

## Disability Done Different: Episode 13

Kevin Stone on...The long game

### Podcast transcript

Audio Length: 00:26:02  
Hosts: Roland & Evie Naufal  
Guest: Kevin Stone

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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:** Hello, and welcome to Disability Done Differently, Candid Conversations, the DSC podcast. I want to introduce Evie Naufal, my trusty sidekick and Maia Thomas, our producer.

**Maia:** Hello.

**Roland:** Today, we're talking to Kevin Stone, Kevin has a phenomenal experience in the disability sector, 40 plus years, I think. We'll talk a little bit about that. For me, Kevin, I have enormous respect for Kevin for the work he's done. I think he's almost universally respected by the sector, except for the people who hate his guts, and that's only a few of them. We're going to be talking to Kevin about being an advocate, but he's also the parent of four children, three of whom have a disability and one of whom is an NDIS participant, so he's bringing a very coal-faced perspective to a lot of the conversations about disability, so welcome, Kevin.

**Kevin:** Cheers.

**Roland:** Kevin, we met way back in 1989 and at that stage, I was working with the Victorian Council of Social Service, VCOSS. You were starting VALID. I often tell people the story of my motivation to stay in disability and to get a leadership role was, I was convening a meeting of CEOs of the disability sector. At that stage, the people who were coming were all male. If I convened a meeting that was about the fringe benefits tax of salary packaging, the place would be full of people completely interested in what we had to present.

If I did one on person-centred planning or individualisation, we'd have very few CEOs turn up. I pretty quickly congealed ambition to become a better CEO than those blokes and to do things differently. But in your experience of 30 years in the disability sector, are we doing things differently? Are the CEOs still more likely to be self-interested than they are in participant-centred processes?

**Kevin:** I think we probably had the same experience back then and probably reacted in different ways. I guess, for me, it's that self-interest factor that's always fascinated me. I use the term; we all use term empire builders. The disability sector back then was being dominated by large scale disability empires. Within those empires, little emperors thriving. Some people would interpret me saying that as if I'm against big organisations or against organisations, that's never been the case. It's that which is... it's the attitude that those professionals working within those organisations bring to their work.

It's the culture of the organisations, that can very quickly turn, it's about them, it's about their power, it's about their empire, and the behaviour of those representatives of those organisations in those meetings being about, I'm here to attract business to my organisation for me to further my career. Even at the expense of the very people that they are at the table talking about.

**Roland:** We said a lot, that ego-driven growth stuff.

**Kevin:** Look, the reality is, it's something about human nature.

**Roland:** Yep, it is.

**Kevin:** It's not as if people in the disability sector are any better or worse than anyone else out there in the business sector. Ego is what drives people, the desire for power is what drives people, generally. But in human services, when our mission is to and our job is to empower people with disabilities, what we see is organisational cultures thriving at the expense of empowering the people that they are there for. You asked me, have things improved? I would say things have gotten worse.

I would say some of the very things that we've done to try and fix that culture or fix that approach, we've basically made worse, particularly in a market environment, where an organisation will thrive or might thrive according to the number of people they might attract. What we're seeing is organisations actually capturing and closing down access to information for their participants, denying them opportunities to really make choices, to exercise choice and freedom and capturing people. That was something back then, but not to the same toxic level that we're seeing now.

**Evie:** It's interesting what you're saying about organisations capturing customers. It's making me think of two things, or two quite troubling trends of what you see. The first is organisations that we see when we talk about marketing, talking about a lifetime customer value. They're really looking at how can they support somebody from cradle to grave, this way of maximizing revenue. Really, not thinking about the implications for that, about potentially creating a dependent support relationship and how that totally reduces the organisations incentives to build the informal supports in somebody's life, or to reduce their need for paid supports. Even just if there are a consistent level of paid supports through someone's life, thinking about that you might not be the best fit for them in 10/20/30 years' time.

- Roland:** I just want to jump in there, Evie, and don't comment, Kevin, because it's a whole other train of thought, but we got rid of the concept of cradle to grave 20 years ago. Now, people are talking about it as if it's okay. Come back, Evie.
- Evie:** I guess the other thing that's coming up for me is thinking about the role that support coordinators play, or I should say, that they don't play often enough in creating variety in people's life and stopping them from being captured in organizations. I'm hearing of a number of organisations. I'm hearing of a number of organisations who are now offering support coordination packages. What that means is that they'll do the support coordination so long as you also purchase your direct supports from the organisation, which is just a total – it's an oxymoron. There's no need for somebody to have support coordination if it's already a full-blown conclusion that they'll purchase all of their supports from that same organisation, which is crazy to me that people are marketing their conflict of interest.
- Roland:** I want to segue there because we've got so many topics to talk to you about, you mentioned markets before. One of the things we wanted to ask you is, we're moving into this quasi-market, it's not a real market. If you've got cap prices, this is not an ordinary market. We're moving into a quasi-market, and we're seeing real market failure. It's not quasi-market failure. Where do you see the worst of the market failures with the NDIS, Kevin?
- Kevin:** Without a doubt, the area of complex needs. It's very difficult to find services that are capable of responding to the needs of particularly with people with intellectual disability and autism and behaviours of concern. Some of the most flexible responses we're seeing are through self-management, of families, but often at great costs to the families themselves. We're not seeing innovation, we're not seeing flexibility, we're not seeing responsiveness from the service sector. I think that's a critical failure. I'm conscious that the agency has different initiatives to try and address it, we're certainly giving feedback and we're involved in those processes. It's really difficult.
- Roland:** That's interesting because both Evie and I, Evie's had a fair amount of contact with Sarah Forbes, from your organisation. When I have contact with you, I think Evie is getting the same response from Sarah, as I'm getting from you. It's intense frustration, it's intense personal almost angst around what's happening with people with complex needs. It's just not okay.
- Kevin:** Well, I think the personal angst is for the fact that for 20 years, we railed against a system that we all knew was broken. Even within that, we sensed that there

was desire to try and address the problems and fix the problems.

We also felt as limited as the department of human services might have been in funding, we always got the sense that they were trying hard. I wish I could say that about services now. I don't see that. I can see it in the agency, I can see in their own way, they've struggled to understand what the issues actually are. There's a whole story in there about their failure, too. Their failure of their mechanisms to hear the stories from people with disabilities and families and to take them seriously. We've had to fight hard to get them to actually take these stories and these issues seriously.

The first thing about responding to the crisis or to the problem, it's to actually understand that there is a problem. For a long time, I don't believe that they understood there was one. They are hearing it, but such is the agency, they're dealing with so many problems and so many issues. It's very hard to get them to focus on this particular problem. We've got a lot of hope invested in the complex needs pathway and the approach that they're trialling there. Time will tell whether that works.

**Roland:** Can I jump in and just ask; do you remain a true believer with all of these issues that you're confronting? Again, I'll just reiterate that we see lots of people, lots of people say they're struggling, it's okay, it's going to be okay. When we see you, you guys are VALID, you're really seeing the pointy end, can you stay a true believer when you see things are going so hard?

**Kevin:** We run an advocacy training program. One of the chief things that we talk about is the need to remain hopeful and to be optimistic because if we advocates don't have hopefulness, then what have we got to offer anybody else, and how can a person with a disability or a family come to us if we're despondent and have no hope? Yes, we have hope, we have optimism, but I have to be honest here and say, there are times and there are days where it just looks pretty, bloody bleak.

**Roland:** I'd like to pick you up and ask you how you get up out of bed on those days? About five years ago, so I've seen you lots of times during your career, about four or five years ago, I met you in Brunswick Street and you were busted, you were down to your last sense of hope and it's all shit corruption, I'm out of here, Valid is about to die, everything was over. This was about four years ago, I think. How do you keep going? How do you get out of bed?

**Kevin:** Well, it's the energy and the hopefulness of the people we support. We've got an amazing community, we've got an amazing organisation, five years ago, we had a different political environment and we had no support whatsoever

for advocacy. It is hard to keep fighting when no one actually believes in what you're doing. When there are things laid down in your path, I guess my nature is and the nature of people associated with VALID is, we do like a challenge. We will rise to those occasions and we will fight back. I guess what I wanted to say about the hopefulness that we have. The question is not that do I have confidence or hope in the NDIA, or government, or anybody else, because my experience is that that's just so variable. It depends on who's heading it, what government you've got in, which particular favourite of the day they're listening to in there and what particular fad they're chasing after at any particular time.

All of those things are variable, but what doesn't vary and what doesn't waiver is our confidence and belief in people with disabilities and what they bring to this. Our job is not about all of that other stuff, our job is to empower people with disability to be the best possible advocates for themselves, to stand up for themselves, to stick up for themselves. No matter what is thrown their way, they'll be equal to the occasion. That's what keeps me going. We're just recovering this week from having a state conference last week. When you see the difference that that conference and our advocacy makes in the lives of people, yes, we achieve outcomes, but the best possible outcome is that people actually believe in themselves.

When they come to that planning meeting, when they come to making that complaint, they will do it with power. We had a session at the conference last week, where we released our new staying safe videos and materials around abuse and neglect. We had an audience of people with disabilities who just one-by-one around the room began to disclose the things that had actually happened to them. I took the roaming mic around to them and just one-by-one they started telling stories they'd never told before. That's the stuff that keeps me going, is that this makes a difference in people's lives.

If you can harness that and bring that into the market, then the market actually might be able to respond. At the moment, the market is dominated by the agency and by providers. The only way this NDIS thing is going to work is, if people with disability and their families have equal power or bring power to the equation. For so many of our people, that's just not the case because they've been kicked around, they've been treated like shit. Their confidence is down. The only way the NDIS is going to work is if we all support the concept of informed and demanding consumers. If we bring information to people,

empower them, build their confidence. They'll sit at the table; they'll demand better than they've had. That's a challenge that we all face.

**Evie:** What about you, dad, are you still a true believer?

**Roland:** I didn't expect to be asked that, yes. The short answer is, it's a real easy yes, but I think it's ten years before we see the hopes and the aspirations come through in the NDIS. Sort of segues back to the hopes and aspirations, Kevin, in a sense that back in 89', we never would have dreamt that the government would commit to one percent of GDP. We never would have guessed that the politics of people with disability could be as powerful as they were with the Every Australian Counts campaign. You've got to say, we've made some – not we – but the sector has made some very significant, you guys have made some very significant gains in that 30 years in a voice being heard. You wouldn't want to be a politician in the next election, saying they're going to ditch the NDIS or cut it seriously. We've seen some change there in the politics, haven't we?

**Kevin:** Absolutely. I think that's probably the biggest take-away from the last ten years or so is, and this is going to sound really corny, but faith in the Australia community, faith in Australia as a fair – it's pretty bloody cool. Particularly if you're looking at what's happening in other countries around the world? Trump's America, for god's sake. What we're talking about here, they'd brand us pure socialism, but it expresses the very best intentions of what Australia is about, it does make you pretty proud. Notwithstanding all of the problems we're seeing with it. It's a pretty good base upon which to build a fair service.

**Roland:** It is. I'd like to go through some of the basics of the scheme with you too, Kevin, and some of what I think are myths in the broader community, now that you're talking about the improvements in the broader community. I think this broader community believes that the NDIS is all about supporting people in a wheelchair to get a university education or to get a job. 60 to 70 percent, it's probably closer to 70 plus percent of the people are going to have a significant cognitive disability. Not a mild one, a significant one.

Another 15 percent are going to have mental health issues that are high enough or significant enough to get them into the NDIS. We're looking at the overwhelming majority of 85 percent or more of people finding it difficult to represent themselves at various times. Yet, the scheme seems to have been written, a lot of the legislation is written as though people are going to be able to undertake their own planning with very little support. I'm going out there, but where would you go with that?

- Kevin:** Well, I guess the question is, what have we done to address it?  
That's been true right from the beginning, from the moment the act was drafted, it was clear that there was very little understanding of the needs of people with intellectual disability.
- Roland:** The majority.
- Kevin:** You might recall... for the first year or two, we conducted a campaign making that point, that they really needed to hear the voice of people with disability. To be fair, the agency responded by establishing the intellectual disability reference group, chaired by Rhona Galbally. I believe that's made a big difference. I think Rhonda has done a sensational job of bringing together a group of people from across the country to hear the issues, the particular issues. I'm not so convinced that the issues have been translated into action by the agency, but that's something upon which we're constantly working.  
The supported decision-making issue is one that's being constantly talked about, but very little action has been taken to ensure the people with cognitive impairment are supported in their planning processes and in the decision-making process. That takes investment. Let me just put in a plug there. there's a lot of talk about it, but very little understanding that that work of supporting people to make decisions, to consider their options has been the main work of individual advocacy organisation across this country for the last 30 or 40 years. It's so disrespected and so poorly understood.
- Roland:** It really is. A little plug for us, too, Rhonda Galbally is on one of our earlier podcasts, if people want to listen to Rhonda talk about the personal becoming political. Let me jump in with, I'd like to hear a bit about your personal story. You were a principal of a special school before you started at VALID. You've adopted kids with disabilities. Tell us about that journey.
- Kevin:** My journey actually began when I was about six years' old. My mum was the director at one of the first day centres for people with intellectual disability in Australia, the Christie Centre in Mildura. I spent a lot of my early years at the Christie Centre and most of my friends were people or kids with intellectual disability. Then when I left Mildura 16/17, I got a job or different jobs in different places, doing work so St. John of God, Yarra View, terrible memories of that place. Working for a year, I drove a bus from a centre in Geelong and did their gardens and learnt that I'm not a good gardener.
- Roland:** A reasonable bus driver.
- Evie:** [Laughter].



- Kevin:** I was a reasonable bus driver. Actually, that was 1973/74', they actually sponsored me to do my special education, which was pretty amazing because I was just their gardener and bus driver, but they sponsored me to go off to the institute of special ed. I did that, came out as a teacher at Heidelberg SDS. I did that for a year or a year and a bit, and then I became principal of a special developmental school when I was 24.
- Roland:** Wow.
- Evie:** After a year and a half of teaching?
- Kevin:** Yes, which is pretty cool. It was a brand-new home environment facility up on the Murray River Cobram. That was a trip.
- Roland:** When does the adoption kick in?
- Kevin:** We'd been... I started as principal in Cobram SDS in 1979, every holiday, I'd come down. My wife and I would come down. We'd take kids out from Kingsbury where I'd taught at Heidelberg SDS. I'd take a small group of kids back up for holidays. One of those kids was Damian. Damian was the cheekiest and probably the most obnoxious little bugger you could ever come across in many ways, but he was just fantastic.
- Evie:** [Laughter].
- Kevin:** He had the quality of calling me dad.
- Roland:** He couldn't help it.
- Kevin:** Couldn't help it. I love him. We adopted him in 1981 I think it was. He came up and lived with us, we had a farm at Cobram. Then our other two daughters, so Damian was the only son we'd ever adopted. Then we had two daughters. I won't say their names, then our son, other son later. It was always interesting because we always thought Damian was going to be dependent on us for the rest of our lives. Couldn't have imagined that both of our daughters were going to have very serious car accidents.
- Roland:** Wow.
- Kevin:** And develop other disabilities. A few people can ever predict that or imagine that, that's certainly given us a different insight into what it's all about. Right now, on a personal nature and I won't get too emotional about it, I hope, but Damian who has always just been so amazing. He's just so energetic, so fit. I always thought, surely with all of his fitness, is he going to avoid the perils that other kids, that other people with down syndrome experience? No, he's 49 and he has premature dementia and all those skills that he developed over time, he's just losing them one by one. It's very sad. It's very sad. It's that... we can talk about the vision and the values and all the positive stuff about disability,

which obviously we do, but we can't forget that for lots of people, the effects of disability is fucking crushing.

**Roland:** Let's finish, we need to wind up with how you stay sane, Kevin, because we've talked about this before, but you write books, you write fiction and non-fiction books. Let's give a plug to your latest book.

**Kevin:** My latest book was: Dead to the World. My first book was: Faith. I started writing that back in 1988. Roland, you'll remember this, remember when the labour government promised that, or announced that it was going to close Kalula because of revelations of the community visitors. There was a strike. Some of us went and volunteered that night. Do you remember that?

**Roland:** Yes, I do.

**Kevin:** The stuff I saw that night was just so horrifying to me, that I went home and immediately started writing a book. I want to try and express the horrors of a place like that in a way that people out there on the streets will actually relate to it. It's not enough for just us in the disability sector to know these things happen, they won't change until we change the attitudes of the people out there. I thought, how do you go about getting these messages across to mainstream? I thought, right, I'll write a murder mystery because that's what gets out there and I wrote it, it took me a year. It was shit, so I wrote it again, and it was shit. Then I wrote it another 20 times over 20 years before I finally got it not shit, or at least in my view, and published it. It would have been 2008. That was called: Faith.

**Roland:** Now, you've gone darker?

**Kevin:** Well, Dead to the World, published, and I have to say self-published because I haven't found a publisher who actually gets my point, but people can be their own judge about that. Dead to the World.

**Roland:** On Amazon Kindle.

**Kevin:** On Amazon Kindle.

**Roland:** I want to finish up and thank you, Kevin. Thank you for a couple of things. Thank you for doing this podcast, but personally having been associated with your career for 30 years, I want to thank you for the work you've done for people with disability in the Australian community, because it's been very significant. It's been really clear through this podcast that you haven't strayed from your values at all, or not for very long if you have. Thank you on behalf of our community, as well, even if that sounds a bit corny, it's very sincere.

**Evie:** Thanks, Kevin.

**Kevin:** Sounds very corny, cheers.

**Evie:** [Laughter].

**Roland:** Thanks.

**End of Interview**

**Outro**

**Evie:** You've been listening to Disability Done Different, Candid Conversations. Created by Disability Services Consulting.

**Roland:** Emphasis on consulting there, folks, we do consulting and training, even though people still ask us, do we do consulting?

**Evie:** If someone's had enough of listening and wants to do some talking with us, how would they go about doing that?

**Roland:** They just look on the website, contact us.

**Evie:** That's [disabilityservicesconsulting.com.au](https://disabilityservicesconsulting.com.au). Links in the show notes.

**Roland:** Thanks, guys.

**End of Audio**