Marjorie (00:01)

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 Carmit-Noa Shpigelman. Carmit-Noa is a single-mom by choice and a woman with a disability. She is also a researcher who conducts studies on the attitudes of workers towards the parenthood of parents with disabilities. I started our conversation by asking her to describe the focus of her research.

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

Carmit Noa-Shpigelman (01:07):

In general, I can tell that in my research I focus on subjective experiences of mainly mothers, uh, with disabilities, and specifically focus on mothers with physical disability, or intellectual disabilities. So the first article that I chose for today is a research that I conducted in 2015. How to support the needs of mothers with physical disabilities. I wanted to learn or to understand and describe the challenges that mothers with physical disabilities face, as well as to focus on the strengths, and the coping strategies. So I interviewed 70 mothers with physical disabilities, various types of physical disabilities. Usually I focus on a disability from birth or a young age.

They described the many physical challenges such as taking care of the child, going out with the child outdoor activities, taking a shower. So the main physical challenges were when the child was young babies. But interesting findings was that except of the physical challenges they described, mental challenges. They described a dilemma about asking for assistance. it's related to the topic of independence. On one hand they perceived themselves as independent, up to the stage of their life until they became mothers. They actually did everything by themselves, and suddenly when they delivered, they needed the support, assistance, especially when the child was young, as I said before.

And it was very odd for them to, to figure out that they need and, and to ask for assistance from someone else. Another mental, uh, challenge was their identity issue. Again, they perceive themselves as another non-disabled woman, and for the first time, they couldn't do everything they needed, someone else to support them, to help them taking care of the baby. So in some cases, they said that they were actually empowered by their mothering role, but, for the first time, they had to deal with the disability side of the identity. So it's created more emotional distress among some of the mothers. Beside that, they talked a lot about social stigma. They experienced a negative attitude for medical professionals. For example, one of the mothers said, the physician told me, "why did you decide to have a child if you suffer from so many medical problems?" So it was a big issue for them.

Another main thing that I found in this study was the strengths. They emphasized that they had their personal strength that helped them actually to overcome the challenges. They perceive themselves as resilient. The disability actually made them overcome or they actually learned how to accommodate the environment, to make solution to think creatively, and to find the right solution for them and for their children.

They also, some of them said that they became activists in the disability community especially, in terms of mothers with disabilities, and they wanted to promote the rights of parents with disabilities and their children. In terms of practical implication or recommendations, they said that they would love to have more recreational activities that are accessible for parents with disabilities to be integrated in the community with other mothers or parents without disabilities to be able to go out with the child and do, non-disabled activities. As other parents. I believe that this study also demonstrates the importance of focusing not only on the physical challenges, usually, it's the easy way to find the solution and to make the environment accommodated to the parent's needs. But it's more than that. It's promoting awareness, and fighting the social stigmas and addressing their mental well-being needs, like support groups for parents with disabilities and so on.

Marjorie Aunos (07:15):

I love it because it really talks about sort of the reality, the day-to-day, you know, it doesn't ignore, um, you know, what, what the reality is, but in the same time, it sheds light on issues that maybe we wouldn't have thought about. Like you mentioned, the mental health, um, you know, and the importance of, of dealing with the stigma. So I'll let you sort of introduce the second one, um, which actually talks about attitudes if I'm correct.

Carmit Noa-Shpigelman (07:42):

So the second one, we wanted to examine the relationship between women’s types of disability, psychiatric versus physical, and the social attitude toward the woman. And also to examine if this relationship is moderated by being presented as a mother. So we gave scenarios, six scenarios. One was about a woman without a disability. The second was a woman with a physical disability, the third woman with psychiatric disability, then mother without a disability, mother with psychiatric disability, and mother with physical disability. And we asked 100 university students to fill the survey to read the scenario and fill some questionnaires about stigma and attitude.

And we found that attitudes toward women with physical disabilities were bad and their attitude, attitude towards women in psychiatric disabilities. But another interesting finding was that when women had physical disabilities, there was no change in attitude toward them, regardless whether they were presented as a mother or not. Okay. But when the target woman was a woman with a psychiatric disability, um, she was, she was presented as a mother. We observed negative attitudes toward mothers with psychiatric disabilities. So here again, the study demonstrates the existence of hierarchy of stigma. So even though we look into the disability community, we can observe, unfortunately different, social attitudes toward the women, and especially mothers with different types of disabilities. And here I can recommend professionals to, again, to promote more joint activities of mothers with different types of disabilities and mothers without disabilities in a way that will promote attitude change. Mm-hmm. <affirmative>, as well as providing the support that matters with psychiatric disabilities need. And then maybe establish social support groups for mothers with disabilities to support each others.

Marjorie Aunos (10:29):

It's interesting. Because you know, when in the states they published that report called Rocking the Cradle, they also highlighted that hierarchy of stigma amongst the population of different disabilities. As well, you know, where parents who have an intellectual disability was probably the parents who were the most discriminated against. And probably the parents with physical disabilities were the ones who were less discriminated against, even though stigma and discrimination was still there also for them. But it was sort of that hierarchy that you mentioned, which is in a way very interesting in terms of how we conceptualize, I guess, the different disabilities and how that impacts the view of the general population of what that person is capable of. You have also suggested a third article which you submitted. So this is a brand new, you know, research. So please tell me a little bit more about that one.

Carmit Noa-Shpigelman (11:31):

These two studies, the one that focused on mothers with intellectual disabilities, and the second one focused on mothers with physical disabilities, I decided to highlight the strength. I wanted to understand and describe the experiences of mothers with physical and intellectual disabilities from the perspective of personal growth, personal development, as well as I analyze the data according to the theory of intersectionality of identities, focusing on the motherhood identity and the disability identity. <Right.>

So in the first one, we interviewed 11 mothers with intellectual disabilities, or borderline intellectual functioning, age 30 to 52. And the second one, we interviewed 20 mothers with various types of, uh, physical disability. The age range was wider, 30 to 70. Again, we wanted to learn about their experiences. One of the things that was common to these two groups of mothers. So both mothers with intellectual disabilities and mothers with physical disabilities perceive the motherhood as achievable dream. They wish to become, like other women, to become mothers. Although they experienced the negative attitude from others, they actually wanted to feel like other non disabled women and they felt that it's like fulfillment of a dream.

I have to say that it's a bit different because the mothers with intellectual disabilities said that they studied in different classes in special education school or, or segregated settings. While the mothers with physical disabilities, they didn't feel that they had the disability. They didn't give it a place because they were in the mainstream education. Then they went to the army, which in Israel, it's required to serve the army when you get the at the age of 18. So for the mothers with physical disabilities, it was like becoming a mother as a natural process. But it was a big issue, big deal. Like a big dream that came true for the mothers with intellectual disabilities.

Another theme that was unique among mothers with intellectual disabilities was that they wanted to become mothers, to not staying alone. They said a lot. I believe it's related to the fact that many of them are staying with the family and other support networks. And, usually they need an intensive care throughout the life. But when they grew up, they figure out that they're getting older and the parents are getting older. They didn't want to live by themselves. So they thought about the future, and it was one of the reasons they mentioned to have children. Another thing was, again, unique to the mothers with physical disabilities. They talked a lot about their practical concerns in terms of how to take care of the baby, how to accommodate the environment. This was not observed among the mothers with intellectual disabilities. Again, maybe because they are surrounded by supportive networks. And they said that. They said that the family was very supportive all the way.

The interesting thing was related to identities and the intersectionality of identities among mothers with intellectual disabilities and the mothers with physical disabilities. We observed that the motherhood was perceived as an empowering identity. Like everyone else, like I'm capable to deliver, to have my own child, to take care of him. While at the same time, they perceived their disability identity as disempowering. Again, the mothers with physical disabilities all their life, they didn't give place to their own disability, but as soon as they became mothers, suddenly they figure out that they couldn't do anything by themselves. They needed the support systems, practical assistance in order to take care of the baby.

As for the mothers with intellectual disabilities, again, they took care of the child, but as soon as, for example, they had to help the child to do homework, which is a cognitive task, it was very hard for them. And suddenly they realized they couldn't help their children in doing homework. So it's a big issue. I believe that professionals has to refer developing interventions and support for mothers with intellectual and physical disabilities, how to integrate disability into the personal identity. To give it a place, <yeah.> To discuss the disability in early stage, not only when they already became a parent or mother. So I believe this is the main message that I would like to convey to professional in terms of identities.

Marjorie Aunos (17:48):

In terms of that, I thought it was interesting because, and I don't wanna take away the fact that disability, you know, adds a layer of difficulty or the stigma associated with disability adds, you know, to potential discrimination or discriminatory practices. But in the same time, I find that motherhood, parenthood as a general is one of the most humbling role that anyone can take. No matter if you have all your physical or intellectual mental capacities. Parenthood will bring you to your knees because it is difficult. And I find that what you found in terms of seeing these mothers, realizing, you know, that they need help in their parenting. So faced with their disability, I feel in a way, potentially that all parents, at one point or another in their parenthood journey, they will also feel like, wow, you know, I'm raising a child or several children, and I can't do it on my own. I need to call my sister to get, you know, advice on child rearing, or I need to, you know, call my mom to please take care of the kids, you know, for the weekend so I can sleep. Or, you know, like there's always sort of something where we're learning about our limits when we become parents–that we have a disability or not.

Carmit Noa-Shpigelman (19:25):

I agree with you. Although I think that it's different among parents with disabilities. Again, because of the issue of independence, <right> They feel many of them report that they feel that they have to prove <mm-hmm > all the time that they are like others. <Yep> So, they don't need any help, but suddenly they had to confront with this need. And it was difficult in terms of emotional, difficult to ask for help. It's not like in case of other parents, non-disabled parents that probably say it as a natural process asking for assistance. It's a big issue for adults, for parents with disabilities. And I can tell as well as for the mothers with intellectual disabilities, they didn't know anything about their diagnosis. Although they mentioned that they were aware of their difficulties, the cognitive difficulties, but no one actually talks with them about their own disability, which is a big issue for professionals to raise and talk about the disability, about the diagnosis. What I have, how to cope with it. And not make it like a non-spoken issue. Like a taboo, but put it there, talk about it, talk about the challenges, talk about the strength, and make it more easy to accept all faces of the identity, the personal identity.

Marjorie Aunos (21:22):

Right. So with all of this research that you've conducted, and I know you've conducted more than those four studies. As you know, our listeners are mostly coming from the child welfare system. Is there general advice you could give them, or recommendation or maybe orientation for their practice or for training, that you think you could draw from those studies that you've conducted?

Carmit Noa-Shpigelman (21:53):

So first of all, provide physical accommodation <Yes> for parents with disabilities not only at home, but also outside to figure out how to guide them and what, for example, assistive technology to use when I'm going out with my child, doing training, accessible training for parents with disabilities, how to take care of the children. And there is a big difference between different ages of the children. I know that many of the interventions focus on, on the young age. <Yes.> But I believe that professionals should also develop intervention and training for older children, teenagers and, over the age of 18, to refer to each of the developmental age of the child.

Beside the physical accommodation, I would say emotional support. Provide ongoing support, and not only for, again, for the parents with disabilities, but also for the children. <Yes.> Older children. And as well as to the extended family, the grandma, grandpa, because they're usually the direct support network of mothers and parents with disabilities, and they play a meaningful role in support or not the parents with disabilities. So I believe the training should also provide to the extended family. <Mm-hmm> And above all this, I believe that training, including knowledge and skills, should be provided to the professionals themselves. To promote awareness of the right of adults with disabilities to become parents. It's actually start from an early stage from teenagers or around the age of 20, to help the adults with disabilities who wish to become parents to fulfill the right. So I believe that training and promoting awareness and attitude change is also necessary among professionals. Also be able to find creative ways to support parents with disabilities.

Marjorie Aunos (24:33):

I think we could continue this conversation. There is just, like you said, so much to do and so much to talk about. But I will end and sort of say, we will continue this conversation at another time, certainly you and I, and all our colleagues. And I thank you so much for taking the time today, to be able to have a chat and introduce the studies that you conducted. So thank you very much, Carmit.

<Thank you.>

New Speaker (24:59):

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