

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 Tommie Forslund. Tommie's research concerns parenting among parents with intellectual and developmental disabilities, child development, influential factors, and parenting support. We started our conversation by talking about his Ph.D. project on the impact of trauma and abuse on attachment.

Enjoy! And don't forget, for more information about where to find the full recording and additional resources, check out the show notes!

Tommie Forslund (01:12):

It's been a big project in, in a sense that it took a lot of time to recruit the families and, uh, um, and we're still sort of working on, on publishing more papers from that project. We ended up with 26 mothers with mild intellectual disability, and their children, the children were between five and eight years of age. And that, that was, uh, mostly because of the, the attachment measure for the, for the children being validated for around that age span. And also recruitment wise, uh, some, some other scholars have had been emphasizing that when it comes to direct research on these families, there's been very scarce research using, uh, good comparison groups that sometimes mothers with mild intellectual disability have been compared with sort of mothers from, uh, from the middle class who have stable partners, good economy, and, uh, well-developed social support and so forth. So we tried our best to sort of create a matched comparison group, uh, finding mothers from similarly impoverished neighborhoods, uh, who had roughly the same income and, uh, children of the same age as the mothers with intellectual disability. Uh, so that also took, took quite a long time to get that matched comparison group. Um, around the time when we published our first paper, um, colleagues of ours, uh, published a paper, um, where they had been sort of reviewing care assessments concerning mothers with intellectual disability and their children. And in virtually all these cases, they found, uh, the professionals in their reports, uh, raised concerns about child attachment quality and the mother's caregiver sensitivity. So I do believe that, that this project has some important knowledge to offer about that.

Uh, what we did then, uh, we had two visits. First we met just the mothers, um, in their homes if they were okay with that, or in a neutral place such as their rehabilitation center, so that they would feel comfortable. Uh, then we got some background information, and we also conducted a thorough interview for abuse, trauma and maltreatment, uh, that they themselves had experienced in their lives. We were inspired by a study by Matt Goal, uh, who found very high sort of rates for having experienced, uh, abuse among mothers with intellectual disability. And we know from lots of other research that such experiences can have detrimental effects on caregiving and child development. So taking into account, uh, Feldman and others work

also sort of emphasizing that we must also look at contextual variables and not just sort of zoom in on the intellectual disability per se.

So in the first visit, we interviewed them their experiences of, of trauma abuse and maltreatment, and got some background information. Um, and then at, in a second visit, um, typically within two weeks, the mother and her child came to us in the lab, and they then got to sort of interact and play together in a semi-structured, uh, observational protocol that we recorded for caregiver sensitivity. Um, we used four different, uh, episodes of free play with toys without toys, uh, collaborating and cooperating on an itchy sketch and drawing together. And then sort of in, in trying to mimic, um, everyday life situations, we gave the mothers a task of their own, a simple questionnaire. And we also gave the children, um, an overly challenging toys so that they would come to their mothers for help and, and attention to see how would the mothers deal with that, similar to having to do the dishes or cook while the kids also sort of signal and have needs. And, um, after that mother and child was separated for like 40 minutes to an hour so that we could sort, so that we could, um, gather information about what both maternal and child intelligence. And we also did, um, the separation anxiety, uh, test for the children to, to get some information about their attachment quality. Um, and this project has thus far produced three papers, uh, that I've been part of a co-authoring. And I'm about to submit a fourth paper, uh, from, from this project.

Um, the study you're alluding to, uh, that, that you're talking about, Marjorie, the first one, that one focused on child attachment. Um, and also then how much abuse, trauma, maltreatment the parents, uh, the mothers had experienced, and how that related to the children's attachment quality. In brief, we found that secure attachment do exist among these children, about 35%, if I don't mis-recall. Uh, were securely attached, and even some children were even prototypically secure in their, in their attachment. So I think that in of itself is important that we can, that we can say that secure attachment do exist in this group. Um, then 35% is a bit lower than in general population. So that that does indicate sort of a risk for insecure attachment at the same time. And it was a marginal, significant, um, difference between the children to the mothers with mild intellectual disability and the comparison group children. Um, but a major finding was that maternal intelligence didn't predict anything but how much abuse, trauma, and maltreatment the mothers had been subjected to, emerged as a significant predictor, uh, in the sense that, First of all, the mothers with, with mild intellectual disability, had experienced an awful lot of abuse, trauma, and maltreatment, both during their childhoods and in adulthood. It was a notable effect size, uh, so that these mothers had experienced much more such experiences than the comparison mothers. And the more trauma they had experienced, the greater the likelihood of insecure child attachment. Uh, so that first study really emphasized also that like these mothers can or at risk for, for trauma, and that can have a detrimental effect that potentially on caregiving, and that that sort of can also influence their children's development when it comes to attachment.

The second study focused on the mother's sensitivity. By Lin Barry and colleagues. And, again, we found heterogeneity just as for attachment. like you can't sort of say that the role the same, it's not a homogeneous group. Some mothers with intellectual disability exhibited fairly high maternal sensitivity, and it was lots of variation. But similar to the first study looking at them as a group, their sensitivity was lower than the comparison mothers.

But again, similar to the first study, maternal intelligence was not associated with caregiver sensitivity. Whereas abuse, trauma, and maltreatment was. The more abuse, trauma, they had been exposed to the greater the risk of low maternal sensitivity. And then, um, I have an excellent colleague, he's a psychologist and he's doing his PhD, work for Professor Pafi and me. when he started, he was really interested in trauma and while we were collecting new data, so, I, together with him, we analyzed, another task that from that project about the mother's ability to interpret and identify facial emotional expressions among children infants, specifically using a booklet with, I think it's 40 photographs of, of infants showing, emotional expressions. Again, the same pattern emerged that the more trauma the mothers with intellectual disability had been subjected to, the greater the odds of problems, they had a risk of sort of biases in attributing shame to infants facial expressions. And, um, that has generally, typically only been found among severely traumatized parents in general, who are perhaps feel shame themselves and that sort of translates to how they process emotional expressions from others. Currently. I'm trying to wrap up, uh, a fourth paper sort of focusing then on to close this project. looking into these previous results, to what extent does it translate to child development in terms of problems with anger, anxiety, psychosomatic problems, high productivity, and, I'm about to submit that paper and there is a difference so that the children to the mothers with intellectual disability, are rated by their mothers as showing higher levels of behavior problems. And caregiver sensitivity is again, related to child behavior problems. In fact, controlling for caregiver sensitivity erases the group differences in child behavior problems. So that those analysis kind of suggests that maternal sensitivity may be contributing to the children's development.

But then again, it's important to remember that once more maternal experiences of abuse trauma maltreatment was also a predictor of behavior problems among the children. So once more, we see this complex pattern where contextual factors such as maternal exposure to abuse, trauma, maltreatment, may influence children's development, in, perhaps, perhaps through the mother's caregiving behavior. So we're trying to wrap up this project that has robustly emphasized the importance of not just looking at the mother's intellectual disability, but also taking into account contextual factors, and the importance of preventing exposure to abuse. How can we as professionals identify this and how can we provide treatment when needed?

Marjorie ([11:48](#)):

Yeah, you said exactly what I was going to, to go with that in terms of, you know, it really tells us about what is needed. And we know from also an array of different, articles and research in the field that persons with intellectual disabilities or persons with disabilities face, you know, more trauma and more abuse than, than in the general population. And so, you know, this is something that we need to sort of tackle because when these persons become parents, then from your research, what it does is that it, it can have an impact on children. And we see that also in terms of intergenerational trauma that we talk about, you know, in First Nations, for example, population in, in the us, Canada, and Australia. And we've seen that in other sort of, um, you know, cultures as well in terms of, you know, passing down the trauma to the younger generations.

And so that's why I, I think that, you know, this, this type of work was definitely needed. It also

teaches me as, um, uh, a professional and as a researcher that when we conduct really robust research like, you and your colleagues have done, we end up with, you know, results that really allow us to make a difference and to understand what is happening. And so I thank you for, for having done and being part of that research and for continuing to look at attachment, um, you know, in parents with intellectual disabilities or in their children, but, um, who, uh, who have parents with intellectual disabilities. Cuz I think it's, it's a feel that is, um, very important and, and can lead us to understanding better what our role might be as professionals and clinicians.

Tommie Forslund ([13:35](#)):

Thank you. We're currently conducting a new project where we're studying the mother's attachment representations. We're using a gold standard, uh, method called the Adult Attachment interview. And, we have met 40 mothers with intellectual disability and, uh, roughly the same number of mothers with ADHD as a comparison group. Because one specific type of insecure attachment, called disorganized attachment. And among adults then, then you talk about unresolved states of mind, and given that's specifically related to abuse, trauma, and maltreatment. So given our previous results and those of others, we have an hypothesis that there's, there's a notable risk of unresolved states of mind among the mothers themselves. so we're looking into that. And, and also, of course, in relation to some other measures of mentalization and, caregiving and, child development, hoping that, that these findings can sort of maybe attest to the importance of psychological treatment for these mothers and, in order to help them, but also, for their children's sake.

Marjorie ([14:52](#)):

You talk about treatments, and that made me think also when you were talking about the previous research, when you were talking about sensitivity, you know, and being able to notice or understand or see what their children's needs are. Um, you know, there are some interventions that do exist, specifically for parents with intellectual disabilities that have proven that when you apply sort of that intervention sensitivity increases. So I think that there's, you know, it teaches us where, where we need to work on, or, you know, what are the things or the elements that we need to check as professionals, but it also know from a larger body of research that we can do something about it and we could sort of work on, on that. And that's, that's possible.

So I thank you for, for, you know, making it clear cuz you know, working in attachment, sometimes it could be very complex in terms of understanding those concept. So thank you for making it sort of clear.

Now, as you know, as everybody know, we have been sort of in pandemic mode for the last couple of years. And, during that time you had an idea to, to talk with parents with intellectual disabilities about their experience during Covid. Do you wanna talk to us a little bit about that, uh, research?

Tommie Forslund ([16:16](#)):

Sure. So I interviewed 10 parents with intellectual disability. I was hoping for roughly the same number of mothers and fathers, but we ended up with nine mothers and one father with

intellectual disability. And, we used a manual for the interviews, based on lots of research on these families. And, uh, well, we ended up with 20 questions in three different sections. The first section, um, uh, asked about potential effects on the mothers themselves, uh, psychological wellbeing and the social contacts with friends and family work economy, finances, participation, being able to be included in society and go to different places. All of that.

And the second section, concerned effects on the children, because I mean, viewing caregiving and context also needs to sort of how do the children fare. children can be variously easier or difficult depending on how they're faring. Then we asked about, uh, I asked about effects on, on parent-child interactions, um, during the Covid pandemic, and humbly sort of stating that like the pandemic may have influenced you or, your child making it, more difficult or easier to be a parent. We also asked about potential positive effects of the pandemic. and what we ended up with was then 10 long interviews. They were, I think on average, more than an hour long. And we analyzed this, using qualitative analysis, thematic analysis. My colleagues are good with that. So we analyzed them that way. And we did find some concerning results. We summarized the results as pointing towards increased caregiving demands and reduced resources for coping, resulting in parent-child strains on the parent-child interactions and relationships.

And then, we addressed four specific, uh, themes under that, that we found. And the first one was information. I think all 10 parents had been very concerned in the beginning of the pandemic and had difficulties understanding governmental information and what was being said on the general news, which made them even more sort of afraid. And, but then there was a difference. Some of these parents got help from friends and family or professionals to acquire sort of a nuanced understanding of the pandemic, the dos and don'ts and the restrictions. And, those parents tended to fare relatively well together with their kids in comparison. Like they were able to sort of, uh, uh, redirect their attention and substitute, activities that they used to do with their children. Like, okay, so we can't do this, but given the restrictions, perhaps we can do this instead. Whereas some of the parents, they had prolonged continuous difficulties understanding the restrictions in the pandemic. They didn't get any help, they didn't get any, any adapted information. And it was clear from those interviews that these parents had difficulties sort of navigating the pandemic for their own sake and for their children. They tended to become more isolated and being sort of confined to the department. And they had difficulties finding new activities to do with their children. So we're really emphasizing the importance of adapted information. The government here in Sweden has been criticized, taking months to make adapted information accessible.

A second theme, if we emphasize effects on social relationships and, and informal support. Um, lots of these, caregivers, they, they talked about how they used to get support from friends and family, but due to the pandemic, they could no longer receive this help. and they also missed friends and family, and it took a toll on their wellbeing. So sort, reducing their own resources by, by affecting their wellbeing, and also then getting less help.

As a third theme, there was a notable reduction in professional support. During the beginning of the pandemic. You couldn't have professionals in your home, like you used to, like you used to. And, I think one of the participants said it well when she said that, when I have my support, then I, then I sort of blossom and I, and I function really well, but now I'm like a wilted rose that, that sort of not be not being allowed to have that support that she needs. And, and that

she were used to really took sort of a toll on her. And the parents talked about chaos emerging, and it was difficult to manage household tasks and get energy over for their, for their children. So that was also notable influence.

And as a fourth and final theme, we're emphasizing difficulties interacting with children's schools. The schools didn't use adapted information. They sent out tons of information and sometimes the parents didn't know from one day to the other if the children should come to school or if they should have distance education. And naturally having an intellectual disability can make it more difficult to sort of help your child with schoolwork. But now during the pandemic, suddenly they were expected to help their children with, with their schoolwork. One parent even talked about how, how the social services, instead of sort of helping her and talking to her about how can we make schoolwork function, then the school called the social services instead suspecting the mother of, uh, of neglecting her child. So kind of that interaction didn't, didn't work well. And, in line with previous research, um, concerning these families interacting with children's schools were really difficult for the parents. And so in some, the caregiving demands really increased because the children, uh, were heavily affected. They couldn't meet their peers, um, and family. Um, their activities were canceled and there were lots of changes for the children, and some of them had disabilities themselves and were affected sort of creating extra demands on the parents with intellectual disability to manage this. I think our findings sort of extend that to parents with intellectual disability who were left more alone, had less support, and an increased, sort of caregiving burden to deal with. One mother actually, felt so she was, she was influenced so much by, by the pandemic. So that eventually, and I think this is kind of impressive, cuz she really sort of had her children's best interest, closest to heart. Eventually she felt compelled to place her children in out of home care because she didn't get the support that she was used to. And she was really, really fighting for her children. But she didn't get adapted information. And she started searching and searching more on the internet for information, which just freaked her out more. She talked about watching things on tv, like how, how they were, sort of barring doors in some countries. And she saw soldiers on tv and she was like, is that gonna happen here? Will there be soldiers on the streets? What's happening? And eventually all these fears influenced her, to the extent that she felt like she couldn't fulfill her caregiving, in a sufficient way and felt she had to place her children in out home care. And I, I think that sort of attests to a failure from the society to support this family

Marjorie ([24:35](#)):

And attests to that, it also attests to, the love that this mom has, just like you mentioned, you know. How hard it must have been for her to sort of, you know, admit that, she didn't feel equipped or supported well enough to be able to do that. And the best interest for her children was that they receive the caregiving from somebody else. That's a pretty big decision to take as a parent.

Tommie Forslund ([25:04](#)):

Yeah, and I think very few parents make that decision. Mm-hmm. That decision themselves.

Marjorie ([25:09](#)):

Yeah, exactly. And you know, I was listening to you a talk about Covid and one, I really wanna thank you for, for bringing their voice during Covid, because I think that there was a lot of research done during the last two years on the general population. Yours to my knowledge, is the only one who really looked at parents with intellectual disabilities, bringing sort of voice or an image and illustration, uh, snapshot of what it is or was for them. But when we look at sort of, you know, in the general population and this population, the stress, the, the lack of resources, the lack of information... I think we all live that and we all sort of struggle at one point or another. The difference may be for parents with intellectual disability is that they require sort of that additional adaptation so that they could understand what the information means and what impact it can have on their lives.

And because that resource or that help wasn't there, then we put these parents and these families in jeopardy. Uh, and I say we, because I think it's a responsibility from society to be able to provide information to everybody so that everybody can understand.

There is something that I would like for us to speak about. I understand that it's not your research, but you work also as a clinician, in a country that has established sort of a national strategy to some extent, called P Y C, Parenting Young Children. So I would love for you to sort of briefly tell us what that program is and what you know of, you know, some of the results of putting this program in place had on parents and workers.

Tommie Forslund ([27:03](#)):

Sure. P Y C stands for Parenting Young Children. It's a caregiving intervention that comes from Australia, my colleagues here at S U F Resource Center, in Uppsala, quite a few years back together with other researchers and practitioners in Sweden, in a consortium. They brought the P Y C here to Sweden, translated it, and have sort of used it quite a bit here in Sweden now because, as you say, we do have a national strategy in Sweden that we should be able to support all parents in their caregiving. P Y C is based on evidence-based cognitive support, it is also home-based so that you're, you're helping the parents practice various skills in the environment where it is mostly to be used. And there's like two dimensions to it, one dimension emphasizing, uh, sort of, uh, protection and security and, uh, basic childcare. Um, and then there's, uh, a second dimension emphasizing caregiver sensitivity and, those aspects of interacting with your child. And, there's been one big former project led by Michaela Starke involving quite a few sites in Sweden.

It seems to have the benefit of being an instrument, for the professionals that can help guide their work. Because one aspect is that, you're breaking down, I think this is inspired by Feldman's work on Step-by-step, so you're using cognitive support and aids for like creating sort of schemes and what order to do certain things and practicing that with the parents. And also together with the parent who you set goals, what should we work with? You're not just coming from the outside and say and telling the parents that you need to work on this. So you're actually inviting the parent into the process. Like, what do you wanna have help with? What do you think, would be good to improve on? And so there's indications that the parents tend to find it, that it helps their motivation. They get to be part of it and it helps them with a therapeutic alliance. That seems to be a good thing too, when also the, um, the cognitive support that you're using and adapting for each and every parent based on

what are, what are we working with here? And often setting goals, you can, you can make observations and then you're practicing with the parent and then you're evaluating to see to what extent have we succeeded in sort of developing this skill and in, in like a circle and you keep going like that and then setting new goals and targets. So you tend to wanna have a long contact for this, and you perhaps you wanna meet like twice a week and over, over a year. So there's lots of indications that it's a, that it's a constructive and positive way of helping these parents in a way that is sort of adapted and, and meets their cognitive needs.

Marjorie ([30:08](#)):

Yes. And it's, like you said, it's, you know, built from, from other programs that also have shown sort of efficacy and, you know, positive results for, for caregiving. So I thank you for, you know, explaining that to us.

Now I'll move on to the next step, which is, you know, a lot of things are happening in Sweden, obviously in the last, I would say at least 10 years even more. What do you think would be next in terms of research, but maybe also in terms of clinical practice, if you had an idea?

Tommie Forslund ([30:42](#)):

I have lots of things that I'd like to see being done. Um, we all have, I guess. um, one thing that is close to heart for me is, how can we sort of take the knowledge on the high risk of abuse, trauma, maltreatment, to another sort of practical, useful level. I've spoken to quite a few parents and professionals now who say that it's difficult to sort of to get these parents, trauma focused treatment. To some extent, psychological treatment in general because in Sweden, habitation tends to focus on the, on the cognitive difficulties per that, that's their area, the, the disability and how can we help them with inclusion and, and, and so forth. Whereas psychiatry, they can often say that, well, we can't do this. This should be, this should be something for the habitation. So they end up sort of falling in between, and they get no help. Some of them. The mother that I mentioned earlier, who placed her children in out-of-home care during the covid pandemic, she fought to get trauma focused treatment because such things had also influenced her. And when I meet a parent, I always tend to take a lot of time so that we're not in any rush and we can talk about other things too. And it turned out that she had no idea about P T S D, the existence of P T S D, and, and she was like, this fits so well. but she had to fight to get like an assessment for, for that and then, and then eventually get treatment for it.

And it's been really heartwarming to follow her, she keeps telling me how much better she's feeling now due to this, treatment that she now has now eventually gotten. And the social services also see lots of improvement and, uh, they, they really push for her taking her kids back, and having them, back at her home. But she's, I think she's wise. She's like, I don't wanna rush to this. I wanna feel stable and work on myself and then gradually sort of increase the contact to get to that state of having the children full-time living at home. So, I know there is some research on trauma focused therapy for persons with intellectual disability, but I haven't really seen any research on trauma focused interventions for parents with intellectual disability.

And that would be a dream project, I think, to see if we can give these parents trauma treatment for their traumatic experiences, to what extent does that translate to and sort of help them with



their caregiving and help child development. That's one thing that I would really like to do eventually. And I think it would require substantial funding, to be able to sort of help habitation and psychiatry to set aside resources to sort of collaborate on this and make it happen. But that's something that I, that I mean to do.

Marjorie ([33:48](#)):

Yeah, so many, so many different things that we could do, uh, if we had, you know, a lot of money and a lot of time and sometimes we have to check. I, really wanna thank you cuz this is like amazing in terms of, of wealth, of information from research and then from clinical. I will ask you now the, um, the last question, which is, if you could speak to child welfare professionals right now, what is the one thing you would like them to remember or to focus on?

Tommie Forslund ([34:20](#)):

That would be heterogeneity? Uh, not sort of assuming that parents with, with intellectual, with intellectual disability are incapable of, being a good enough caregiver. There's still research coming out showing, suggesting that professionals and laypersons still sort of have these stereotypical views that parents with ID are incapable, due to intellectual disability per se. So heterogeneity, like our research and lots of research from other scholars around the world have continuously emphasized heterogeneity. Like we found that some others with id, were fairly high in sensitivity. We also found that some of their children were securely attached, even prototypically securely attached. And some of these mothers had not been subjected to, to abuse trauma maltreatment either. So kind, there's lots of variation. So I would like practitioners to remember that. And also to remember that caregiving and child development is influenced by so many different factors. Not just assuming that it's about the, the caregiver's intellectual disability, but like abuse, trauma, maltreatment, social support, access to professional support, for example, which can be difficult sometimes that, that it's too, that support is too inaccessible and perhaps also, um, leading to some, pessimism concerning the parents and children's prospects. And so remember sort of that the multifactorial nature of this, that there's so many things we could help these families with as well. How can we sort of help them with social support, with all their contacts. often their children can have disabilities of their own. And not just assuming that the child's development is about caregiving, but may maybe they need help with sort of a, a referral so that the child can get an assessment and, and perhaps sort of interventions to help the child's development that way. And how can we make it easier for these families with all their contacts, with the social services, with rehabilitation, psychiatry, uh, schools. Like how can we simplify things for them?

Marjorie ([36:36](#)):

I think that's an awesome, way to end the podcast. And I really want to thank you for the time that you took to talk with me and to share all of your knowledge and um, you know, I can't wait to see what you're gonna be doing in the next little while. So thank you very much, Tommie.

Tommie Forslund ([36:56](#)):

Thank you Marjorie. And thank you for interviewing me.

New Speaker (37:04):

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