# Episode 8: Needs and Service Gaps

Marjorie (00:07)

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 Evelina Pituch. Evelina is a graduate student who is about to defend her Ph.D. dissertation. I met Evelina a few years ago and I knew right away she would become a rising star in the field. Evelina showed her passion for this work and her respect for parents with disabilities through her research and publications and I am so happy you will hear from her today. We began our conversation talking about her doctoral work and what she learned from several stakeholders including parents with a physical disability or neurological condition and their partners.

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

Marjorie (01:30):

Let's start with your Ph.D. and what results you got and what lessons you would take on that.

Evelina (01:38):

Absolutely. Well, as you know, a PhD is during a few years and it's like a marathon and I did a number of studies. I think one study I would like to showcase today is a study in which you had actually some major contribution. And I thank you for that Marjorie. So actually here in the Province of Quebec in Canada, uh, I believe to my knowledge, we conducted one of the first, and it's kind of funny to say that cuz we're in 2022, One of the first studies, um, about early parenting with a physical disability, here in the Province of Quebec. And I would say one of the first involving multiple stakeholders. So actually involving or hearing the voices, making sure the voices of numerous plural participants are being heard. And by that we conducted a focus group study with of course parents, themselves, spouses, rehabilitation clinicians, community organizers, and some scholars. So researchers in the field.

And as funny as it may sound, I would argue that the field of parenting and IDD is much more mature than the field of parenting and physical disability. So, we're kind of starting at the basics. So with that study, our purpose was really to explore what were the needs and what services and resources were made available to the families, headed by parents with physical disabilities and we were really open. So we considered parents with a number of clinical diagnoses, either parents with cerebral palsy, some had, for example, a spinal cord injury and concussion, others, traumatic brain injury and so on. All were reporting in that study their experience of parenting a young child. So we've specifically focused on children aged between zero to five years old as, I know, you know, how the issues are different as children grow and evolve and so on. So we kind of focused on the preschool period here for that study. And we're just still waiting to hear back from the journal where we submitted. So hopefully this study will be published and available to the public very soon.

I think with that study, there was a number of findings that really struck us. So of course, maybe one which is a little bit more self-explanatory is how much, the participants in our samples that we were actually fortunate to have 35 participants in our qualitative study. They were, of course a lot of them reported the lack of physical accessibility. So some parents like we discussed previously use a mobility aid or equipment, um, and a lot discussed how difficult that may be. In part, if not for most, do, how our society is actually inaccessible for persons with physical disabilities. So going out and about from your home to some public, facilities like daycares and schools and, the library and so on that can be very difficult for someone who uses, for example, a wheelchair and has also a young one to take care of.

So I, I think that would be one of the first findings that was really evident in our study. And in parallel, and I know that was a topic of discussion in your previous, episodes is how society can also be unwelcoming for parents with physical disabilities in all sorts of way, conscious or unconscious, due to the biases, and prejudice some may have in thinking about parents with physical disabilities. Thinking for example, that these parents are struggle that they're not capable, which of course research has demonstrated is not true in many ways.

So I think there's still a lot to be done in how society actually makes parenting easier for everyone. And that includes of course, parents with physical disabilities as well. And in discussing how society actually, what places given to parents within society, par participants also highlighted how services were actually either disconnected from their own reality of parenting with all the strengths they have. So for example, I do remember one father in our study sharing when we ask the question, can you talk a little bit about the services that you received as a father and his answer was “what services?” This is in spite of actually having a program like Parents Plus here in Montreal, which he benefited from, but like you said, Marjorie currently that program is for zero to two years old. So parents having zero to two years old, I know they're working very hard to actually expanding their services to include more parents, and children of different age groups as well, but still that father, shared how he felt he perceived that services were very little aligned with what was his most significant role, his fathering role.

So I think there's again, a big reflection that should be made in terms of what services are made available to these families and these parents. And I know Dr. Llewellyn kind of discussed this in terms of having specialized services for parents, but here again, participants complained how services in the general population were in inaccessible or un-adapted for parents with physical disabilities.

Marjorie (09:03):

You summarized it very well in terms of what the parents brought forward. I remember also, because I was part of the focus groups, staff, you know, and clinicians sort of saying also, and admitting to not having enough services or not having enough resources to be able to either help the clients that they had or to help more clients that they know they could have if only they were allowed to offer those services. And so feeling sort of frustrated with, you know, a system that sometimes does not allow us who care and who wanna help to help actually. And that was a big thing. Do you wanna tell us a little bit more about sort of what, you know, those clinicians said, or, you know, the other, like community organizations as well?

Evelina (10:00):

So clinicians, some of them actually, and researchers as well mentioned how services could be disconnected. So for example, and this all circles back, how services are actually organized within our health and social care services system. So for example, here in Quebec, we have services for children and we also have services for adults, but then again, those two types of services don't necessarily collaborate well or collaborate on a regular basis. Whereas when we discuss parenting while we're actually discussing a family unit, so we have a parent who takes care of a child, there's maybe another parent involved, a spouse, a caregiver, a significant person, and so on. So basically our client, it's not just one individual, it's a whole family system that we're talking about. And so I think our systems need to work better together at first to make sure that parents are being heard and receive the services that they are entitled to receive.

I think that was one of the key messages that was shared within the focus groups. I think another key message was perhaps in terms of how some participants perceived that there was a lack of training, around parenting and disability within the current realm of things. For example, if we draw back to my how I entered the field, so my own set of examples, I could witness firsthand how parenting was not, or very little discussed within my own program, when one would actually expect that parenting would be discussed in four and a half years. Right. <laugh>. So I think this is also another topic of discussion, how we make sure that the people who will actually assess and intervene with parents with disabilities -and I think we could argue any kind of disabilities at that point - how they're actually trained and prepared to work with these families and what is actually out there for them in terms of continuing education. And what do we have in terms of university materials courses, that integrate disability within their curriculum.

Marjorie (12:48):

I love this because as you're talking, of course you you've listened to the first few episodes I'm up ahead because I know what's coming and some of the episodes that are coming that are right, right, right before yours, are actually with Susan Collings, who is a researcher from Australia. And we have a beautiful interview that's coming also with twin daughters of Amanda, who is a mom with intellectual disability. And in both of these interviews, you know, the twins and Susan also mentioned about services being disconnected and not taking into consideration the family as a whole, but also every role in that family as a role that they need to take into account, take into consideration and work with. And so an example that Beth and Lily gave us was, you know, talking about how services were offered to their mother, but they weren't offered to them, the kids, the children, and so whatever services they needed was always coming from the angle of their mom. But they were saying like, we also had sort of needs in terms of maybe understanding how I, we should explain to mom certain things or you know, if we struggled about the stigma and how can we do that. And Susan in her research, which is research where she talked to children who were in that middle school age. So around seven to 12 years old also brought up sort of the, the need to basically sort of be taking care and by the services and taking into consideration basically. So it's sort of like, to me, it's beautiful, cuz it's sort of like highlighting a point that's very important that, and that many of us have high highlighted and know, you know that it's necessary to be able to offer support to the spouse, to offer support to the kids that it's not just about, you know, the parenting.

And when parenting happens like after parenting or rather when parenting happens before the accident. Like for me an example, offering support to, you know, my child who was also reacting to the changes that my injury happened is also necessary. So I think that that's beautiful cuz it really talks about sort of the need of looking at services in a way in a different way.

Evelina (15:19):

Absolutely. And if I can add to that. I think it's a tendency or even it's more than a tendency. Future healthcare professionals are more and more being trained to be client centered, patient centered, whatever the terminology you're familiar with. And for example, as an OT, we learn at the university to be family centered when we're working in pediatrics. So with children, but it's as if, when we consider the adult, when at that period of time, we're kind of losing the focus of being family centered for those who already parent like yourself, for example, Marjorie or those who are thinking about it, that maybe, maybe it's something that they would like someday to do. So I think that's something I would like to critique it within my own field of study and clinical work, we should learn a little bit more to be family centered with adults and not only with children.

Marjorie (16:35):

Yes. Great point, great point. So that's a beautiful, thesis that you gave us and research. I can't wait for people to have access to it. And of course there will be a mention in terms of where to find the article once it will be published, cuz I'm sure it will be. Um, so that will be part of the show notes for sure. If we were to look now more in terms of the future. You're gonna graduate soon, uh, what happens after?

Evelina (17:12):

Well, I know in one of the previous episodes, so I was really a keen listener, as you may see. You mentioned that there's a momentum around parenting and disability and I see all sorts of clues actually pointing in that direction as well, Marjorie. So I'm really optimistic and really excited about what the future holds. Now from my perspective, I am so grateful actually to have been awarded a Canada Institutes of Health Research Scholarship. So I will be in just about a few weeks starting my CHR research fellowship program at the University of Toronto Scarborough with Dr. Hilary Brown, which you, I hope you've heard of actually, as she's been producing some great research work around mothers with disabilities and she's actually the first in Canada to my knowledge, to produce some population based data around mothers with disabilities. So that that's huge and that's actually great. Cuz when I started my PhD, I had no argument in terms of recent statistics to put forward as this is an issue of interest for a lot. So I'm happy that those are actually available and out nowadays.

And so as a post-doctoral fellow, with Dr. Brown, we will be investigating and conducting a number of projects, but one which is close to my heart is circling back to what we've been discussing previously in terms of educating clinicians. Our goal is to develop a web-based training modules and specifically intended for healthcare professionals, such as physicians, midwives, lactation consultants, et cetera, who are actually working with mothers with disabilities. So we would like to create a set of training modules, which will be online evidence based informed by the lived experiences of mothers with disabilities. And that will serve continuing education purposes for healthcare professionals, already out there and giving their best right, but giving our best doesn't mean that it's always evidence based, although we're well intentioned. So I think having this sort of training specifically intended for healthcare professionals on the topic of mothers with disabilities and perinatal healthcare will be something I hope very useful.

Marjorie (20:08):

Yes, definitely. I look forward to the future with that in mind, for sure. It makes me think of a mom who did a beautiful documentary. I'm hoping that this documentary by the time that this podcast is finished, that you know, it will be shown to, to many. And her story is really about how she went through pregnancy while being, uh, a quadriplegic. And, uh, it really showcases, you know, sort of the work that she had to do with clinicians in terms of making sure, you know, that she picked the ones that would support her in that role versus sort of discourage, her choice of becoming a mom. And so, anything in terms of supporting clinicians, but also in a way opening up opinions and attitudes to pregnancy and disability I think is very much needed for everybody. I'm sure the parents would agree and I'm sure also the professionals would agree as often we feel a bit sort of led down by our professional orders or, you know, our schools. And for some of us, the school has been a long time behind us. So,it's always good to see it in terms of continuing education as well.

So I am at the last question of the podcast, which is if you were to speak to workers who work for child welfare, what is the one thing you would like them to retain from our conversation today?

Evelina (21:52):

I think it's a great and important question. And I would like to have a conversation with them, an extended conversation, but if I had only one thing to say and perhaps it's not that original, but I think we need to go back to basics at some point. And I would like to tell them like, like other scholars have been telling, in the field of IDD. So, don't assume that parents cannot parent because they have a physical disability. This is absolutely a false assumption. We have data that demonstrates the contrary. Don't misinterpret that parent because parents have needs that they cannot parent. Try instead to find resources, or services that can help parents and their families to live meaningful lives. And promote what is perhaps one of the most meaningful role they will have to do.

Marjorie (23:02):

Yes, that's a good one. I'll tell you that as you were talking, and I think it was a conversation that you and I had in the past, you know, where we reflected upon the fact that we offer services to children who have disabilities and society is very open to offering services and support to these children. Yet we forget that these children actually grow up and when they grow up, they become adults with disabilities who have been pretty much taught all their lives that yes you can, and see, I can support you and, and services are there to teach you and to show you that things can be done differently.

And so, we need to continue that message to show to these kids that we've, you know, supported all these years to basically continue and sort of say yes, and now you're gonna live to be, you know, adults that are self- actualized and who can, you know, decide for yourself if you want a family and how many kids you want. And if you wanna get married or not, and how you wanna raise your children. And we are going to help you in terms of making sure you have all the resources to be able to do that the way that you want to do that, and you've dreamt about it. And I think that, you know, ending on that note in terms of reflecting about what we can do as workers to make that future happen is definitely something to thrive towards definitely.

Evelina (24:39):

I couldn't agree more and I have a short story to share here at the end, cuz I think it really is on point. So at the start of my career, I was actually working as an OT with themes. And just to say how for Many, parenting is like ingrained within our DNA. And we, we aspire to that role someday, perhaps. So in my caseload I had one teenage girl and she was seeking my services in occupational therapy. She wanted to be the most independent possible. And when I asked her why she was doing all those efforts, well, she basically answered something like, well, someday I will be a mom, so I need to be able to cook for myself. So here she was. She was on the edge of having 16 years old, but she already had this end life goal of being herself, a mom one day.

So definitely I think we're teaching all those life skills to our children who live with a form or another of disability, but we need to make sure that these children, once they grow and become adults, they still thrive in our society. Whatever form that takes if it's in the form of parenting or not.

Marjorie (26:04):

I thank you so much for this conversation. It was an awesome, very inspiring and very energizing conversation. So, uh, thank you so much. And I invite everyone to follow your career because I can foresee your career of being, just really plain SP special. And you are definitely in my mind, one of the rising stars of this field and I thank you for all the work that you do and for all the advocacy that you do as you're doing your research. And I look forward to seeing you work on all those future projects of yours. Thank you

Evelina (26:48):

It's an absolute. It's an absolute honor to be invited to your podcast. And congratulations on the fantastic work you're doing with the podcast.

Marjorie (27:00):

Thank you so much.

New Speaker (27:03):

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