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 Maurice Feldman. Maurice and I go way back. I convinced him to supervise my thesis work. As he represented the type of professional I wanted to be. Maurice conducted seminal research in the field yet always ensured his research would have impact on clinical work. He created several manuals to teach parents and a book we co-wrote on assessment. I began our conversation by asking him about his early groundbreaking work. Enjoy. And don't forget for more information about where to find the full recording and additional resources. Check out the show notes.

I wanted to dive into some of the work that you've done that is pivotal or seminal in terms of the impact that it had at the time, explain the types of research and articles that you've done, that you've published that led to, making an impact.

Maurice Feldman (01:37):

When we realized that we were pioneers here, that there was no published data using experimental designs on demonstrating the effectiveness of interventions for these families, that I felt strongly that we were obligated to do as systematic research as we could. Given we were still a service delivery program. And luckily I have been trained in how to do single case experimental designs so that. This lent itself well, these designs lend themselves well to providing an ongoing service, but still carefully and systematically evaluating the impact of the intervention on each individual parent, and if possible, the child as well. And so I started doing some single case experimental research, right? And the advantage of that besides the fact that you can do it with, within the context of a clinical service, is that it does yield cause and effect results. If you do a systematic, single case design, like a multiple baseline across skills, the parent only improves when you start training on that skill and you replicate that within the same person across a variety of skills, you've demonstrated that it's the training, it's the intervention that was responsible for the increase.

And because when we took our step by step approach developed a task analysis checklist, had them vetted by pediatric healthcare professionals. So we had our checklist of parenting skills. We would go and observe parent, you know, we'd ask them, please diaper your baby. We're gonna watch you, you know, or feed your baby or play with your baby. And we would actually check off what steps they did correctly, what steps they did incorrectly or not at all. And based on that, we'd identify what skills they needed training on. And most of the parents needed multiple skills on which they needed training. So immediately I was thinking multiple baseline design across skills, right. And that's what we did. So our initial research, our initial publications are actually in behavior analytic journals, like Journal of Applied Behavior Analysis, because the approach we took fit kind of an ABA approach for research, even though our intervention was more than just ABA, it was a more contextual view, which, you know, we'll probably wind up talking about in a minute.

But the actual training piece lent itself well to single case experimental designs. So we were able to get the first intervention publication published in Journal of Applied Behavior Analysis, and then some follow up studies over the years. However, we, it was a little bit more difficult to demonstrate the effects of the parent training on the children. So we realized that when we wanted, for example, to see the effects of our interaction training, when we taught the parents how to be more responsive and sensitive to the children during play, right, basically just know how to play with your infant or toddler. We showed the training was very effective in increasing skills, like talking to your child, playing with your

child, praising your child, copying their words, several of the skills that come both from the attachment literature and the language in development literature.

And we incorporated that in identifying important skills, we found that many of our parents black those skills when they were playing with their kids are interacting. And when we trained them, the parents improved and we did see some improvement in child development, particularly in language. The problem is with single case designs, there's possibility of maturation effects over time. So it's certainly possible the kids would've improved their language anyway, just, but by day to day experience from what we call maturation. So we needed a design that controlled for maturation effects. Would our training produced a bigger increase in child development than just maturation alone. And of the design we had to use was called randomized control design or randomized clinical trial which is the gold standard in most intervention research. So we tried to figure out ethically, how do we do this?

Because we didn't wanna run a no treatment control group. We didn't wanna tell parents who are referred to our program. You know, you can be randomly assigned to either get training or have to wait months before you get training. We knew our training helped the parents. And so we didn't want delay training. So what we realized is that while these parents were coming into our program needing to learn a bunch of skills of which interaction is one. So we knew we would have to teach them interaction and teach them other skills like home safety, how to handle emergencies, like if the child cuts themselves or, burns their fingers or whatever. Right? So what we did is we gathered those parents from whom we had done the assessment who needed to learn both interaction and home safety and emergency skills. And we randomly assign them to which training they would get first.

So this relieves some of our ethical concerns because we realized that everyone's gonna get training and what they need. It just the order, which they get training has been randomly determined. And furthermore, the home safety group becomes a really good control group for the interaction group because they got approximately the same number of home visits from a trained parent educator. They got training the same way, just on different sets of skills. And we made sure we included play observations so that we could have data on parent interactions and child language within the home safety group, but we didn't do any training in interactions. We just observed them. And what we found was that the interaction parents improved in their interactions. We already knew they would, the home safety group improved in home safety and skills, but not much no improvement in their interaction skills.

We hadn't trained it yet. The children, this is the important result. The children in whose parents got the interaction training first, they jumped up so that their language was looking very similar to a comparison group of children who were raised by parents without intellectual disability, same age, you know, age matched. So those kids that were showing delays when we first started in the pretest were no longer showing delays after we gave the training and interaction to the parents. Again, is this maturation? Well, now we have a control group. We have that home safety group there. The kids whose parents did not get interaction training got Home Safety and Emergency Skills Training. Did their language improve? Yes. But not by much, 20%. Right. Whereas the interaction kids increased by 80% in terms of the amount of words they were saying, which was one of our measures. The kids whose parents got Safety and Emergency training, yes, they did improve by 20%. That was the maturation effect. So it says 60% improvement in the children was the training effect. And then when we trained the parents who first got home safety in interactions that the kids in that group jumped up, their language jumped up as well.

Marjorie Aunos (11:00):

I love how you took us on sort of your journey and your reflection and how you created the research studies. And I think that that's incredible. Now one of the conclusions, certainly that is in those articles. And by the way in the show notes, we'll have the articles and the references. You mentioned that there was also a lot of different variables that you were witness to, that you thought might have an impact. And so you mentioned serve, for example, abuse, substance abuse, housing difficulties. So being like moving on a regular basis and several other like mental health, being also one of them. Is that where you sort of figured out or decided or reflected upon those variables and thought, you know, there's something larger than just parenting that's happening in those families?

Maurice Feldman (11:56):

Yes. I mean, we were aware of a contextual issue surrounding these families. I mean, based on my training as in psychology and developmental psychology, I was aware of contextual ecological views of a family life from Yuri brown, from Brener and others. And that was always in the background for me. But it took a while for me to hone in, in that as a research area and also as an advocacy area as well, cuz it was being ignored by child protection and other people. And one of the reasons we ignored it is, is we found that our training, kind of overrode a lot of those stressors that, and we looked at those stressors and we didn't find any relationship between parents who reported being highly stressed or even a little depressed in our baseline. They still improved with our training.

So in a way, our training overrode a lot of those contextual issues. But then I started realizing that the parents, you know, in general have these contextual issues going on and no one's dealing with them, <affirmative> right. And they could in fact impact on long term success, you know, we were concerned, okay, you now know the skill, but you're in an abusive relationship, you know, are you gonna really, you know, remember and use your skills and is that a priority right now? So and of course we did help parents who were in abusive relationships, try to get out of those relationships. But so I started looking now at research on contextual issues. And once again, it was very little research on parents with intellectual disability. There was a lot of research on typical parent, typical families, right? So I looked at some of the existing contextual models of family life and I said, okay, do these apply to our families?

Right? And a lot of the variables do apply, such as family health or, you know, parent health, you know, child variables like child having disability or health problems, their social economic status and social support is an important one. So those variables hadn't been researched with typical parents and with parents who were known child abusers. And Jay Beslky developed a model to try to predict child abuse. So I said, okay, what variables are missing from these families lives that weren't part of like when you look at typical families and one of the important variables was what I called a social variables, which is basically how society treats people with disabilities and specifically how society has treated parents with intellectual disabilities and the issue of stigmatization discrimination, exploitation, right, trauma that unfortunately many of these parents report experiencing at a much higher rate than typical children growing up.

So I started then thinking about a model that was, would adapt from existing developmental models to include some additional variables that were pertinent to these families and, you know, your, your dissertation and research on the health and stress of these mothers and showing, you know, that despite, you know, in Canada, you having universal healthcare, most of these mothers were reporting having poor physical and mental health and figuring out, you know, it's gotta be something broader than just going to the doctor, right. And looking at their history. And so many of them having experienced trauma. And so I developed this conceptual model, did some research on it, you did some research on it and it kind of exploded. And, it resulted in other people from all over the world doing some research in Australia and Sweden, Netherlands, and beginning to put the pieces together of the contextual model.

And now we have a lot of data that strongly support the view that when a parent's experiencing problems parenting, you cannot blame it all on the parent's intellectual disability. In fact, it accounts for a very low amount of the variance in parenting ability, things like having a traumatic experience and poor upbringing, not having much social support, not having great health, right. All of those factors seem to explain more of the reason why these parents are having difficulty caring for their children. And that opened a lot of people's eyes about how we need to view these families and how we need to support these families.

Marjorie Aunos (17:46):

It was definitely your model was definitely a game changer. And I think it was probably something that a lot of researchers and clinicians hopefully anyways had thought about, but putting it on paper and sort of showcasing it and then being able to research it to demonstrate that the model made sense and that it was, you know, reflecting reality, I think was a pivotal moment in, certainly this field in parenting and parents with intellectual disabilities. So that was like amazing. And I was so happy to be able to contribute, you know, my 50 moms interviews and to look at that and to grow from there and to see how everyone sort of put in their little 2 cents with their, each of their studies. So that was incredible. So there's another part that we've done, together that has been also sort of a game changer and that's a book that you, that we, published together or coauthored. Do you wanna talk to us a little bit about that book?

Maurice Feldman (18:55):

Yes. So once I developed a contextual model and realized there were a lot of factors that needed to be considered to understand where the parents are at, with being able to care for a child. And I saw that so many of these parents were going to court or losing their children based on parenting assessments, what we call parenting capacity assessments in Canada that were based on mainly the fact that they had low IQ scores. Again, it was this assumption that you can use their intellectual disability to explain all the problems they had. And so we realized that even though my focus had been primarily on intervention, and I know you ran a program in Montreal doing a lot of great intervention, I think we realized we gotta move up <laugh> to an earlier stage. We've gotta talk about assessment because if the parents lose their kids, we're never gonna get the intervention that could have kept the family together.

Right? So we looked at the current state of affairs for parenting capacity assessments and realized they were not evidence based. They did not look at the contextual lives of these families, and they were blaming all the problems on the parent intellectual disability. So we wrote this book, where we presented the contextual model as the framework for our recommended assessment practices and the PCAs that we propose. And we do when we actually get referrals is two main sections. One is a contextual analysis, and we gather data from multiple sources. We gather data from the parents themselves through interviews, through doing questionnaires like the parenting stress index, which we always, you know, will read. We don't expect them to be, to read it on their own or answer the questions on their own, social support; we wanna know about their support networks, their health and so on.

So the parents are a rich source records from child protection and other professionals, another source of information. Although we sometimes see things that are incorrect, mm-hmm, <affirmative> in them. And then, you know, other information that we gather from interviewing workers who are actually, let's say, monitoring access visits or trying to teach the parents new skills. So we gather all that information for the first part of the assessment. And we use the contextual model to say, okay, what's the parents' health? Like, what was their history? Did they experience trauma? What's their financial

situation, their housing situation, their social support network relationship with a partner, all that information goes into contextual analysis. And we're looking to identify barriers and supports things that are working against these parents being successful and things in their lives that could support them to be successful. And unlike many other PCAs, we do try to identify strengths within the family.

And that is a somewhat unique aspect of our assessments. Then the second part is taking those step by step parenting programs, observational checklists, and actually watching the parent parent. We know that you read a lot of these assessments. They never actually watched the parent with the child to see if parent could perform the skills that they needed to do with the child, or if they did do an observation, it could be in the psychologist office or in the child protection playroom, and not a natural environment. And they, and the observations were very subjective. You know, if you are going in with a negative bias that this mom is not a good parent and you're watching and you have no checklist or anything structured, well, guess what, you're gonna see. You're, it's confirmation bias. You're gonna see everything they're doing wrong and dismiss anything they're doing.

Right. So, the second part of our assessment is that direct observation. And the third part is we take a parenting skill that they scored low on during those observations. And we try to teach it within the assess session. And these assessments, you know, can take one or two days. It's not like do an IQ test and you're done, right. So they are more labor intensive, but they're much more valid. And we actually then try to teach the parent, we're not expecting the parent necessarily to now become competent in that skill. We're just showing that if you teach them the right way, using the step by step method, then they'll actually improve in that skill. They'll score higher than they score. Let's say in the morning when we just observe, and this counters, any arguments that because of the parents' learning difficulties, they could not benefit from intervention. And it counters any arguments that, oh, they went to a parenting group and they didn't improve. Right. Well, you didn't give them the type of intervention that works for them. So if you give them an intervention that works for them, like step by step, they start improving. So that's kind of the Parent Capacity Assessment book that we wrote that by the way was published by NAB press, but is outta print there. But I have copyright now and we are allowed to distribute our copies for free.

Marjorie Aunos (25:24):

It's great. Cuz I was listening to you and you know, with the book, with the model, these are things that I've used also in my own research with some of my colleagues, were our, our colleagues like Laura Pacheco. And you know, we looked at those Parenting Capacity Assessments from different child welfare and from specialized services. And we were able to highlight all those errors in a way, you know, that professionals would fill and not consider sort of all the context or not use instruments that are valid with this population or that have never been used or not adapting how they use those instruments. So there was a lot of different things that didn't work in terms of how it's done, which to me it's very important because often those Parenting Capacity Assessments are what lands in front of the judge. If we go to court and the inform, you know, interventions or the outcome, you know, the direction of the, the dossier.

and so that's like hugely important. So definitely a great resource there, that you've created for all of us to use and to base our own clinical work and research work on. Now, I would like to switch it up and sort of say, now that you've done all of this great work and that you've continue to do all this great work, where do you see us as a field, as you know, clinicians and researchers go, like if you were able to tell us which direction to take, which one would you direct us towards?

Maurice Feldman (27:10):

I think, you know, you guys who are doing the research, the younger generation, you have to decide the directions. But I think that it has to be multi-pronged, there's some great research coming out in looking at large national databases from different countries. We should make sure that questions that are relevant to our population can get in there, those national databases as they're being designed, right. Questions about parenting. So if there is a national study people with disability, that there are questions about parenting, right? And not just parents with intellectual disability, but all kinds of disability, and that's started to happen, which seems those databases from the UK, US, Sweden and so on, having at least some measures that relate to a parent having a disability. So that's one area we wanna make sure, as we get, you know, more and more into big data using machine learning anaylses to capture, predicting what leads to success, right.

And then providing the supports that will lead to success if the family's missing those supports. So that is taking the big data and bringing it down and back to the service level and showing that connection. And that research is not easy to do. But I think it, it needs to be done. It's hard to get large sample sizes and several reviews of the parenting intervention literature have critiqued my study and others having small sample sizes. Well, you go out and try to find 500 parents with intellectual disabilities who are willing to participate in a randomized controlled trial. Right. Not gonna happen, right. So, I mean, one thing we've talked about together, as a group, at conferences is multi-site research very hard to coordinate with technology now and maybe a little bit easier for video conferencing. And that may be something in the future.

We can go back to and discuss, setting up a multi-site at least within a country, if not across countries to get a large scale intervention study going where, where everyone's using the same intervention and that has been done has been done in the us with different interventions. So it is possible costs a lot of money and we would need a big grant, but it's something to consider anyway, more research on validating our assessment model. Right? Also lot of reasons, this research hasn't been done, I'm picking things that are hard to do, cuz we've done the easy stuff. I mean, it didn't seem easy at the time, but now that we've done it, it looks easy. Right. So a lot of the challenges in doing this kind of research, we would need to overcome, but validating the assessment model when we make recommendations, are they follow through and those are result in the child being returned to the parent eventually is the model predictive of which parents will succeed versus ones that won't succeed. So these are, you know, that's another whole area of assessment research that could be done. I could probably go on and on. But those are just some examples of research I think needs to be done.

Marjorie Aunos (31:03):

Yeah. Those are great examples. Thank you so much. I have one final question. And that question is if you were to speak to child welfare professionals, what is the one thing you would like to tell them?

Maurice Feldman (31:17):

Well, for me, it's not a hypothetical question. I have spoken and continue to speak to child welfare professionals in different capacities. Sometimes it's in the context of myself as a independent assessor coming in to do a PCA on a family that was referred by the child protection agency to me. Sometimes they, that referral is positive and sometimes it's reluctant, but has been ordered by a judge. But nonetheless, I get to speak about individual families and talk about the contextual model. If I noticed, for example, that there were previous assessments that did not use a contextual approach, did not use direct observations. I can point out how my assessment will be different, right. And what do you think of that? Right. And do you realize that there are other issues going on that if directly or indirectly affect this, how this parent does?

Right. So I try to educate them more just through describing my approach, right? I also have job protection workers who actually attend by step by step training. And the first thing I always say to the audience, cuz sometimes I don't know if there are any child protection workers in the audience that they're doing a very difficult job under very trying circumstances. Right? And it's amazing. They're very dedicated and they're very caring, right? And I don't think that they go into the, to this job thinking my role is to take away kids from their families. I think they hate when they have to do it, but sometimes they feel it's necessary. Right? So what I want to do when I tell them is when you learn more about the step by step program, both the assessment piece and the intervention piece, maybe your criterion for deciding on child removal or going for permanency will change, right?

It may also help you recognize any biases that you have while most biases tend to be negative towards these parents just cuz society is negative towards people with disabilities. In general, I have come across workers who are just the opposite. They don't see any problems. They're so supportive of these parents that they're advocating very much for the parents. When in fact there are concerns for child welfare that have to be addressed. So it can go either way in terms of the bias, although the tendency is negative. So I want them to, self-identify their bias, to self reflect. What biases do you come in with and how does it affect your work with this family? That one I like to deal to talk to child welfare people. And I always offer the agencies to come in and do an in-service because a lot of them just don't realize that the research we did in Canada and have done in other countries that even though the number of parents with intellectual disabilities or learning difficulties in our country is relatively low.

1 to 3%, perhaps they actually can make up 30 to 40% of child welfare cases. And a lot of the workers don't realize that, right, that you're gonna come across these parents in your work. Right. And it's something you gotta be prepared to deal with. And that's a real eye opener for them. And I present our data when I'm talking to Canadian agencies or present the US data when I'm in the US and they're going, like, didn't realize there were so many. So, it's not something they can just say, oh, it's just one or two families in our service. You know, it's a lot of families. So that's kind of what I try to explain to them. You know, recognize your bias, learn more about it. You know, it's funny how many emails I get. I never knew there was any research about these families. I said, have you never heard of Google? <laugh> like Google research on parents with intellectual disabilities, all kinds of things pop out.

Marjorie Aunos (36:08):

No, and that's great. And all of those things were made possible. I think because of pioneers like you who set the stage and you know, showed us that one it's possible to do research with this population and to show sort of improvement and to show, you know, that there's multi factors affecting their lives. And I really wanna thank you for taking the time today to have this conversation with me and thank you for all the, the work that you've done and for being in my life for the past 25 years, I look forward to what we do next toger as a community and together. So thank you so much.

Speaker 3 (36:51):

Yes. It's been a pleasure Marjorie. Thank you so much for having me.

New Speaker (<u>36:58</u>):

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