Yeah. That was very personal for each yet. You know, it gave you a sense of sort of like, you know, using probably those visual images, really enriched all conversations later on about what that meant for them. And it actually made me, um, think of a, an article that I read a couple of years now it's a couple years old and it was about moms with all kinds of disabilities. And photo voice also had been used in terms of identifying sort of, you know, their life and, and, um, any narrative around accessibility and those photos I had seen, some of them were also very evocative. Um, and an example that will always sort of stay with me was this pile of dirty laundry in one of the photos and the mom who took that photo had said, yeah, you know, workers come in my, my apartment and keep telling me, like, you should do the laundry.

You should do the laundry, you should do the laundry yet. None of them has asked me with my physical disability, if I can access the laundromat, that's three floors down. And so for her, that was like an image that was very, you know, uh, important her daily sort of struggles of accessibility. And so I find that it's very, um, sometimes when we can't find words, uh, and sometimes it is difficult. And I would say with children probably even more that we're given sort of another tool to be able to get sort of to, to the core

Susan Collings (31:42):

Absolutely.

Marjorie (31:43):

What it's. Yeah.

Susan Collings (31:45):

And that's a perfect image. Yeah. I can, that speaks volumes, doesn't it? Um, and, and actually, yes, because part of why we did this, and I think the same as the study you're talking about is to really sort of, um, um, you know, throw this up to, um, to, to workers in a way we, we did this as a research to practice. Um, and, and it's really, this study really hit home. So the state government department did a webinar. It's been shared as part of training for workers now. Um, and I think that's, that's a Testament to, um, you know, something that's gonna have a bit a lasting impact because it, um, they're having discussions now about what questions are we not asking? What are we not asking like about where the laundromat is and how accessible it is? What are we not asking about how we can make, how we can help this child feel this is their home, and really feel that sense of safety and, and permanency rather than us just assuming we know what it is as adults. So, yeah, spot on. Yeah.

Marjorie (32:55):

And the other thing that I would add also is, um, I have a very strong interest in like life stories and using storytelling, you know, to yeah. To, to build sort of like a sense of ID identity and sort of be able to be reminded. And so, in a way also those photos could be used for them in terms of later on, to be able to say, like, this were the cookies that I baked, and this was, you know, the part that I went to when I walked my dog, you know, absolutely. That becomes their own sort of, I guess, storytelling and, and legacy in some way that they carry with, uh, with them. So

Susan Collings (33:32):

That's so true. Cuz life story work is about doing that. And we, that was one of our recommendations was, you know, ask, ask children directly, don't just ask the carer, um, what the child needs, ask the child and ask them in ways that they can communicate back to you best, you know, ask in a variety of ways. Um, and yeah, kind of get to know that again, it's the message is get to know this child and, um, and what what's important in their, in their world. And, and we, we did say that, you know, photographs are a great way. Um, and it doesn't have to be in a therapeutic, um, context where a professional trained clinical, um, um, psychologist does it. You can do it as a case worker. You can do this work. You can, we're all part of this, um, support structure around this child and this family. Um, and there's no nothing stopping you from doing the same thing. Yeah. It doesn't have to just be a research tool either. Yeah.

Marjorie (34:33):

Which is amazing. Cuz basically, I mean, that's what you, you, you talk about, right. It's like you did research, but with, um, sort of an end goal of something that would be useful and, and um, you know, put back into practice. And I think that that's, that's the best way to do research in my opinion. Um, yeah. Or the one that I prefer let's say because

Susan Collings (34:55):

Absolutely. Yeah.

Marjorie (34:58):

Um,

Susan Collings (34:58):

Cause we wanna, we wanna change the world don't we Marjorie. So we do, it's the best way to do research if you

Marjorie (35:03):

Exactly

Susan Collings (35:04):

Gonna change things. Yeah. Yeah.

Marjorie (35:07):

Okay. So I'm, I mean we could go on and on because it's always fascinating, uh, to dive into those, uh, specific questions. Um, but let's move on to the third part of the, the podcast or the chat, um, where, you know, knowing all of this and knowing that you've done research that you haven't spoken about as well. Um, where do you see sort of the field of parents and parenting with intellectual disabilities go in the future?

Susan Collings (35:35):

Um, I'll leave it open like that. Yeah. Um, so we, I know we've had conversations and um, and I, um, about inclusive research and really kind of coming to understand what this means. I mean, there's a, you know, we, we, we have some level of understanding of the importance of nothing, you know, nothing about us without us. Um, and there, you know, there's, there is, um, you know, the disability research deal has led that the way in, in terms of inclusive research, I would still argue it's in its infancy in terms of intellectual disability, inclusive research, um, and genuine, um, genuine sort of partnership and Le to support people with intellectual disability to lead research. So I guess I think I, that's what I'm really, um, that's what I'm the far in my belly. And I guess what inspires me is trying to find ways to, um, to support lived experience experts, um, and to work alongside them and to develop their, their skills and to understand what it is that they think the research questions that we should be tackling are.

And, and again, as I, I guess I kind of talked about earlier to some of that is really about building strong relationships, not just with individuals, but with the services and organizations and, um, advocacy bodies who know and support and have, um, relationships with, um, people with intellectual ability who have already said, we wanna be leaders, please, please involve us. Please let us take this. And, and I'm really excited by where this can take us Marjorie. I feel like we it's completely untapped potential. And, um, you know, there are some excellent groups forming in Australia that are kind of a part part of that family inclusion network, um, you know, particularly around child protection involvement, um, and leadership in that that I think has, again, not really involve parents with intellectual disability, but we are starting to see greater interest in hearing and involving those parents meaningfully with the support of their allies, because that it, we can't just do business as usual.

We can't, we have to adapt, um, our approach to make sure that this is genuine inclusion and genuinely, um, lead, you know, led by, um, those parents. And we've done a tiny little study. It's very, very small and I won't talk about it, um, here, but it's been working with a group of, um, six mothers with intellectual ability and we're hoping we just finished it and we're really hoping that, um, it will lead to other opportunities for those people, um, and for us to work with that group because they are quite simply, um, you know, amazing and inspiring and have again, messages that, that, that need to be heard. And, um, yeah, so that's an emerging area that I, that I'm really, um, I'm really fascinated by. And, um, and I hope to see more of, you know, more research that is like, um, that is, um, reporting on studies that have used co design and co-research is parents with intellectual ability.

Marjorie (39:13):

And what I like also, because I've, I've heard of some initiatives that you you've taken you and your team and the people you work with. Um, I know that also when you talk about inclusive research, it's not just a name on a paper that you're actually really doing inclusive research where, you know, um, they lead in terms of like their questions and what they wanna talk about. And I think that's really like how we could be efficient in doing that. It's not just like, oh yeah, I asked a few questions to like three people. Um, but it's actually involving them in, in from the ground up

Susan Collings (39:49):

Building, that's it? Yeah. And children and young people actually, I think that's something we haven't yet also heard enough of. There are some, you know, some, again, if we're thinking about change, social change, uh, and social movements, um, I think, you know, there is also, um, opportunities for young people, um, and young adults who have been, um, raised by parents with intellectual disability to be part of, um, the conversation in a more, um, active way. And for them to tell us what research would've, would've been, um, what would've been useful, what would've been helpful, what questions they would've wanted answered to Marjorie. I think, you know, again, I know there's, there's so much to talk about, but yeah, I guess I I'll just say,

Marjorie (40:43):

Hey, maybe, you know, we'll continue this conversation. Uh, and, and another one, cuz I think that this fascinating in terms of what we could do, definitely. So I will ask you, uh, one last question mm-hmm <affirmative> if you were able to talk to childcare workers right now about their work, uh, what would you want them to hear?

Susan Collings (41:09):

I, I think the main thing that the main strikes me that one of the biggest things that gets in the way is, um, feeling a sense of hopelessness, um, feeling that things are stacked up against families. Um, and that, that, that there isn't, um, a way through, without, um, without sort of state intervention statutory, you, you can't that you as a worker feel alone and you can't see being able to, um, I guess, reduce risks or, or build that connection that you want. There's not enough time, there's all of those problems. And I think I just, I would just like to encourage workers to, um, I guess re fake it to me, make it really kind of, um, believe in the potential of, um, families to thrive families and parents with intellectual disabilities and find the people in their life who can help them thrive. Be one of those people, a believe in them. Um, listen to them, listen to what they think is important and find other people to, uh, in their lives. There are other people, you know, circles of support, um, around the parent, um, building that community is critical. And you can only do that if you believe that whatever the problems they have can be changed you, that they can, you know, you can be part of that change. Yeah.

Marjorie (43:00):

Yeah. I like how you end, you know, um, one in the belief that it's possible. Um, and two in, in also sort of talking about community, cuz you know, each of us who are parents would tell you anyways that we didn't do it on our own. No, there were a lot of people involved and I think it's, you know, it would be very unfair if we, um, thought or sort of held parents with intellectual disabilities to a different standard saying, no, you have to do it on your own. Yeah.

Susan Collings (43:30):

Right.

Marjorie (43:31):

So, so I really liked, you know, how you brought community into it and uh, and also sort of to talk with the person and sort of say like, had you figured, you know, who could help out in your network already there?

Susan Collings (43:46):

Yeah.

Marjorie (43:47):

Yeah. Yeah. So I wanna thank you so much for, um, having this chat with me and who knows. Maybe we'll have, you know, another chat at another time to discuss about all of the other stuff that we wish we, uh, we had time to discuss this time around. So thank you so much to Susan for the time.

Susan Collings (44:05):

Yeah. Absolute pleasure. Thanks NA

Marjorie (44:09):

Great. Okay. Don't stop it. Don't stop the, the phone right now. We're gonna have 20 seconds of silence recorded, um, for any edits. So we're gonna go now. Okay. Okay. Let's so now we could stop. We're gonna stop.