

Disability Done Different: Episode 16

Sylvana Mahmic on...ECEI and role of family

Podcast transcript

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Hosts: Evie Naufal, Roland Naufal

Guests: Sylvana Mahmic

Intro

Maia: This is Maia Thomas, the producer of the DSC Podcast. DSC is a team of 33 people across Australia, all working together to bring specialised training and consulting expertise to providers in the disability sector.

[Guitar strum]

Evie: Hello, and welcome to Disability Done Different Candid Conversations. My name is Evie Naufal and I'm joined in the studio by...

Roland: Roland Naufal and our producer...

Maia: Maia Thomas.

Roland: Today, we learned how to say her name properly, Sylvana Mahmic.

Evie: [Laughter]. Sylvana is the CEO of the early intervention organisation: Plumtree based in Sydney. So, here's the interview with Sylvana.

Roland: We hope you like it.

[Guitar music]

Evie: All right, here's what's going to happen now.

Roland: Hello, and welcome to our podcast.

Evie: We are DSC. Your turn, you're the boss.

Roland Disability Done Different

Roland/Evie: Candid Conversations.

Evie: I hope you're ready because we're starting.

Start of Interview

Roland: Welcome, Sylvana.

Sylvana: Hello, thank you.

Roland: We had a party recently and Evie was introducing herself and she introduces herself differently to how I introduce myself in saying our last name, because we come from a Lebanese background and as we're going to talk to you I'm sure in this podcast about your background, as well, how would you say our name: N-A-U-F-A-L?

Sylvana: Naufal?

Roland: Yay.

Evie: [Laughter]. That's very different to how we say it.

Roland: That's how my brother says it. My brother is full Lebanese and he says it, but Evie can't say it, none of her sisters can say it like that.

Evie: My partner says Nafuffle.

Roland: [Laughter]. Yes, mostly it's been Naufal. Sadly, my story was in primary school, my best friend was Robert Winky, so it was Awful Naufal and Stinky Winky.

Sylvana: [Laughter].

Roland: Let's move onto the podcast. We've got so much to talk about and so many areas we could go to. Sylvana, this coming June, we're very excited, we're running a national conference called: Get your strategy together - GYST. One of the key issues that is sure to come up in that is workforce. It seems to me and to the sector that you're taking a different approach to workforce, when I looked at your website doing research for this podcast and getting to know you better, there were a few professionals here and a few professionals there and then a very long list of peer workers and allied health assistants. You're taking a different approach to workforce, is that fair to say?

Sylvana: Yes, it is. I guess my perspective is really coming as a parent of a young man who has a disability, as well, and I think that in the current environment that we've really started to look at workforce in early childhood intervention, really examining where is our workforce right now in the early intervention field? What is the ideal workforce in early childhood intervention? What kinds of roles make the biggest impact and really challenging other prevalent belief that therapists are the only people who deliver early childhood intervention? That has really taken us along a pathway of reinvigorating the role of educators in our organisations but introducing to new workforces. One is our therapy assistance and the other is peer workers.

- Roland:** Let's spend a little time on that, Sylvana, because it's so important and what you just said, as you know, is an incredible mouthful because you've covered off new approaches to early childhood, early intervention, or early childhood intervention is probably the better way to say it, but also new approaches to workforce. Can we start with peers and then work our way backwards to the actual approach you're taking to working in the space? Just for listeners that don't know much about early childhood, in some ways, it's a very different sector to the rest of disability, isn't it?
- Sylvana:** Yes, rather than the focus being only the child, the focus should be the whole family and then, as well, the family within their natural environments within their community and really acknowledging all of the informal supports that families start out with and not negatively influencing those but preserving those and harnessing those and working really in a family-centred way.
- Roland:** So, taking a holistic approach to the child within family and the divergence that you're talking about and what we've known to be best practice for 20/30 years now in disability in early childhood, the sort of thing you're doing is saying, it's not just about doing therapeutic interventions to the child to make them better.
- Sylvana:** Exactly.
- Roland:** What is it about?
- Sylvana:** Well, it's about really looking at how the whole family engages with the child and preserving family routines and preserving relationships, building really strong interactions and engagements with all of the family members, that also includes the siblings and taking that much more holistic approach as the child within the family, rather than just fix the child, so I guess that is a critical change that has happened over the last 25 or so years in early childhood intervention, is that we have moved away from focusing on the child and their deficits, but really looking at it much more, or you can see it much more akin to the social model of disability, where we say the natural environment for the child is the family, that's their environment, let's look at adapting that environment and other environments that children are in.
- Roland:** When you talk about a 25-year journey in the changes of early childhood, early intervention, that's also the journey you've been on with your son more or less, isn't it?
- Sylvana:** I guess that is the point. My son Karim has just turned 30 and we were very fortunate that when he was diagnosed with a delay in his development when he was just under three years old, that we were connected with an early intervention group at Macquarie University back then, who had really transformed what they were doing and were experimenting with this new concept called family centredness. It was about working in partnership with us, so that we were doing what we needed to do in our everyday family lives to support Karim's development, who he was as a person, focusing in on that, and focusing in on our skills and capabilities and competence as family members, to feel like we can do this. Professionals are here today and gone tomorrow, but we're going to be the best people to invest in because we'll be there to support him in the long-term.
- Roland:** Sylvana, you're really starting to touch on some of the edgy bits of early childhood intervention, where some practitioners and a lot of allied health professionals really

want to focus on working on the child and other parts of the sector are saying, “No, we’ve really got to take a broader focus on child and family.” The NDIS has come along and its focus doesn’t really support child and family, does it?

Sylvana: Well, it doesn’t. On that, Roland, 48 percent of participants in the NDIS scheme at the moment are children 18 years and under. For those children, families are the most important influence in their lives, they’re the people who will be making the decisions for them and it’s the family who in that context who are going to be the most influential in how funding decisions are made and how all sorts of other decisions about how that child will be growing up and the opportunities and the way that they’re being supported, so the families themselves then are going to be the ones that in my opinion, where the most amount of investment needs to go.

Roland: It’s the one constant, isn’t it, in any family’s life, is the family itself, the parents, they’re there for the journey. One of the things that’s always bothered me is it’s a sort of bracket creep in disability advocacy which is adults with disability should be speaking on their own behalves, wherever possible. I don’t think we argue with that. That somehow creeps down into the children’s area where we’re expecting young children who don’t make decisions in their own families independently anyway, that somehow we’re expecting young children with a disability to have independent voices and advocates are speaking on their behalves as if they’re not members of families. Am I taking that too far?

Sylvana: No, I think that’s a fair assumption. I guess I’ve got to say that I’ve learned so much from colleagues in the advocacy space, who have really educated me, and my perception is, working in the other age range with early childhood, there is no one that really is making those messages transparent and clear to families. I think that’s where the gap is, we can’t have an independent, capable, 18-year-old, unless somebody, and in my opinion, that’s the family, has had a very big part in understanding where they need to head with their child by the time they’re 18. What do you want to achieve and how is the family, how is the parent, how the rest of the community, how you can harness your community to help your son or daughter get to where they need to be because they don’t just pop up independent and capable at 18.

Something has to happen in the interim. Right now, I’d argue that we don’t have a comprehensive, strategic, funded approach where families are getting these messages at the earliest possible points. Right now, it’s your child will never walk, will never talk, they’ll never attend their local school. I’m sorry your child has this disability, here are some professionals who can help you, off you go. I’d argue that that’s not the right messaging that we need to give to families in the very beginning. We need to really reframe that conversation about how we’re having that first conversation with families, what we’re telling them that they should be headed for, inspiring them and creating some hope and encouraging them to think of the a life of opportunity for their son or daughter and follow that up with lots of practical opportunities to learn how to do that. I think families are best placed to be building that, but for them to build that for their child, they really need to be building that for themselves.

Roland: Evie, can you jump in here and tell us where the problem is that we’re talking about, so why is it that the NDIS price guide, that’s the bible in a sense, doesn’t support a holistic approach to families?

Evie: I'm not sure it's the price guide where the flaw lies, in some ways – and Sylvana, you probably know a lot more about this than I do, so correct me if I'm wrong – in some ways I think this is one of the failures to implement the promise of the NDIS into practice. I think if we really looked at the insurance principles, a family centred approach that looked at building the skills of the informal supports and building toward a good life, exactly as you say, Sylvana, taking that long-term approach, that that is very much in line with what the NDIS was supposed to create, but in a day-to-day sense, or a year-to-year sense, we're not seeing that translate into planning. I can only imagine that's because in the short-term it's more expensive right now to invest in a three-year-old knowing that they'll one day be a 12/18/30/40-year-old. We're trying to keep the three-year-old package as small as possible and not having that long-term view that the NDIS was designed to bring. Does that resonate at all, Sylvana?

Sylvana: Sure. I would agree. I'd say that scheme design was always about intending to have that insurance-based approach and, for me, I think that is very much a capability building approach, but we all recognize that right now, that there's only the investment in capability building through the information linkages and capacity, that's really very young and not very sophisticated yet, so there will hopefully be in the future some improvements in the way the scheme funds capability building, but in terms of children more specifically, my view is that individual funding can be family centred, but the NDIS funding model has to value and be based on family centredness and that will then allow families to use it in ways that meet their unique ways.

Evie: You are seeing it them being a problem of policy and practice then?

Sylvana: Yes, I do agree to that, but I do agree with you in that the intent was always there, but I think somehow in the rollout, we'd lost our way, but that's very, in my opinion, very retrievable, but an example that currently packages children six and under have all of their budget in daily living, which is driving an overly therapeutic approach. It basically means that families can only spend their money on therapy. Now, I've been in early intervention for almost 30 years, when did therapy equal early intervention? We've somehow lost our way over the last ten to fifteen years with other government individual funding government systems, driving an overly therapeutic approach.

Evie: I just want to jump in there, Sylvana, because we know in July this year, the Minister at least has announced the intention to make core and capacity building budgets flexible, which would mean that who people who didn't necessarily get large core support budgets, I can't speak yet about whether it's going to be any core support budgets, but at least for many families, there should be a large degree of flexibility there, do you think that'll be a gamechanger for kids and families?

Sylvana: Gamechanger, so absolutely welcome. I think the focus that the Minister has announced on flexibility and combining those two budgets is going to be critical in giving families the option now to be able to use their funding in more family-centred ways.

Roland: Can I add controversy to complexity then and say that this is one of the pointy ends, and I know you and have had this conversation before, Sylvana, of control and choice, and we risk offending a lot of people here, but let's give it a whirl. Basically,

my experience of young parents with younger kids with disabilities, your child who is first born, there is truckloads we don't know and it's obvious that a bit of support may help the child with speech therapy, a bit of support may help the child with physiotherapy.

In my day, parents would spend endless amounts of money on speech pathology, and that wasn't always the only intervention that was required, but it was the only intervention that they could see was needed. One of the problems with the NDIS is giving control and choice to people who don't quite yet know what's in the best interests of their child and family, so it's a direct contradiction to what we were talking about before. Families do need to be empowered, families do need to take control, but don't spend it all on speech pathology. Can you help me out here or are you just going to get in trouble?

Sylvana: No, I'm happy to have this conversation as an individual who runs an organisation who employs a lot of absolutely awesome therapists. This isn't a question about therapy is bad, this is a question of what is the workforce for early childhood intervention, saying who are the natural kind of people who should be working in this industry, who connects with children generally? It's educators. Where are the educators right now? They've been downgraded over the last decade in terms of their impact and capability to offer families a lot because educators, early educators are a part of many children's lives, yet, they've somehow been side-lined in the disability sector and the role of therapist has really come to the fore.

I think bringing a little bit of balance back to our early childhood intervention fields by discussing workforce much more constructively, talking about the make-up, really challenging and being comfortable to say what does a great workforce look like for families of very little children and those children themselves? As we started off in this conversation, looking at more innovative opportunities and looking at expanding our notion of who should be working in this sector, who are the people that families are dealing with? That's where our exploration around therapy assistance and peer workers has really been, I think, critical in helping us push the boundaries of what we see as good early intervention and a workforce in early intervention.

Roland: Let's touch on peer workers because one of the things we keep hearing about the NDIS is it requires 80,000 new workers over a very short period of time, it's a few years. No one knows where that workforce is coming from. Yet, one of the great successes of the NDIS is supporting parents of kids with disabilities to return to the workforce because they're getting enough support that they can get back into the workforce and you're actually tapping into that group of workforce potential in an amazing way. Do you want to tell us a bit about that?

Sylvana: I'm almost embarrassed that it's taken me over 25 years to really explore systematically what the potential for peer work in early childhood intervention is, and here I want to credit some of my colleagues from the IAC who come from the mental health space, who are really advocates who have really helped me to understand and feel convinced that parents and families as peer workers in early childhood intervention, so we did some research into this area and we have found a few things, which is peer work does offer unique benefits to families of young children with disabilities.

That's complementary to the kinds of services that are already offered, both therapeutic and educational, we also understood that our experience very closely mirrored the experiences of peer work in the mental health space, which is decades further than peer work in early childhood intervention, so it's giving us a little signal that we could perhaps learn from the use of peer work in the mental health space. We don't have to start from scratch in terms of introducing more systematically a peer workforce in early childhood intervention.

Roland: So, it's bringing people who've got lived experience of parenting kids with disabilities into the workforce and one of the problems we've seen with that in the past is that some of those people are rescuers, Sylvana, and I think you'll know what I mean by that, but basically people who feel they have to solve other people's problems, which is not the approach you're after, is it?

Sylvana: That's right. It's not enough to say, "I'm a parent of a child with a disability, so I'm a great peer worker." So, there again is a lot we can learn from the mental health sector in terms of recruitment, training, support of people who will be employed as peer workers. I think that you've raised a very good point. Is that this isn't about rescuing, this is about helping families not start from the beginning. If we could message with families that host and vision for a best life, a good life for their child and then utilize a range of specialist service, but also peer-led services, that help them to understand how to get there, it's having that kind of trusted but experienced and trained peer worker within organisations that I think that can influence service design and create opportunities for new services in the future.

Roland: Sylvana, recently, you and I were at a national roundtable in early childhood intervention. One of the presenters spoke about tele-health. Basically, the basic premise was, they were supporting families to do stuff in the home with the therapist or the person doing the intervention on the other end of the tele-health connection. Basically, that forced the family to do the work themselves, instead of stepping aside and allowing the therapist to do the work and going and making a cup of coffee for the therapist and learning nothing, tele-health was actually better than having the therapist in the room. For me, that was a bit of a revelation, that the technology can actually produce a better outcome by forcing the therapist to do the intervention through the family. Does that make sense? Did that excite you? Or you probably already know it.

Sylvana: Well, yes, it is important because that's the premise of good family-centred practice, is coaching families. I think that particular example, in terms of using technology creates an environment where it's actually difficult for the family to expect that the specialist is doing the work because you're actually not there. The family are in a true coaching situation and you are coaching them in terms of just embedding it into an everyday routine, the family are doing it, you're modelling it, you're supporting them and refining how they might try it out. Then you leave the session inviting them to try it out during the week and then come back and share how it's gone for them. I think that really is a wonderful example of how we can magnify and intensify the opportunity, for practicing these strategies as a part of their everyday routine. That's not only cost-effective, but it makes sense for the whole family.

Roland: That's just great. Thanks, Sylvana.

Evie: I want to take us on a little bit of a tangent, Sylvana, I hope you won't mind, we have a book club at DSC and we've been reading a book, we've just started reading a book called: Far From the Tree.

Roland: It's a virtual book club too.

Sylvana: Love that book.

Evie: You do? Okay, great. It's a book that's written by a gay man and I've only – it's a very long book, it's a 40-hour audiobook, so I finished the chapter on deaf people and I've just started the one on people of short stature and it's significant that he's gay because he makes the parallel between the acceptance and cure or conversation with gay people as on the side. The thing that was very interesting for me in the book that I wanted to test with you is that he speaks to hundreds if not thousands of people in families with disabilities and it's been so interesting to see the role of parents because in about two thirds of the interviews, he speaks solely to the parents. Many of the individuals with disability he speaks to reflect on the fact that their disability is just one part of them and actually, it's been a much bigger journey for their parent than it has been for them. That just struck me as super interesting. I just wanted to put that to you, whether that was consistent with your experience?

Sylvana: I've got a little story about that. I love that book and I can certainly recommend it to the listener, but, yes, it is a doorstopper, if you get the book version. Since 2009, my son has been having access to a very flexible self-managed, individualised funding option in New South Wales Australia. Consequently, both he and I at that time, he was just leaving high school, did a lot of talks to different community groups and professional groups on the benefits of a very flexible individualised funding approach, and this is before the NDIS. How we were able to use that individualised funding to just fit Karim and our family at the kitchen table, ask him for the first time, to Shane, involving him in planning and asking him what do you want for your life now and then using that individualised funding in flexible, creative ways to help us to help him to achieve what it was that he wanted.

So, we used to do this circuit and do talks and it involved me asking questions and him using his communication device to comment and co-present and pictures and videos to give people a sense of how this has changed his life and how it's giving him an opportunity to find himself as a young adult. I remember that every presentation, I would get theory at different points because was still processing, even with him as an adult, 19 and early 20s, I was still processing and had deep feelings when I talked about Karim building his life. That would spill over into tears into those presentations. Yet, Karim would just slap me on the back of the head...

Evie: [Laughter].

Sylvana: ... playfully in every presentation when I burst into tears and say, "Come on, mum." That had to happen half a dozen or a dozen times before I realised, I am not helping him in not dealing with my stuff. It's not helpful for him to see me talking about his wonderful best life and for me to get tearing about it because that was giving him a really conflicting message. That I think that that book: Far from the Tree really expresses. That was me and my feeling that was spilling over into the presentation. Whereas, the presentation from his perspective was: Look at my life, it's awesome,

I'm meeting people, I'm doing new things. I'm employing them. This is amazing. I'm finding myself as a young man. It's a coming of age kind of story. At some point, the penny dropped and Karim and I split as a partnership and he now presents his own show called: Karim's Mojo Disco, where he really challenges...

Evie: [Laughter]. Sounds fun.

Sylvana: Yes, he challenges community perceptions about disability and the notion of inclusion and being excluded from society but in a positive, uplifting way. We had to separate because I think this is so common, is that families talk about, even their child's successes with such deep emotion, that that kind of sometimes sadness can still come through, which is not helpful. At some point, we have to help families change the balance and allow their child's voice to grow stronger and I'd say that I learned that lesson way too late. Too many slaps on the back of the head. Thankfully, Karim kept at it.

Evie: It sounds like we maybe need some adults with disability to run some: How to be a rebel classes.

Roland: Sylvana, this has been fantastic. I'd like to finish up by just asking you something a little bit personal. Growing up, you grew up in Sydney a while ago as a young Muslim woman, you wear a Hijab and you would have experienced that experience of being other and there's a whole body of work on other which I'm sure you're aware of. Then you have a child with a disability, and you enter another land of otherness. Did growing up as a Muslim in Sydney inform your approach to disability as a CEO?

Sylvana: I think, yes, it has in that I think it's made me much more mindful in terms of diversity of our workforce at the organisation but also looking at the kinds of services and opportunities that we offer to families to make sure that we're open to all family. I think that personal experience of being the minority group and that's certainly sharpened I think since 2000, I think prior to 2000, it wasn't as significant as it has been since September 11 and that's certainly feeling pressure for society and greater scrutiny as a Muslim woman. I think personally feeling as a minority, I didn't when I first started wearing the Hijab when I was a teenager, but that has grown I think over the time and feeling much more marginalised over the years.

Where it's even become more intense is when Karim was born, I guess back then, I was who I was and I didn't really notice I wore a Hijab and that I was mostly in black and looked quite conservative, but when Karim was diagnosed with a disability, I would catch myself in a reflection at a shop window or something like that and I would see myself with quite conservative Muslim outfit on and this disabled child in-toe. Then suddenly I felt this double whammy of Muslim woman and therefore, actually triple them, Muslim woman and then child with a disability. Suddenly, I just had this moment where I thought, I feel like I'm on the most minority of the minorities.

I think it's made me more sensitive and aware of the kinds of issues that are faced by lots of different groups in society and that it's a fallacy for us to imagine that we can create a one-size-fits-all sort of approach to supporting people in organisations. I think I'm much more attuned to the reality that all families are different, all children are different, we've got to be including and embracing of everybody and that takes work. I don't think that work right now is happening in the context of the changes

that we're undergoing with the transformation and the change management and the change that we're dealing with as a part of the NDIS. Hopefully, we become much more attuned to this in the future.

Roland: That's such a strong image of you seeing yourself in the shop window. I wonder if it's a topic for a podcast another time about my experience is that so many of the best workers in the disability sector come from an otherness of some sort or another. I don't have to say what that is, but they'll be a bunch of us that are coming from different backgrounds, otherness, difficulty, marginalisation, and I think you're really starting to touch on why that can be a very significant advantage in the sector. I do love that image of seeing yourself in the shop window. Thank you for today, thank you for the podcast. It's been really special.

Evie: Thanks, Sylvana.

End of Interview

Outro

Sylvana: Well, thank you very much. I really enjoyed talking to you.

Evie: You've been listening to Disability Done Different Candid Conversations, a podcast by DSC. If you want to read Far from the Tree, you'll find the link in the show notes. We've also got a link to some fantastic papers by the IAC, the Independent Advisory Council that Sylvana mentioned. If you want to hear more from us, you can sign up to our newsletter on our website, Disabilityservicesconsulting.com.au, or you can subscribe to this podcast wherever you get podcasts.

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