

Disability Done Different: Episode 17

Dougie Herd on...

Podcast transcript

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Hosts: Roland & Evie Naufal

Guest: Dougie Herd

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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.

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.

Evie/Roland: Candid Conversations.

Start of Interview

Roland: Welcome to Disability Done Different, Candid Conversations. Welcome Evie.

Evie: Welcome Roland.

Roland: And welcome Maia

Evie: And welcome Dougie.

Roland: Dougie Herd, our guest today is one of our key speakers at GYST2020 June 10 and 11 conference. So we're really excited to have Dougie on board. We made up our hit list last year of the people we'd really like to have at a conference. The people that are both informing and entertaining, and Dougie was very high on the list and Dougie said yes. So you'll be getting a taste of the sorts of things Dougie is capable of saying or talking about for GYST2020 today.

Dougie Herd has over 30 years experience in the disability sector and some of you may wonder with that thick Scottish accent, but he's mostly been in Australia. A fascinating career because a lot of it's been in advocacy for people with a disability, and a lot of it has also been in government policy development. He was there at the beginning of the design of the National Disability Insurance Scheme in 2012, 2013, playing a pivotal role. And he's been around it ever since. And one of the things we'll talk to you about Dougie is just recently getting your NDIS plan.

Dougie, why don't you tell us what you're currently doing now as you introduce yourself?

Dougie: Yeah, sure. Thanks for the invitation. I'm very happy to be here. I'm currently, have been for the last 18 months, chief executive officer of an organisation based in Canberra called Community Connections. It's been around for about 22 years and has provided disability supports before the NDIS to people with disability in their families. And like lots of other organisations has been transitioning to the NDIS since the trial scheme was launched here, I think, now six years ago, five or six years ago. I joined the agency about 18 months ago to become its chief executive officer. We provide support, coordination, plan management, and a variety of other bits and pieces, including home-share. Some of it's funded by the ACT government, but most of it, 90% is funded through the NDIS.

Roland: I'll just jump in straight away Dougie, one of the things we're going to be talking a bit about with you is your career, a really interesting career. A lot of it is activist, and a lot of it is as a policymaker, working in government, but you seem to studiously avoid being a service provider for an extensive career. And now you find yourself as a CEO of a service provider. How did that happen and how does it feel?

Dougie: They asked me if I'd like to take the job on and I said yes. But I'm only halfway into service providing because we do support coordination and plan management. We're an intermediary organisation, a member of Disability Intermediaries Australia, the new national peak body for intermediary organisations. But I also remember a politician's chief executive officer, chief of staff, once said to me when I was previously asked if I would join an organisation, a government organisation, and I said, oh no, it's not really my thing. I don't really do service provision. As for other people, and he said, yeah, well that's the easy answer because all the hard stuff is in service provision, so why don't you come in and do a real job. He was joking of

course. But you know, my 18 months here have certainly proved, it isn't any easier in the service providing sector than it was in the advocacy sector, because you've got to come up with some of the answers as well as some of the questions.

Roland: I wanted to ask you a question about advocacy too. I'm going to let Evie jump in in a moment, but from what I can see of your career, it's pretty evenly balanced. You've done a stack of significant advocacy work across Australia and even back to Scotland, but you've done a stack of government policy development work. So you've seen both sides of the fence. Could you give us some tips about what works for advocacy? What really, you know, coming forward when you're sitting in government, where are advocates most effective and how can they get the change that they want achieved?

Dougie: Well, I wish I knew the answer to that question. All I know is, my advocacy begins with my own experience, it always has done. And that was true before I became a person with a disability. And it certainly has become true since I had my accident 36 years ago. And so I broke my neck in three places on a beach in Scotland, not swimming, but almost drowning to misquote the poem. And I spent 10 months in hospital, and that was a joy. But even there, I encountered power systems. They wanted to tell me how to behave. And before I went into hospital, I wasn't told by anyone how to behave, not since my mother let me go to university.

And so I began advocating for myself inside the hospital, joined with others to advocate for hospital regimes to be changed. And just kept on advocating for people with disability because I was in my, kind of fundamental principle it is not an original idea by me of course, is that you use whatever tactics you can to get the best result for the people on whose behalf you are advocating. Do everything you can to produce change and be unambiguously on the side of the people that you're advocating for. But always remember the people against whom you are advocating or to whom you are taking your advocacy are human beings working in a human being system. They're flawed like all the rest of it. So I prefer not to kick people's heads, but to try and persuade them that we are right and they might want to change and listen to us. And I've been doing that forever.

Roland: You were an activist before you had the accident, as you said, you were a student activist across a range of issues. You have an accident and then in your own words, more or less, you're saying that your activism doesn't stop, the subject matter changes. And the subject matter changes to disability. And I always struggle with this and I want you to help me with it, in the sense of, you're a person with a physical disability and you're doing advocacy for a highly disparate different field, which includes people with intellectual disability, people with mental health issues. Tell me why as a person with a physical disability, and I know there are some really good answers to this and I'd like to hear them. You have the imprimatur to speak on behalf of that group.

Dougie: I try not to speak on behalf of anybody. I really do. Although sometimes I forget. But that's just because I'm enthusiastic to speak. And I think in the world of disability it's a real problem, I mean, I think anyone who spends a nanosecond looking at the sector can see that there has always been and there remains still a hierarchy. And people like me, you know, white, Anglo-Saxon, protestant males in a wheelchair. We're supposed to be the cutting edge age in leadership of the movement. And in some places at some times, men of my type have made fantastic contributions to the movement. But sometimes we've also liked to talk to ourselves about, you know, we

need wheelchair-accessible buses. We need steps to be out of the way and all the rest of it. And that of course is important, but I think we need to do everything we can to build a diverse, genuine movement that brings people together, respects one another and listens to what one another has to say. And that for some people, the seeing of what is important to them can take time, maybe carried out in ways that use different language, different ways of communicating, and have different pressures placed upon them. And we just need to build something that is fully inclusive of everybody. And we haven't got that, still haven't got that right in our disability movement. But that doesn't make a bad place to be, you know. But it's a challenge at times, shut up Dougie and listen to other people is what I think, because people have got tons of things to say.

My experience of being an advocate, being involved with people with disability is, I have never met someone who didn't want just to be normal. And the injustice is that people with disability have to fight to be treated just exactly the same as everybody else. I've never met a person with disability that wants to be king or queen of England. They just want to get up, go to work, pay taxes, go home and have fun at the weekend. And yet for some reason we're not allowed to.

Roland: I think that gets back to my slightly awkward question about how does a person with a physical disability advocate on behalf of a larger group of people? And I think you're bringing it back to that sense of otherness is spot on Dougie.

Evie: Yeah I think you're spot on.

Roland: Well, I want to ask another personal question Dougie. So years ago I worked with parents of kids with disability, and I was so amazed by their ability to adjust to sometimes extreme adversity. Sometimes those parents wouldn't sleep for 20 or 30 years and they still had a sense of humour, they still got on with life. I want to ask you about pre and post-accident, if that's a reasonable thing to do and feel free to say it's not. Is it true that you can be just as happy, you described yourself as a C6 quadriplegic. Is it possible for a person who is a C6 quadriplegic to be as happy as a person without that disability?

Dougie: Yes. Completely possible. And yeah, I'm a Scottish Presbyterian and we're never happy with anything. But I think people's happiness derives or unhappiness derives from their social condition, the economic wellbeing and that ability to form human relationships. And those are all the things that are constrained by poor policies towards people with disability and bad attitudes. I broke my neck in three places. I almost died. I spent 10 months in hospital and I had to completely reconfigure my life. Not because of anything to do with me, something's to do with me, but primarily because of other people's attitudes towards me that changed. And I think, well, you know, when people didn't offer me jobs, when I couldn't get a taxi because there weren't any wheelchair accessible taxis, there weren't any wheelchair-accessible buses. I was asked three times whilst in hospital to go and live in a group home with people I'd never met before in my life. And to this day never understood why I was asked to do that. But the barriers I have encountered in my mind are nothing to do with Dougie Herd, because I was Dougie Herd the day before I had my accident, and I was Dougie Herd the day after my accident.

And here I am 36 years later and I'm Dougie Herd. And I think that's how people with disability usually feel inside, that they are the person that they are. And that the thing that creates what we now call psychosocial disability or stress or anxiety in people

who've got a disabling condition of some sort is the way other people treat us badly. I like to say this, but it does prove a point. I was supremely happy as a C6 quadriplegic when I was sitting in the Maracana football stadium, at the final of the 2016 World Cup watching Germany play whoever they beat, Argentina in that cup. I've always as a Scottish boy wanted to go to the World Cup. But the point is, it didn't matter to me that was a C6 quadriplegic. I was just a wee boy, 60 something years old sitting in a football ground that happened to be in Brazil watching a football match. And I wish that joy could be had by everyone with a disability because nobody cared about my disability.

Roland: You're taking this very much into NDIS land and about economic security and the sorts of things the NDIS provides, and you've got a really interesting career. You've worked as a ministerial level advice. You've worked with advocacy organisations, you've worked in departments, but I met you in 2012 when you were at the pointy end of the creation of the National Disability Insurance Scheme. And there was so much going on. Canberra was crazy as you well remember with FaCSIA as it was in those days trying to get this new scheme up, and people were running around like headless chooks because it was happening a year earlier than anybody expected. Did it go too fast? Did we stuff it up in that first year?

Dougie: That is a very complicated and difficult question to answer. But perhaps not for the reasons that you might intend. Because I think operationally, it's happened. If you look at how the NDIS has developed, \$22 billion project with half a million people and their families to benefit from it. If you look around for a comparable reform inside the government, I think it's very, very difficult to find anything that big that happened that quickly. And so it's no surprise that, what some people euphemistically refer to as teething problems still exist, because we're only in year six. Sometimes those teething problems are considerably larger than that, but here's I think the political conundrum that we're in.

I think if the development phase had taken any longer, I think there's a real risk that we might know have got the National Disability Insurance Scheme off the ground. And I mean no disrespect to any of the politicians who voted for it, some of whom did remarkable work. You know, Prime Minister Gillard, you know, the minister. Even the opposition to be fair, if one must, to the former Tony Abbott. But they did terrific work. But I think if there had been much longer debate about whether or not it was a good idea, I think business as usual may have kicked in and we might not have got the scheme up and running.

Roland: Well let's go somewhere else because you were doing a lot of work and have done a lot of work around communications. And I think it's fair to say the NDIA is a case study in how not to communicate, and now you're outside of the agency, can you make some comment on why they've got so much so wrong so frequently?

Dougie: So I have to put my hand up and say, I must bear some responsibility for that, because for nearly two years I was the branch manager of the communications and engagement section of the agency. So, you know, when people look at the website, they're looking at one that my team initially designed in six weeks. Because you remember how fast it was all moving. You know, a whole lot of stuff that I would take a personal responsibility for. But I think some of the difficulties of, just remember the NDIS is a \$22 billion startup. It's bigger than most startups most of us can think about. It was always going to be a challenging project to launch and get going. And

therefore there would be things that needed improving as we went along. So that's fine.

I think the problems that we're now facing in, because another thing I should say is I'm on record as saying since I, you know, there was a parliamentary inquiry here about a year ago in the ACT into the relationship between the agency, the NDIA and the territory departments, because they're not functioning properly. And I went out of my way to say that I thought that the task my former colleagues were doing in the agency was heroic in trying to get the scheme up and running. But the problem, one of the fundamental problems that no startup should have to deal with was the government's decision to impose a cap on the staff of the agency, because it has distorted everything that then flowed from that. And we're only now beginning to see a bit of a realisation in government's part that that cap skewed everything so much, created unintended consequences that we're now having to roll back from.

And so was it the recent Tune review begins to see. Yeah, it was always the intention of the scheme always, even during the period I was working for the agency, always the intention that there would at the heart of the scheme would be an NDIA planner sitting down with an NDIA participant having a conversation that would lead to a plan, that would be funded and then implemented. And here am I, six years later, only been in the scheme myself for about four months at the very most. And I have no idea who made the decision about my plan, I didn't write the first person letter that says this is my plan. I own it. These are the things that I want to do. And I didn't take the decision, never met the person who took the decision about my plan. And that's just fundamentally wrong in terms of the legislation. How can you have choice and control over a process if you've never met the person who makes the decisions about how you're going to live your life.

Evie: Dougie, you mentioned the Tune review and the planning inquiry that's happened, 2020 is already shaping up to be a huge year in terms of policy reform for NDIS. I'm wondering, what are you seeing as being the biggest changes on the horizon that providers in particular should be looking out for?

Dougie: Well, I think providers should look out for what they were always meant to look out for, and myself included as a provider is, the fundamental point about the NDIS. It's become so clichéd in our thinking now, is that the people with disability at the heart of it should exercise choice and control over the reasonable and necessary supports that they receive through funding, and that all providers should absolutely place people with disability participants at the heart of decision-making. And that has to begin going back to the agency. The agency has to get back or get maybe for the first time really, to putting people with disability at the centre of decision-making.

Evie: But will they, do you see that that's being indicated in any of the inquiries that are occurring right now?

Dougie: Well, I said earlier that I can be a happy person, I also sometimes slip into being slightly cynical. And forgive me if this sounds like the more cynical Dougie coming out. Amongst the many criticisms I would have about the whole environment around the National Disability Insurance Scheme is that for a scheme that is only entering its six year, it has been reviewed, researched, discussed, considered like permissions and parliamentary inquiries more than any six year old organisational child ever should have been. And the really, really concerning thing is, that I think many of the recommendations of the second productivity commission report, the ACT legislative

assembly committee report. The other reports that have been done, have been paid lip service to by the government of the day, or I'm afraid the agency, if they find them inconvenient. And I've got a real concern that the agency finds it difficult in the current environment to just accept what is recommended should be done as the best way to proceed. And the reason I think I can legitimately express that concern is because there is at least one administrative appeal tribunal decision on transport for people with disability who need access to work, that the agency has just ignored.

Evie: Totally ignored, and in fact worse than ignored. What you're referring to there is the AAT versus McGarrigle, and the way that that played out, just for those of you who may not have memorized AAT history like we have, is that there was a young man who was awarded at least 10,000 I think it was around \$16,000 of transport funding. Don't quote me on that figure, either way, it was a lot more than what most people get to travel to and from work. The AAT originally said that only part of the cost had to be paid, and so he lost to the AAT. It was escalated to the federal court where he won. And so you know that now obviously overrules the AAT decision, but not only have the NDIA not followed the federal courts ruling, which said that any reasonable and necessary support should be fully funded. On the website they quote the original AAT decision saying that they will only partially fund some reasonable and necessary support. So if that's not, I mean cheeky is a really understated way of putting it, I don't know what is.

Dougie: Well, it's more than that. And forgive me if I sound like a smartarse, which I do sometimes. I was arrested by the police. It was in an anti-apartheid demonstration when me and some friends ran on to the pitch of a rugby game in Scotland trying to prevent the game from going ahead. Because at that stage Nelson Mandela was still in jail. And I was arrested and spent a night in jail and appeared in court the next day and was fined 50 pounds, which was a lot of money when you were a student in those days, for breaking the law. It would have been inconceivable that I could have said to the judge, well thank you very much judge but I'm just going to ignore you. I'm not going to pay the 50 pounds, and I'm just going to go home and get on with my life. I was brought up to believe that you didn't break the law and you did what the judges told you. And it's disappointing to say the least that the agency doesn't seem to have to do that. And if I'm wrong, I apologise to the agency, except I think I'm not wrong.

Evie: Yeah, it's an interesting way to put it. I want to go back to the Tune review for a second. And I want to ask about one specific point that was raised in the Tune review. You and I both sit on the board of Disability Intermediaries Australia, DIA, which is the peak body for support coordinators and plan managers. But particularly for independent support coordinators and plan managers. But Dougie the question I want to ask you is that the Tune review raised the point that the support coordinators should not be working for organisations that also provide other supports to the same individual. And it made a recommendation that that should be reviewed. Now I'm wondering what you have to say about that as somebody who runs an organisation that is an independent support coordinator and obviously has a lot of interest in the sector more broadly.

Roland: So a conflict of interest issue?

Evie: Yes.

Dougie: Well, Community Connections for whom I work is absolutely clear that there should be a formal separation between work like support coordination and plan management

and direct support provision. And that sometimes, perhaps most times the potential conflict of interest can be so great that it creates difficulties for both support coordinator and for the participant if people find themselves recommending their own support staff. And I think I can say with some kind of practical experience here that Community Connections took that seriously enough that when the NDIS was established some of what it was doing, this is long before I arrived here. It was doing kind of traditional support work for some people as well as case management or whatever it was called. And in the early years of the scheme, Community Connections created an entirely separate company, with its own board, its own membership, its own staff. And they go off and, you know, they do the support work, and community connections does its support coordination and plan management work. And that separation needs to be absolutely clear for everybody to see.

Evie: It is going to be a controversial change though, isn't it, like it's certainly going to be, it's going to meet a lot of resistance from a large part of the sector, and some of that resistance will be really valid. Like when we look at people in really thin markets, remote areas, people who find it particularly hard to find providers to work with them. You know, we're going to definitely see some resistance there. So it'll be interesting as we see the NDIA's response to the Tune review, how they, if they indicate how they'll approach that.

Roland: They actually implemented it back, you'd remember Dougie back into 2015, 2016 sometime it was, you could not be a support coordinator and a service provider and back down on it within a week or two, because they realized how many problems they were going to have.

Dougie: Yeah, and so I probably want my cake and eat it here, because I think separation is critically important, and the point you're making about thin markets particularly, but in other circumstances, I think the practicalities of living particularly outside the big Australian cities, but not just big Australian cities. So for instance, here in Canberra, you know, Capital of the country, 500,000 people we are trying to find behaviour support practitioners for some of the people we do support coordination. We're flying people in from Queensland to do this work, because if you want a Canberra organisation with skill and practitioners who meet the NDIS commission new arrangements, they tell us we can't even see the person that you're coordinator for at least three months. And one or two people or organisations have said, come back and see us in a year. And that's happening in Canberra, what's it like in Broken Hill or Bendigo or anywhere in Western Australia that isn't Perth.

And so where those kinds of thin market questions pose real practical irreconcilable problems the key has to be that the transparency about the relationships is crystal clear and upfront so that people can make whatever quasi compromised decision that they need to make. But only through that kind of caveat I think, that of transparency and openness, can people have any chance of maintaining choice and control.

Roland: I don't think anybody has ever really grasped including the original productivity commission work on it, the complexity of disability, have they Dougie, that there's no simple answers in this stuff, it looked like a market-based scheme, although a lot of people were sceptical before the market base scheme would work. But it misses the point in so many different ways, using a market to create opportunities for people with disabilities. And then pure policy that looks so clear. You know, there's a conflict of interest in being a support coordinator and a service provider. Let's stop that. The really negative outcomes that can result in lots of areas by doing that, it's just, and

you've been in policy long enough to know it's freaking hard to get those nuances right. So.

Dougie: And the longer we take to get them right, the greater the risk is that bad practice, if that's what it is, will be kind of enshrined in the kind of DNA of the organisation forever.

Roland: And the more we rush, the more we'll stuff it up.

Dougie: It will be so difficult to get back to the founding intentions for the scheme.

Roland: Which is one of the questions I wanted to ask you Dougie. So going back to 2012 when it was all, we weren't even sure it would happen, and now it is, are we getting there?

Dougie: Oh yes, we're definitely getting there. I mean, that's part of the contradiction of all of this, which is that, I mean I do accept that for many people there have been improvements, genuine improvements in their lives as a consequence of the scheme. But for a substantial number of people, it still remains a really problematic environment in which to try to live one's life. And you know, and we mentioned, we talked earlier about, you know, well I talked earlier about white guys with beards in wheelchairs. Generally we have the easiest path through the NDIS. And the people that we support through community connections, it's pretty clear that people with a psychosocial disability, with an intellectual disability or somewhere on the autism spectrum, then those people struggle with the NDIS much more than people like me do. And I think that's a reason why the NDISs current default approach to support coordination and other intermediaries is the wrong one.

Because the thing that also is forgotten about the NDIS is we've got used to the idea about talking about people inside the NDIS as being, you know, more or less complex. And the system seems to have forgotten that unless you qualify to meet the old ABS terminology of severe and profound disability, unless you're among the most complex diagnostically group of people with disabilities in the country, you can't even get into the NDIS.

So everybody who comes our way lives complex, fraught lives, almost all of them on disability support pension, who need support just to navigate the system. And we haven't got that balance right yet between the participant, their allies and supporters and the whole big system. And we don't want to create another big bureaucratic system. And sometimes that's what it looks even more like we're heading too.

Roland: So Dougie, I just want to explore something again, you were saying that people like yourselves, that articulate people are doing much better under the scheme. I saw you in 2012 in a senior role working on the design of the scheme. You've been seen around the scheme now for seven years and you got your plan four months ago. What's the story there?

Dougie: The truth is I'm not very good with paperwork, but here's another thing. This is going to sound really wanky to be honest, so forgive me. So I'll try and explain it this way. I got my plan, well two things. It took eight months for the agency to approve my plan, which is shockingly bad operational behaviour, completely unacceptable. And I let that eight months run because I just wanted to see how long it would take. But you have to be I think, a chief executive officer of an organisation getting paid a decent enough salary to not have to worry about the financial consequences of waiting eight

months. I didn't think it would take them eight months. I thought four or five and I can still make a smartarse political point. But eight months was certainly a joy to my political advocacy ears.

But, the plan when it came back really isn't that good. And I know it's not that good because I read the NDIS quarterly reports, and I see that on average, people with a spinal cord injury get a higher average package than anyone else, any other diagnostic group in the scheme. And mine is not certainly above average. And some people say, well, why don't you go and appeal and review and all the rest of it. And, I might have done if it was somebody else, but part of my job is to help prepare people to review and do all those things they want to do. And I just kind of thought well, you know, they need it more than I do. So, you know, I'm doing all right. I'm comfortable. I can get by. And, so it just wasn't a priority.

And here's another thing that I have to say, because it's true, but also because I think it's a reality of the lives that people with support needs are forced to live. The support I get from the National Disability Insurance Scheme is amongst, it's close to being the first-ever funded support I've ever got from a government organisation for my personal care and other matters. And that's because, to be perfectly Frank, I would like to live my life without people come in through the door at six o'clock in the morning, seeing me naked, helping me shower, evacuate my bowel and get me ready for work. Because my brain tells me, you just want to be yourself Dougie, you just want to be on your own. You want to live a private life and make choices. But when you've got a disability that, what I regard as a luxury is no longer available to you, so I've just delayed it as much as possible. But I'm getting old, if I had not have joined the scheme now I'd have been too old to join the scheme. Getting my new wheelchair in a few weeks I believe, it's fantastic. The NDIS is a wonderful thing and it's completely problem-free, or not.

Roland: Probably a perfect note to end on.

Evie: Yeah. Dougie thank you so much for speaking to us today. What we're trying to do with our conference in June, which you'll be speaking at, is to try to be really future-focused and not be dwelling in the problems, but at the same time to be quite realistic about the context we're working in. And I think this conversation has been perfectly striking that balance, you're such an entertaining speaker.

Roland: Thank you very much Dougie.

Dougie: Thank you very much.

Evie: You've been listening to Disability Done Different, Candid Conversations, a podcast by DSC. If you want to learn a little bit more about us, you can head to our website, disabilityservicesconsulting.com.au or if you want to sign up for that conference, the website is GYST2020.com.au.

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Maia: And just before you go, if you have an extra five or so minutes to spare, we decided to keep in an additional conversation we had with Dougie that we thought deserved some airtime. So this is Dougie on Mary Shelley and the apocalypse. Stick around, I think you'll enjoy it.

Roland: So most people don't know Shelley's most famous book is Frankenstein. So tell us about your thesis in that space and connect Mary Shelly to the discussion we're having if you can.

Dougie: Well, I graduated from the ANU about a year ago with an honours degree in English literature. And Mary Shelley was absolutely central to my thesis, which was about post-apocalyptic fiction. Mary Shelley is really important for other reasons, particularly in the context of writing about and reading disability narratives, because she's the 18 year old writer who gave us Frankenstein's monster. The nameless creature created by Baron Frankenstein.

I think many of us, by which I mean people with disability and our allies don't see Baron Frankenstein's creation as, oww scary the monster. I think we see him as different certainly, and the other for sure. And he's regarded as a less than perfect form of the idealized notion of the perfect human being, a bit like myself I suppose. I just don't believe that any of us is perfect and there's no such thing as normal. So I guess that puts me on the outside, on the same side as the monster, imperfect in body, soul and mind.

But you know if the alternative is being Baron Frankenstein, then to be honest, I'm quite happy to be on the outside, to be one of the others, to be out there advocating with the rest of the world's imperfect creatures.

Evie: I just want to come back to the theme of apocalypse here, because I'm so curious, where as you said, we're experiencing a time with these extreme climate change related events. We're potentially on the brink of a global pandemic. I'm certainly one of these peoples who gets really swept up in the panic of a lot of these events. But I'm just curious Dougie, as someone who's spent as much time thinking about apocalypses as you have, how does all of that impact your experience of the current events?

Dougie: Yeah. I am an eternal optimist, and I believe, not an eternal optimist, actually that's not true, because science tells us that eventually everything comes to an end, including one's own life. The world in which we live, physics tells us it won't be here in like 8 million years time. I'll have been long gone by then. I think that the time we're living in, for me, is a time for activism. It's a time for people to come together and recognize what binds them, rather than what separates them, whether that be race or class or disability or gender or sexuality or whatever it might be. And that ordinary everyday people have both a right and a duty to come together and say to the people who are in power, we will not live our lives in these conditions. I mentioned earlier about, you know, working near the more Monash air quality station, which registered an air quality level of, poor quality level of 5,000, which was 27 times the hazardous label. And they came in to work last week when the new Canberra fire was burning, and the air quality level for some reason was only down about 400, which is twice the hazardous label. And I find myself saying to myself, well at least it's not as bad as it used to be. And then I thought, wait a minute, it's twice the hazardous level.

And it's funny, ironic, but kind of, it's a cautionary tale in my mind that our capacity to get used to things being bad is quite impressive as human beings and we tolerate and we work together to get through adversity. But striving against adversity I don't believe is the natural human condition, I think we should work with one another to make things better. And in the disability world, that means recognising who we are and where we come from and what are our experiences, and respecting the

differences that we've all had, and saying, okay let's fix a problem. And some of them we'll fix and others we won't. But I remain eternally optimistic about our ability to make change. You know that thing that Barrack Obama was always famous saying, that the ark of human history tends towards social justice. I believe that, except sometimes it takes longer to get there than i want, and that just says to me, we've got to be, here comes the 1970, I wanted to be a hippy young man. I think we've just got to seek love and peace and work together and make the world a better place.

End of Interview