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Transcript
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In The First Person… Living with Fetal Alcohol Spectrum Disorder

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Host (00:01):

Hi there. Welcome to Mental Health Professionals Network podcast series. MHPN's aim is to promote and celebrate interdisciplinary collaborative mental health care.

Prue Walker (00:18):

Welcome to this episode of MHPN Presents In The First Person, a podcast series that provides you with the privilege of hearing people's stories in their own words as well as how multidisciplinary care has helped or impeded the management of their health and mental health issues. My name is Prue Walker and I'm joined today by Jessica Birch. Welcome, Jessica.

Jessica Birch (00:40):

Hi, Prue. It's so great to be here and thank you so much for being in a podcast with me.

Prue Walker (00:44):

Jess, I have really been looking forward to our chat. Today we are talking about fetal alcohol spectrum disorder, what it is, what it's like to live with, and what health professionals need to know to better support people living with this diagnosis. Today, you are going to share your story of living with FASD, but before we dive into your story, perhaps we should share how we know each other.

Jessica Birch (01:05):

Yeah, it's been a while and I think we've developed our friendship over quite a lot of time.

Prue Walker (01:10):

Quite a few years.

Jessica Birch (01:11):

Yeah, and it was, our first meeting was just after I was diagnosed with fetal alcohol spectrum disorder, and it was the opening of the Monash FASD Clinic.

Prue Walker (01:21):

Which opened in 2019, and I was lucky enough to be the social worker there at the time. And I met Jess, she stood up in the audience and spoke extremely eloquently. And after that we had her come back and do some training with our team. And it's been great to see how you've developed your advocacy work since then. Jessica. Amazing.

Jessica Birch (01:39):

Thank you so much. It's been an absolute whirlwind and I really like going back to those sort of initial days and those first interactions and networks has really made a big difference in how the journey has gone.

Prue Walker (01:51):

Well, let's talk about FASD Jessica. What is FASD?

Jessica Birch (01:55):

When I was preparing this podcast, Prue, I was trying so hard to find the succinct way to answer this question while also making sure that those listening could really grasp the complexity of a FASD presentation. So I dunno how well I can do both, but I'll give it a red hot crack. So for our listeners today, fetal alcohol spectrum disorder is a permanent lifelong brain and body injury, and it's caused when the fetus or the developing baby is exposed to alcohol in the womb. And what people may not know is that FASD is actually a blanket term for a whole range of disorders. It's not any one thing, but a number of cognitive and functional impairments which present in these myriad combinations. So an individual with FASD will present on a spectrum with differing challenges and severity because of the individual variations in the amount and timing of the prenatal alcohol use. This brain injury is expressed predominantly as behavioural, but there are a lot of physical symptoms and differences as well.

Prue Walker (02:55):

It sounds very varied.

Jessica Birch (02:57):

It is very varied. And because of this, it's very difficult, nigh impossible to manage FASD without diagnosis, understanding and support. And what people don't understand is how prevalent this actually is. Please make no mistake that you will see individuals affected by prenatal alcohol exposure coming into your clinics. It doesn't take excessive amounts of exposure to cause impairments, and if the concentration of alcohol is enough, it can also lead to intellectual disability. But I'm very lucky that that is not a part of my story because most of FASD, most of the reason that FASD occurs is a result of late pregnancy recognition. Women often just don't know that they are pregnant and they're drinking socially.

Prue Walker (03:43):

That would be pretty common, I imagine.

Jessica Birch (03:45):

Hugely common. And because of the complexity of this spectrum, it's not appropriate to use linear terms like high functioning or low functioning to describe an individual's capacity. It's really nuanced, it's quite complex, and it cannot be measured that way. So really for health professionals to be able to identify these behavioural symptoms accurately, can profoundly change the trajectory, quality and outcomes of someone's life. And I'm definitely, I feel a testament to that and it can really also change the life of their family. And I think it's deeply important that our health professionals can recognise these brain differences. And usually this involves simply asking the right questions and being able to adopt a brain-based lens when looking at behaviour.

Prue Walker (04:30):

Yeah. So Jessica, can you tell us a bit in your own words about how it affects you and give the listeners maybe some examples of what this is like?

Jessica Birch (04:38):

Sure. Honestly, Prue, we talk about this a lot, but in every way and every aspect FASD has and the consequences of my late diagnosis affects every aspect of my life. And for me personally, my exposure happened in the first trimester. So I have a lot of damage to my frontal lobe and nervous system, and I have some structural changes to my face, my fingers, and my ears. So I think what's important that people know is that there are 10 different functional brain domains that can be damaged by alcohol, and I won't list them all, but I personally struggle in areas of executive and adaptive functioning, my emotional regulation, my memory, attention and learning. But I also have problems with sensory and auditory processing. I can't block out competing sounds. I get a lot of vision issues and headaches. I also have dysautonomia, which is the dysfunction of my autonomic nervous system. So a lot of those internal signaling and those internal systems of my body don't really respond or work properly and send the right signals to my heart, my arteries, bladder, guts, hormones, adrenals, the list is quite long and this barely scratches the surface. My body tends to work much harder than a typical person to do very basic tasks like shopping for groceries and I fatigue very quickly, and I become overloaded quite quickly.

Prue Walker (06:08):

That's quite a big physical toll, isn't it? And probably not an aspect of FASD that we hear a lot about in Australia. The physical aspects of that.

Jessica Birch (06:16):

I think that often gets left behind and forgotten, but it does cause a lot of dysfunction. It cause a lot of difficulties when you're trying to sort of navigate the world and be in the world and be part of your community.

Prue Walker (06:28):

And obviously that's something that people meeting you are not going to be aware of. And when they see all the work that you do, the public speaking and the advocacy, they're probably not aware of what's going on underneath.

Jessica Birch (06:38):

Absolutely not. And I don't think that they fully always comprehend how much rest I need in between the tasks. But I'm also deeply affected by my cognitive load, not just my physical one. So how much information I'm receiving, how many tasks or responsibilities I have to navigate and complete at any given time, I'm quite affected by. So my working memory, for example, is poor and it doesn't allow me to clearly manipulate, sort, organise, prioritise, or hold information I'm receiving to sort of form a plan of action. I often need help to do that efficiently and help to follow through. So I become overwhelmed very quickly when I don't get that sort of support. And on top of that, I can't always regulate my emotions and I will probably melt down if I've got too much going on. And despite my age, the meltdowns still do happen. So really ultimately I find it difficult to work on multiple goals or projects at once because I can't shift my focus and attention. Well, I can't juggle multiple balls in the air, so to speak.

Prue Walker (07:44):

And yet you seem to do a lot and achieve a lot in your life. Can you give us an example of what that looks like for you in daily life?

Jessica Birch (07:51):

Sure. So a simple example would be if I'm making a coffee, I can really only successfully and efficiently navigate the steps to make the coffee. It becomes difficult for me if someone comes into the room to chat. If I chat and make the coffee, I'm very slow, I'm prone to error. I usually miss repeat or mis order the steps or I'm unable to properly listen, absorb and respond to the person speaking. The stress of both actions together tends to overload me very quickly. And then I'll have less capacity for upcoming tasks. And of course this type of multitasking happens all the time. And if you add sleep disorder into the mix, then usually individuals with FASD are fatigued all the time.

Prue Walker (08:38):

Yeah, I can imagine exhaustion would be a huge factor and you might want to commit to doing something, but it may mean sometimes I guess that you get overcommitted if you need that rest built into your life often.

Jessica Birch (08:51):

And it's often difficult for me to gauge the balance and I do actually have help to pace myself. I am a very ambitious person. I do want to do a lot of things.

Prue Walker (09:02):

I remember you told me about a time you went to a conference I think, and they said, okay, we haven't got the agenda ready and you just landed somewhere and they're like, we need you here at 8:00 AM and the day's going to go till 10:00 PM And I just remember thinking, I dunno how that's going to work.

Jessica Birch (09:16):

Months to recover.

Prue Walker (09:17):

Yeah.

Jessica Birch (09:17):

Honestly, it was an intense time and these sorts of difficulties, they've definitely complicated my ability to engage meaningfully in multiple settings like that, and particularly with my peers and making friends and keeping them has been really difficult and painful throughout my life because of these difficulties, both the cognitive and the physical ones.

Prue Walker (09:43):

I know you came to Melbourne when you were quite young and you set up a life here for yourself. How did that work?

Jessica Birch (09:49):

It was a difficult start, I must admit. But since diagnosis and support, life has definitely improved, I definitely have a lot of difficulties around my executive and adaptive functioning. So all these higher order adulting skills like prioritising and initiating tasks, problem solving, managing money and time, getting from A to B, adapting to different environments, oh my gosh, there's so many things. Shifting my attention and staying focused is all a challenge. So when I moved to Melbourne, I was only 21 years old and I needed to buy a bed and I knew the steps, but a year later I was still sleeping on a blow up mattress and I had completely destroyed my back. I was miserable. And I called my mother in a complete meltdown because I didn't know how to start or navigate the steps to find a bed. I couldn't make the decision, I couldn't get it delivered. I struggled to source it, but I didn't know that that was the issue that I was having. It just felt inexplicably hard that there was no context for the difficulty. My mum ended up flying to Melbourne to help me and she had a bed in my home within six hours of her arrival on the same day. And I absolutely cried my eyes out because I couldn't understand how she achieved it so quickly and easily. Something that I couldn't do in a year, she could do in six hours and I couldn't understand.

Prue Walker (11:18):

It couldn’t make sense to you.

Jessica Birch (11:19):

It made no sense. Executive dysfunction can be hard to see, but I really don't navigate things that involve multiple steps. Resource finding, decision-making, organisation, and timing very well. My brain doesn't like to do that. And so this is executive function impairment that often looks like avoidance. It often looks like laziness and procrastination and it's really none of those things. And I become very distressed when I can't do these things and I feel people will judge me in this way. And what it has led to is a lot of masking and behind closed doors, meltdowns and difficulty.

Prue Walker (12:04):

I could imagine it might also look like perfectionism, like you can't move forward till you've got everything perfect, but what you're describing is kind of just getting stuck.

Jessica Birch (12:13):

Absolutely. Really. I often need people to bounce off to make decisions. I struggle particularly when there's lots of options and lots of choices. I become overwhelmed by choice and it completely incapacitates me. I cannot move forward in a decision without someone to bounce off.

Prue Walker (12:31):

And people probably just say, well, just pick Jessica, just pick it. Doesn't matter that much, but I don't imagine that would be very helpful.

Jessica Birch (12:37):

No, no. And really as you grow, these difficulties tend to become harder to manage as demands and responsibilities increase. So of course when I was under the care of my mother, I lived at home, a lot of these responsibilities weren't placed upon me and I didn't realise how much I would struggle when I left home. There's this real snowball effect that happens of failure and shame and confusion. And it's important to know that you don't grow out of these things. You can't fix this brain damage. What you can do is try to support and accommodate it. And there's different varying levels of success.

Prue Walker (13:18):

So I know from talking with you that this can be the kind of challenge that is hard for professionals, whether they're mental health professionals or occupational therapists or whoever might be supporting you, hard for them to understand how you can be so good at some things but struggle with other tasks. I imagine that people might offer some unhelpful solutions at times if it's about sequencing or whatever, but tell me what's been your experience?

Jessica Birch (13:45):

It's an interesting one, and I have learned a lot since my diagnosis, but FASD presents as an uneven neuropsychological profile, meaning that an individual will have unique strengths and significant challenges below, but also above the developmental age. So brain damage does become quite easy to mask when you have very good expressive language skills. And I can express myself quite well, my receptive language, however, what I can absorb process and understand is markedly lower and it gets complicated by my auditory processing issues. And people often don't realise that these are different parts of the brain. So I can express complex ideas much more easily than I can understand complex ideas coming at me, particularly if it's a verbally, unless they are communicated to me in the right way that I need to hear them. It's often assumed that if you speak well, then you can do everything else well also, and that if you're intelligent, you can also navigate and function well in society. But these things are not mutually inclusive. Intelligence, executive and adaptive functioning are not the same thing, but many people think they are. I thought they were. I truly did. It was an eye opening moment to understand that they weren't the same thing. People tend to think that intelligence supports executive functioning, but nothing in my experience actually reflects that. You can be very intelligent and have very poor executive function.

Prue Walker (15:20):

And I think that's something that's sort of characteristic of FASD that perhaps is not present in other developmental disorders or cognitive impairments because I know from the disability literature that generally cognitive ability and adaptive function are closely linked. But there are studies that have shown that with FASD that's not the case. That adaptive function is not necessarily predicted by IQ or intelligence. And that's something I think that it's hard for professionals to get their head around, particularly when they haven't had training or education specifically about the profile of people with FASD.

Jessica Birch (15:58):

Absolutely. It was definitely an interesting thing for me to learn and accept about myself that I could know the things that I know and want to achieve, the things that I want to achieve and even have an idea of the steps that I need to go through to achieve them, but not being able to really navigate and action those steps in a meaningful way to achieve that. And the same with my adaptive function, the struggle that I've had to engage and really, I don't know, be at the level of my peers and sort of stay in tune with what my peers are doing is very difficult.

Prue Walker (16:38):

So you must see people kind of going ahead in their life, maybe achieving things that aren't quite on your radar yet?

Jessica Birch (16:44):

Just racing past me. And that was really part of my mental health challenges in my early twenties is because I was seeing that happen and everyone raced past me in achievement and personal growth and I couldn't understand it because I was working really hard for that as well.

Prue Walker (17:01):

And that would give yourself esteem a bit of a -

Jessica Birch (17:04):

A knock.

Prue Walker (17:06):

Absolutely.

Jessica Birch (17:07):

It definitely did.

Prue Walker (17:08):

So can you tell the listeners how you came to be diagnosed with FASD? How did it all unfold for you?

Jessica Birch (17:14):

Sure. It's a long journey and I'll try and make the answer a bit quick. So my journey really spanned over a decade and a lifetime and it was deeply difficult. And so throughout my life I had many symptoms and quirks that mum tried to address and sought help for. Yet these issues were always treated as quite benign and my mother was told consistently that I'd grow out of them. Of course I didn't. But at any time had anyone asked about prenatal alcohol exposure, it would have been confirmed either by my mother or myself. I knew my birth story as a child, I was aware, but we didn't make the connection.

(17:56):

And neither did any of our health professionals. I'd had a very hard educational experience because of these unrecognised difficulties and I learned to mask very well. But it took a significant toll on my mental health and my sense of self as we talked about a little bit earlier. And so I sought help in my early twenties for these issues, but also the significant physical symptoms I was experiencing. And instead of receiving the healthcare that I really desperately needed, I became trapped in the mental health system. I was gaslit and dismissed by my GP. I was told that the pages of multisystem physical symptoms I had were essentially a psychosomatic presentation of my anxiety and depression, and I was ultimately blamed for my functioning. This went on for about six years and my physical and mental health completely deteriorated in that time. So by the age of 26, I was completely crippled by chronic fatigue syndrome. I could no longer work my menial job. I couldn't even stand long enough to shower. I had to sit on the shower floor and try not to pass out. I had very few friends, no money, no answers, no prospects, and I fell into deep, deep, deep depression. I'm still recovering from this both physically and emotionally. It was a very difficult time.

Prue Walker (19:23):

That sounds very tough.

Jessica Birch (19:24):

My mother ended up fearing that I was going to die either from ill health or my own hand, and she stepped in to take over my healthcare and the journey really started there with her extensive research into my symptoms, finding new doctors and with a lot of work and a bit of luck, mum discovered FASD and she immediately knew, and I was 28 years old. She then had to tell me that she thought that I had FASD, and that is a story in itself, but I will skip over that for now. The path forward really wasn't straightforward. The stigma is quite significant, and there are next to no specialists and no multidisciplinary clinics for adults with FASD in Australia. It was a process of elimination that took us four years.

Prue Walker (20:19):

That sounds exhausting, Jessica. And it's interesting, the physical symptoms that you are describing, while they're really commonly associated with prenatal alcohol exposure, they're not part of our diagnostic criteria. That's all about brain functions. So all those autonomic nervous system difficulties and comorbidities, we know they happened with FASD, but they're not the diagnostic criteria. So that must've been really challenging.

Jessica Birch (20:45):

There was just really no answers. And because I was seeing general practitioners, mostly everything was looked at separately. So the gut issue wasn't related to the heart and the tachycardia and the tachycardia wasn't related to the anemia, and the anemia wasn't related to the fat. There was all these sorts of separateness when it really, I needed to be having healthcare that looked at me holistically.

(21:09):

So when my mum took over my care and we started on the journey for a FASD diagnosis, understanding that that is likely the problem that I was facing and reason I was struggling, I underwent a lot of assessments. So first was neuropsychological and genetic testing. I saw a speech pathologist an OT, I had my facial features measured and there was other screenings while extensive research was collated by my mother. This research included my childhood and adolescent presentation of FASD with regards to school reports, specialist visits, my birth records. And once we had all this information, we still couldn't find a specialist who would diagnose FASD. We ended up making contact with a specialist pediatrician who was willing to see me and would look over the evidence. And that's how it was finally confirmed. And I was 33 years old. And that's just before we met Prue.

Prue Walker (22:11):

It is, yeah. You had just recently been diagnosed when we met, and I think that's really interesting too about at 33 you're going to a pediatrician because FASD being a developmental disorder, often other medical specialists aren't confident to diagnose it because they're like, well, I dunno, the developmental history, and that's the whole definition of a developmental condition is it presents in childhood. And so it's hard as an adult to access that child specialist, if you like.

Jessica Birch (22:39):

Absolutely. And that's where mum really had to do a lot of searching and she really tore apart all my history, my NAPLAN tests, my early doctor's visits. Again, my birth records really to get a really clear picture of what had happened in my childhood and the experiences that we had had. But yeah, it's absolutely difficult. And even though I had a specialists who were assessing me and said, look, this likely is FASD and it fits. You meet the diagnostic criteria. They weren't willing to put their tick on it.

Prue Walker (23:15):

And I imagine this is all in the private health sector.

Jessica Birch (23:18):

It was, yeah.

Prue Walker (23:19):

So you've had a long journey. I mean, how many professionals do you reckon you saw before you got this diagnosis?

Jessica Birch (23:25):

Oh my gosh, so many Prue. I saw GP's, of course I had a psychologist, then my psychiatrist, a gastroenterologist, a hematologist, an immunologist, an audiologist, a specialist, exercise physiologist, a specialist physiotherapist. I also underwent sleep studies. I had tests for autoimmune disorder, diabetes, thyroid dysfunction. But most of these things happened, I have to say, after my mother intervened,

(23:54):

not before. The GP I was seeing before insisted I was fine despite the fact I couldn't stand for any extended period of time. I was always out of breath. I had lost 15 kilos during our time together and I was in her office every two weeks. The first thing my mum did when she took over my healthcare was enlist a naturopath. And the naturopath made sure I was given proper testing to see how my body was functioning. And when the results came in, they were the worst the naturopath had ever seen. And some of the worst, the reporting health professionals, those that give the reports back to the naturopath also said that they were the worst results they had ever seen. I was told to cease all work, that I was at a high risk of a stroke. I was really unwell.

Prue Walker (24:38):

Wow.

Jessica Birch (24:39):

Yeah.

Prue Walker (24:39):

And I imagine from that, that even though you're seeing all these people and you haven't got a diagnosis, any treatment they're giving you doesn't seem to have helped your symptoms even without that diagnosis. So did the diagnosis then help you figure out what support you needed?

Jessica Birch (24:56):

Yes and no. I still have a lot of difficulty just managing my nervous system and the nervous system dysfunction that's ongoing. I honestly dunno how to fix it.

Prue Walker (25:08):

So that might be like something you just kind of live with?

Jessica Birch (25:11):

Perhaps.

Prue Walker (25:11):

Rather than expect it to -

Jessica Birch (25:13):

- Improve

Prue Walker (25:13):

Resolve.

Jessica Birch (25:14):

It can improve. And I would say it has improved actually. But resolving it, I don't feel super confident that at this moment that I can resolve those issues. But I'd have to say to your question, Prue, it wasn't the diagnosis per se. What mum did was collated three folders of research and resources for me to read alongside my childhood history that I talked about. She had been collating for the diagnostic purposes. She did that to help me see FASD in myself and reframe a lot of my experiences. You do need to learn how to see FASD, but once you do it is so obvious, I feel like you can't unsee it. It's like a smack in the face. I can't believe it was ever missed. So I got a lot out of the information that Mum had put together for me, and I also got a lot out of my neuropsychological report. It was very telling and it clarified a lot of where I fall down.

Prue Walker (26:14):

And I think this is something we hear a lot in the FASD world is that power of lived experience. And I know a lot of families who've gone through the diagnostic process have said, I saw a Four Corners programme and I recognised my child on it, or I recognise myself on it.

Jessica Birch (26:29):

That is exactly our story. My mum happened to be watching Four Corners at the end of 2015. The episode is called Hidden Harm, and it features a wonderful advocate called Anne Russell and her adult children. And mum was watching that episode and she knew, she absolutely knew that this was what was happening. And so my mum was really my constant FASD teacher for perhaps a good six years. And it drove me nuts actually. But I'm very, very grateful that she persisted despite my clap backs. And I think the most helpful thing about my mum's guidance is that she always brought it back to brain. It wasn't about what I was doing or what I wasn't doing, but what my brain was doing. So for example, when she was teaching me why I struggle to keep on top of multiple things and why I get super overwhelmed, she described my working memory as this plate in my brain where all the information I'm receiving gets placed.

(27:33):

Once it's on the plate, you can see it all together and you can sort of sort it out. And in your mid thirties, you should have a really strong, big, steady plate. However, my plate is a bit too small for all the information a 33-year-old at the time needed to take on and it's a bit cracked and wobbly and doesn't really hold the information. And so what she actually described it a lot better than that, but that's kind of the gist of it. But another thing I found very helpful was from my neuropsychologist, and she told me that it wasn't my memory that was broken, and I got a lot of understanding from this analogy, but she said, it's not your memory that is broken, it's the filing system for those memories that is not working properly. Another one is when I get overwhelmed or too tired, my mum would list all the sensory input that I had received leading up to the overwhelm.

(28:28):

And she did that to illustrate how much my brain had taken on and why it was valid that I would need a rest or I would be reacting in some way because I had really hit my cognitive load. And so those sorts of things I found very helpful in teaching me about FASD and how FASD presents in me. The other really helpful thing that mum did to teach me my support needs was to identify them for herself. And then she began supporting me and accommodating me with those difficulties considered. So she gave me much more scaffolding and things got much easier. So there was this realisation through the process of seeing what I could actually achieve when someone was there to help me move through the steps. And that was incredible for me. That was a mind blowing moment. And so she taught me my support needs by example, essentially.

Prue Walker (29:21):

And are you okay to share something about how your NDIS services help you with those sort of support needs? What have you got in place for your daily life?

Jessica Birch (29:30):

Sure. Look, I think people really assume a lot about my functioning and capacity because of the way that I dress and express myself. But there really should no surprises that I require a lot of support to maintain my health, wellbeing, and my role as an advocate. I would not be here speaking today without considerable support. I have at least 10 hours of support a week, and at times it's been much closer to 20 hours. I need regular help to organise my weekly schedule and complete my chores and tasks for that week. I need help remembering and booking appointments, maintaining my home, maintaining good nutrition, sticking to a budget, oh my goodness, getting out into the community. Otherwise, I really do spend a lot of time home alone. I often need prompting to drink water. People are often surprised by that. I don't like drinking water or swallowing pills. That's a pretty typical sensory and swallowing thing that happens for individuals with FASD. But there's lots of things, and I'm quite an ambitious person. I have a lot of goals. There's lots of things that I'd like to achieve and skills that I would really like to learn, but these things rarely happen without someone to facilitate me and help me move through the task. Even if I'm really excited and wanting to do it, I still need the help. The excitement doesn't override the executive dysfunction.

(31:04):

When I started on the NDIS, my mum trained my support workers on how to support me. So my NDIS team usually looks like a service coordinator, a money manager, a social worker, occupational therapist, my neuropsychologist support workers, and a few home services and sensory supports to help me around the house. But I've also engaged with an exercise physiologist and psychosocial recovery coach. So my team is quite big. I also regularly engage with my psychiatrist, who I've been with since before my diagnosis and mental health support is really an integral part of managing the things I find difficult and healing from past experiences. I find that CBT isn't usually the right approach for someone with FASD, but I have gotten a lot out of ACT therapy, acceptance and commitment therapy, as well as talk therapy with my psychiatrist, and I really need someone to bounce off pretty constantly. A lot of that second brain support.

Prue Walker (32:07):

Many clinicians in Australia aren't particularly aware of FASD, so I can imagine it could be hard to find the right sort of supports. Can you tell us some of the challenges you've had working with professionals and getting them to understand how you need to be supported?

Jessica Birch (32:23):

Sure, yeah. There are other supports, absolutely, that would be very helpful. However, I have had ongoing issues having FASD understood and recognised within the NDIS or to have informed healthcare generally. So what ends up happening is I hire a lot of clinicians. What I find is a lot of support workers don't seem to know how to recognise preempt or support executive dysfunction, which is the main thing that I get help with. Or they simply cannot seem to understand that FASD is a brain injury and not a mental illness. I can't be encouraged into better functioning.

Prue Walker (33:06):

Yeah, it's not about your motivation.

Jessica Birch (33:08):

It's not about my motivation. The motivational interviewing's not going to cut it. So yeah, those sorts of things don't work, and it's been problematic in that sense. So I've come to a point where I won't hire a support worker who doesn't have a particular skill training or is willing to undergo training. My capacity is often overestimated, and then people don't understand why I'm crashing and burning the next week and that I won't just recover by getting a good night's sleep.

Prue Walker (33:40):

And I can imagine a lot of people come in and go, okay, let's make a list

Jessica Birch (33:45):

Yeah.

Prue Walker (33:45):

Like oh, you've never thought of making a list before, but there's more to it than that.

Jessica Birch (33:49):

There's absolutely more. It's all about facilitation. I can make lists for days,

(33:55):

So I kind of needed to take the reins in teaching my support, how to support me as my mother couldn't always be there. But what I feel happens is that as soon as I express the problem, then I'm somehow able to overcome the problem and not enough support is given. A lot of my support needs are about preempting the number of tasks and steps needed to complete an activity and really help to minimise the amount of steps for each task, help me to make the decisions and prioritise what is needed, then move me through the actions. There's this fallacy that because I can express the issues I'm having, I must be able to fix the issue. Or having an understanding of the issue means I can overcome it. I really speak publicly a lot in this arena to try and bolster understanding in this area as well as the many others. I'm really lucky that my social worker has been with me for five years and had training in FASD when she was working with you Prue, and it was our connection that actually facilitated my social worker coming on board as part of my team. And she remains to this day, and she is such an invaluable member of my team and helps me so much because she's gotten the chance to really get to know me, and she knows where I fall down.

(35:17):

And so having consistent support for individuals with FASD is deeply important, but is often not how the NDIS system is working. A lot of support is quite transient.

(35:30):

But please let me say that despite these challenges around my support, having support services and being an NDIS participant has completely changed my life in every way for the better. I'm living a new life that I never, never in a million years thought that I would be living. I'd never believed it was possible. And I really believe that this is absolutely a testament to my family, my NDIS team and the support I received from so many people such as yourself, Prue, and many others. Six years ago, if you had told me I would be sitting in a podcast recording room talking about this, I probably would've laughed at you. The positive changes in my life is really a testament to the importance of diagnosis.

Prue Walker (36:24):

That is so great to hear. And we've got an audience of health professionals. So for my last question, I'm wondering if you can reflect on what this FASD diagnosis has meant for you and what you most want them to know.

Jessica Birch (36:36):

Well, I can say it certainly doesn't mean all the shaming, blaming, and stigmatising rhetoric that others associate with the diagnosis, which is often what leads to the avoidance of asking the questions around prenatal alcohol exposure and a parent's resistance to disclosing it. My brain and how it functions shapes my perceptions, how I see the world and how I engage in it. I'm not a disability. I am a person, but my sense of self and ultimately my reality has been shaped by my brain differences. I cannot be extricated from it or it from me. It's really part of my identity. Who I am as a person and how I move through the world is a reflection of the fact that I have FASD. And if I didn't have it, I would be moving through this world fundamentally differently. And I would like to think that I am worthy and valuable to be walking on this earth just as I am.

(37:34):

But it has taken me quite a bit of time to actually come to that stigma and lack of awareness denies individuals correct diagnosis and support. It denies us the ability to understand ourselves and find pathways To navigate a complex world fearing an undesirable label is not helpful, not for individuals who are struggling in the dark or for the parents and carers who are trying to support them. And I think health professionals play a significant role in minimising the stigma through safe, non-judgmental conversations, information and advice. I feel it's, and my experience is that it's a very lonely road when you are striving to achieve your goals and desires, striving to be part of the world, engage meaningfully and succeed, and there's no context for why you can't and seemingly no pathway to overcome it. You were told that ultimately you are responsible. And I internalised that struggle as my own failing, and it led to despair, profound despair, and without the tools to regulate my emotions,

(38:44):

is it any wonder that anxiety, depression, and trauma becomes significant secondary issues for those of us with FASD? So what I'd like to say is that FASD presents often and is often confused as mental illness, yet they are fundamentally different problems. FASD cannot be managed effectively as a mental health issue. It will lead to more harm. The brain differences need to be supported first and then mental health can improve. And it doesn't usually work the other way around. However, the high likelihood an individual with FASD will suffer mental illness means mental health professionals have this integral role to play in the assessment, diagnosis, and ongoing support. Knowing how to recognise brain differences and support mental health with regards to these differences is crucially important in this space. I wrote a blog recently that FASD is often seen as condemnation, but I truly believe that it is a revelation. It is the key that unlocks understanding the gateway to support and the first steps towards healing and hope. And I really hope that it's made a difference talking to you today.

Prue Walker (39:59):

I'm sure it has. Jessica, thank you so much for sharing this story and for professionals who'd like to know more about alcohol, pregnancy, and FASD, the Every Moment Matters is a nationwide project sharing the latest evidence-based information about alcohol during pregnancy and breastfeeding. The Every Moment Matters campaign features, resources, and training for health professionals about alcohol, pregnancy, and FASD. If you visit the Every Moment Matters website, you'll see links to free and accredited online training to support alcohol-free pregnancy, and it also gives professionals the tools and information to discuss alcohol in a non-judgmental way with parents who or patients who are planning a pregnancy already pregnant or breastfeeding. There's a whole range of downloadable brochures and fact sheets on these topics, evidence summaries, guides, and links to support services. So you can find out more at everymomentmatters.org.au/forhealthprofessionals and the links will be in the episode notes. So I'd like to thank you for joining us on this episode of MHPN Presents In The First Person. You've been listening to me, Prue,

Jessica Birch (41:06):

and me, Jessica.

Prue Walker (41:08):

Thank you, Jessica. This has been a wonderful conversation and really enlightening. I've got no doubt that our listeners will be really grateful and appreciative for those insights that you've shared. As I said before, this episode's landing page will have a link to the Every Moment Matters website and any resources or research we've discussed. There'll be mine and Jess's bios and a link to MHPN'S feedback survey. We all really value your feedback, so please follow the link. Let us know how this episode was received by you. Was it interesting? Was it helpful? Provide comments and suggestions to help shape the future of MHPN podcasts. To stay up to date with future episodes of In the First Person and other MHPN podcasts, make sure you subscribe to MHPN presents. Thank you for your commitment to multidisciplinary care. It's goodbye

Jessica Birch (41:57):

from me,

Prue Walker (41:57):

and me.

Jessica Birch (41:59):

See you later.

Speaker 1 (42:00):

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