

## Disability Done Different: Episode 12

Samantha Jenkinson on...sexuality, activism and being bolshy diva

### Podcast transcript

Audio Length: 00:23:56  
Hosts: Roland & Evie Naufal  
Guest: Samantha Jenkinson

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#### Intro

**Maia:** This is Maia Thomas; I am the DSC podcast producer and I just wanted to give you a quick rundown of DSC as an organisation before we get started. 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. Our focus is on helping providers to survive and thrive in the NDIS. Our purpose is better outcomes for people with disability.

#### Dialogue over intro jingle:

**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. Disability Done Different, Candid Conversations.  
**Roland:** Disability done different.  
**Evie:** I hope you're ready because we're starting.

### Start of Interview

**Roland:** Welcome to Disability Done Different. Today is slightly different, Evie is in the studio in Perth with our guest, Sam Jenkinson, and I'm sitting here in Melbourne, so we're using ZenCastr, it'll be a different way of approaching a podcast for us. I'm excited to have Sam on the line because I've known Sam's work for a number of years. And I think she's a rare combination of public servant and advocate. I think those two don't go too well together in a sentence. We'll be exploring today with Sam how she's been both a Bolshy Diva and past chair of the Women with Disabilities Australia. Over to you.

**Evie:** Welcome, Sam.

**Samantha:** Thank you, welcome, it's great to talk to you both.

**Evie:** Sam, I thought I'd just jump straight into the deep end. When I was sitting out in the waiting room, we're here at Disability WA's office. I saw that you've got a brochure about people who might be looking to engage with a sex worker. That's really topical this week because just last week the AAT ruled that it was reasonable and necessary for somebody to have sex therapy put into their NDIS plan. So I wondered if you could give a little bit of a comment on where sex therapy and where sex work fits within the NDIS.

**Roland:** Interesting, Evie, when we did have this conversation internally on our Slack channel, it went off, there were so many different people, different consultants at DSC that have an opinion on this, and a lot of us disagreed across different issues, so it would be interesting to hear from you, Sam.

**Samantha:** Sure, it is very topical at the moment, so actually from quite early on in my career, I've always been interested in the promotion of people with disabilities as sexual beings. There's been stuff that I've done with the lovely George Taleporos in the past, talking about sex and sexuality and what all that means. It's really important I think that this ruling has been had. I really hope that even if the NDIA appeal against it, that it stays in place and is held, because there's this underlying thing about the NDIS, which is all about having the same opportunities as anybody else.

If someone didn't have a disability, would it be expected normally that you would access a sex worker, or sex therapy of this sort of nature. The reality is, most people probably wouldn't. What is it about having a disability that makes it different for some people? There are two elements to it. There's sexuality counselling or support that might be from a therapy-type perspective. Then there's the actual element of physically assisting someone to have sex. So there are couples out there, who both have physical disabilities who need the assistance of a third person to be able to enjoy a sexual relationship. That should absolutely be funded, I think. Then there's the element that we know that for some people, being able to access sexual services, to be able to do

something like masturbate, which is actually a normal human thing that we all do, is really difficult because of their disability.

If that's something that anybody generally in their life should be able to do and can easily do, and someone with a disability needs support to do that, they should be able to access funded support to do that. That's sort of what the whole basis of reasonable and necessary is about. Bringing it back to the same principles is absolutely perfectly fine for me. I think we should be giving people that information.

**Roland:** Sam, you mentioned George Taleporos. It's Dr. George Taleporos. He did his PhD on sexual relationships and disability. He'll probably kill me for paraphrasing it that way, because I don't know what the actual title was. George is certainly on our list of future interviewees for our podcast, but can you tell us about the work you did with George or one of the questions we should ask George in a podcast?

**Samantha:** Absolutely, very happy to. As a participant in his research study, I can tell people about it myself. Yes, I was a participant in his research study.

**Evie:** Yes?

**Samantha:** Way back then, which is really interesting because there was both a focus group of a number of people with disability who talked about all of these issues, what help do you need? How do you view yourself? It was very much about people's personal perception around sexuality and how they felt other people perceived them. Also, when George was with No Limits, the lovely community TV show, we actually did a section around sexuality, disability. I talked about my experiences as a person with a physical disability and how often you're very much seen as being asexual.

People don't think about the fact that you might have sex, that you might have kids. Both of my children were born after I acquired my disability. Just interesting things like my husband, one of his friends before we got married said to him, "Gee, you're a braver man than I. You must really love this person if you're giving up sex." He was like, "Yes, well I'm not." In fact, just to say, I'm pretty good in bed.

**Roland:** That leads me to another question, Evie, I'm not giving you a chance just yet, but I do just want to jump in. I don't know, Sam, if you've had a chance to listen to our podcast with Rhona Galbally, but with Rhonda, we talked about, did the personal become political, or did the political become personal? What was your journey in the way, I was going to say in terms of, but I hate using in terms of, but I think it fits, in terms of having a disability and becoming political, where does it work for you? Where was the tipping, tricking, tipping point?

**Evie:** You just gave up on that question halfway through.

**Samantha:** I think it's a really good question, Roland, I guess for me, as a good social worker and feminist, the personal is the political. I did have my accident when I was in first-year university. After my accident is when I studied social work. Yes, I do really think the personal is the political. It's really anybody can take the aspects of their personal

experiences and look at what do they need to do, or what should they do that has a political element to that in my personal life as a person with a disability, I do a lot in that political space and can see the policy and legislative and political nature of disability discrimination that affects me personally. It is very much about really how aware you are of those things happening around you. How everything we do shapes our perceptions on what community looks like. To then shape it to be what you want, you need to be involved.

**Evie:** Your first response to that question reminded me of this quote that I found online today, describing the Bolshy Divas as disability activists in the style of feminists masked avengers. Loved that. Since you might not be familiar with the Bolshy Divas, can you tell us a bit about yourselves?

**Samantha:** Sure. Look, the Bolshy Divas was sort of setup through some of the initial national disability strategy development, as well as the NDIS development. Really, it was a lot of women with disabilities mostly, sort of coming together and saying, "We need to be able to say some of the issues that are underlying how things are done, where we can just really be open and honest and just put it all out there." One of the women who was involved early on, I remember she talked that a lot of the time in the disability sector, you get a bit of a shit sandwich, there's the ordinary, then there's the shit, then there's the ordinary, but things are often dressed up.

We use terminology. Right now, for example, we're talking a lot about co-design. Co-design actually the principles behind it have been around forever. It's nothing about us without us. Nothing's changed about that core concept of what it is. We keep trying to find different language because the language gets subsumed and we relabel the shit stuff that we do with this new fancy name to try and make it sound better. The Bolshy Divas was almost that we're going, well, often sometimes in our jobs that we're doing, we have to work with people, you have to find compromises.

That's part of how you move things forward. Change happens slowly. You also need people who can just go and put it out there, warts and all, the emperor has no clothes on type stuff. That can bring the conversation forward and move it up swiftly for all the people that are doing the hard negotiation work behind the scenes, so to speak. The Bolshy Divas was sort of a way to trying to get some of that conversation highlighted and pushed up to the next level.

**Evie:** Yes, you've got some awesome stuff that another quote from the website that I liked was that there are no requirements to be a Bolshy Diva, just owning a desire to bring about change, a sense of humour and a tonne of Bolshiness. I think that's totally reflected in a lot of the great resources you guys have created, well, you ladies have created, I should say. We'll link to some of those in the show notes for those of you who are curious to read a bit more.

- Roland:** Tell us one of the more outlandish things that the Bolshy Divas have done that you're proud of, Sam?
- Samantha:** I think probably, and, look, I must say that I'm just one person. In fact, there are a number of Samanthas involved. I'm certainly not the most famous one of them. One of the things which I think, as a collective Bolshy Divas should be proudest of, is some of the work around the senate enquiry into disability abuse and neglect. When the senate enquiry came to WA, a number of the women came along and placed a white rose down for every person that they talked about who had died as a result of abuse and neglect through our systems. I think that was something that was really powerful.
- Roland:** Sam, I really understand your humility in not wanting to take credit for the Bolshy Divas, so we want to preface everything you say in that respect, but one of the things the Divas have done, which I've really enjoyed and a lot of people do, and it's in the name of the group is, you're using theatre and you're bringing humour, you're bringing theatrical effect to issues that are often very difficult and the example you just gave was a pearl. There are a lot of advocacy organisations out there that sometimes seem to lack a sense of humour, or sometimes seem to not be able to bring forward things in positive ways. What is it about the Divas that you've found this sense of theatre? Is it a group of failed drama students at work?
- Samantha:** Well, I think there is an element of creativity that's trying to find some outlet, definitely. Look, big kudos to Samantha Connor for a lot of that because she's come from an arts background. I think there are a few of us which have come from that background of arts and creativity and I think there's also an element of being... having a disability. You're often trying to find a way around things. You often do you quite dark humour sometimes, as a way of just coping with things not always going your way and having to find a different way to do things, or to explain things to people. I think that comes through a lot in the way we approach topics. That gives it a bit more of a flare, I think.
- Evie:** There was a little bit in what you were saying before around the work you're doing now around co-design and having to find new ways to describe that. It was making me think about the local area coordination model, which is supposed to have been designed on the local coordinators that you've had in WA for decades, is it that long?
- Samantha:** Yes.
- Evie:** It would not be a fair characterisation to say that the NDIS model vaguely resembles that you used to have pre-NDIS.
- Roland:** Bastardised it.
- Samantha:** That's correct, yes, it really isn't like the LAC model that we had here. There are still... I'm an optimist, there's still hope. It's still early enough in the stages. I think the thing is that there are some things that could change it quite significantly. It's about having the people with the will to make the change. Co-design, nothing about us without us. Back to that core element. Right now, the board of the NDIA, I'm sure they're all lovely

people, but they're all coming from a particular background, which is about processes, money, compliance, there's not as many of that. The board actually is balanced toward the model that we've got. It should be having the sorts of conversations that we're having. It might not be having them because the makeup of the board is not actually the right balance.

**Evie:** Yes, and you're doing quite a bit of work with People With Disability WA, to increase the number of people with disability on boards, right? That's one of the major focuses.

**Samantha:** We are, yes. We are. I wasn't saying that to try and get to that point.

**Evie:** Go on, give it a plug. [Laughter].

**Samantha:** Certainly, yes, look, the core principles behind the NDIA and the NDIS, it comes back to that core principle of choice and control. How do people with disability have choice and control, not just at that individual, what am I choosing to eat and wear everyday level, but how are people with disability shaping what this looks like? To do that, they have to be at board levels, senior management levels.

We've actually been really successful with the project that we're currently doing, because we've got board chairs from some of the big services providers here in WA, who haven't in the past necessarily had people with disability on their boards. They've often had family members and carers, which is important, but they've not had people with disability who are not going, yes, this is important, we need to make this change. They're championing that for us, which is great. I'm proud of that, that's a bit of a win.

**Roland:** Last Friday, we were involved in a national roundtable on the NDIS on rural and remote issues. A couple of things were really put strongly there. One is that the agency has not been good at listening, it talks about co-design, but it's not good at executing co-design. On a very positive note, the people there were saying, we're about to hit the next generation of the NDIS, the mad rollout to get the bilateral met is still going and will continue for a while, but there is now an opportunity for us to take a breather and perhaps do things a little differently. If the agency is willing to listen, is willing to do co-design, can you give us some tips on how to go about it and do it well, given your vast experience in the area?

**Samantha:** Look, I'd love to. I think you're right. I think there is a time now where the rush for transition is pretty much over. It is like, what do we want to bed down now as being how we're going to do things into the future. I think there are some really important parts about co-design and why it's co-design and not just collaboration or partnership. We've actually developed up a bit of a co-design matrix, the co-design group actually being representative of the diverse mix of people with disability and the community is really important. We've always tried to ensure we've got young people, old people, people with diverse sexuality, a mix of gender, ethnicity, aboriginality, as well as then diversity of disability, as well. That's really important because what works for me as a person with a physical disability doesn't always work for someone with a different type

of disability. One of the things that I think is a big issue for the NDIS is how are their systems flexible enough to cater to that diversity of disability. The other part is, that the co means that the decision-making is co-decision-making, not just here we've done this, and the decision is made by somebody else, elsewhere.

Which is a hard thing for a government department to do. But the design part is often the bit that's also not done well. Design thinking is actually about problem-solving, really identifying what the problem is, and you're designing something, which means that you need to look at options, come up with prototypes, not just modify an existing document that you've consulted on. That design thinking part I think is probably the newer element of what makes something co-design rather than just collaboration or a partnership approach, if that makes sense.

**Roland:** That makes a lot of sense. Sam, we've got a younger woman working with us, Sara Gingold and she's an absolute star, I'm sure one day she'd like to be a Bolshy Diva, as she's got all the key elements required. What advice would you give a young woman coming through the system that is a born advocate in terms of doing what you're doing?

**Samantha:** Gosh, tips and tricks and advice, look, I think one of the things that I've always found is about finding where I need to be at the right time. Bear with me for a second here...

**Evie:** I like where it's going.

**Samantha:** I'll often use the analogy of the environmental movement, because it's a good one to look from the outside and see. We've got people who are activists and then you've got your conservation council, or your land care groups. That some are doing things by going out and practically doing stuff, some are doing things by negotiating with government behind the scenes and then, yes, there are the activists, your green peace and all of that. The Bolshy Divas was a way of being at the activist end for those people that may be more comfortable most of the time in that middle space of being an advocate.

Being an advocate is very much about coming up with ways to solve problems, as much as it is about raising what the issues are. It's often there is a negotiation and compromise in it, even though it might not always be right there at the forefront. Figuring out which bit of that spectrum are you in at different times is really useful to know, is this the right way for me to approach how I'm going to deal with this issue. For example, sexuality stuff, is that an issue that's going to be better off with me having a few quiet conversations as an advocate or getting dressed in my leather.

**Evie:** This is literally the exact same conversation you're having with Sara today. I emailed her today saying, I'm speaking to Sam Jenkinson today, we'll see should it be one article or multiple articles, or quiet conversations. It's the exact conversation that she's having. It's interesting.

**Samantha:** It is because actually it's not me being the activist this time, maybe this time I'll be the quiet conversation, but I might just let Sam Connor know that something's happening.



[Laughter]. Don't try and do it all yourself. I need to make sure I've built relationships with other people that feel the same as me, as well. Finding those other people that will engage with you in the conversations, can think creatively about how you might address it. It's really difficult not to get bogged down in the detail, and it's really difficult sometimes not to just be angry all the time, and it's okay to be angry, it's not, don't be angry, it's be angry but know when you can go, ahh and hit my pillow and tell my husband that the whole world is shit.

When I go, okay, what am I going to do about that? Who do I need to get engaged with to make something happen? I personally am a bit action oriented, so I will think about projects, partnerships, who can help me move this forward? That's the way that I think. Other people might go, I'm going to write a blog about it, I'm going to do a Facebook post. You've got to find how is it that you're going to express to do that? I do think that the biggest thing is building some relationship with like-minded people. To move that forward is so important.

**Roland:** That's fabulous advice. Thanks, Sam. I think we're done with Sam Jenkinson and the Bolshy Divas. We thought you were going to be a great guest and you turned out fabulous. It's been a real treat talking to you, Sam.

**Samantha:** Not a problem, I'm happy to be called absolutely fabulous.

**Evie:** [Laughter]. Thanks, Sam.

**Roland:** A good fit.

### End of Interview

### Outro

**Evie:** You've been listening to Disability Done Different Candid Conversations. If you want to learn a bit more about the Bolshy Divas and Sam's work at People with Disabilities WA, you can find some links in the show notes. We have a fabulous newsletter as well, that beautiful Sara Gingold that we were talking about, writes some of the sector's best resources, if we do say so ourselves. You can find that newsletter where you can subscribe at: [disabilityservicesconsulting.com.au](https://disabilityservicesconsulting.com.au).

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