diHARD Series 1 Ep 6 PODCAST DISABILITY

[CJ] (0:00 - 0:18)
We at diHARD acknowledge the traditional owners of the land from which we broadcast, the Yalukit-Willam clan of the Boon Wurrung people of the Kulin Nation. We pay our respects to elders past, present, and emerging, and Aboriginal people who are listening, as well as all Indigenous peoples who may be listening from other nations. We acknowledge that sovereignty was never ceded.

[grab voice] (0:24 - 0:25)
What a day.

[grab voice] (0:25 - 0:29)
You just can't ask me your questions. You wouldn't hurt a guy in a wheelchair. Not that question.

[grab voice] (0:29 - 0:33)
But I would hurt a guy with his wheelchair. But you're black-ish.

[grab voice] (0:33 - 0:42)
Ish? They're just people, James. They're just people exactly like us.

Oh, you's a guy. No, I just don't identify as male or female. Not a girl.

[grab voice] (0:42 - 0:42)
I'm not a girl.

[grab voice] (0:42 - 0:45)
What about that are you still not getting exactly?

[grab voice] (0:45 - 0:46)
Well, obviously the core concept.

[grab voice] (0:47 - 0:49)
Hey, you want straight answers, ask a straight lady.

[grab voice] (0:49 - 0:52)
By the way, everyone here thinks I'm Taiwanese. I'm Filipino.

[grab voice] (0:53 - 0:54)
I'm actually racist, Orlaf.

[grab voice] (0:54 - 0:56)
Your dad left your mom for another dude.

[grab voice] (0:56 - 0:58)
I am not a homo, homopebic.

[grab voice] (0:59 - 1:00)
Have you been checked for ADHD?

[grab voice] (1:00 - 1:04)
I've had several STDs, which were probably caused by ADHD.

[grab voice] (1:05 - 1:11)
Imagine shutting up. Thoughts? Fasten your seat belts.

It's going to be a bumpy night.

[Grant] (1:12 - 1:14)
You're listening to diHARD. Diversity.

[CJ] (1:15 - 1:16)
And inclusion. The hard topics.

[grab voice] (1:17 - 1:18)
Shut up, it's starting.

[Grant] (1:19 - 1:29)
Good evening, everyone. And welcome back to diHARD. Diversity and inclusion.

The hard topics. Tonight, of course, we're your hosts, CJ and Grant.

[CJ] (1:29 - 1:30)
Good evening.

[Grant] (1:31 - 1:36)
Now we've got a very special episode this evening where we're talking all things disability.

[CJ] (1:37 - 1:43)
Yep, it's very exciting. Very close to our hearts in many ways. It's one of the parts of our intersections for both of us.

[Grant] (1:43 - 1:47)
Yep, yep. We've both got very different types of disabilities.

[CJ] (1:47 - 1:47)
Absolutely.

[Grant] (1:48 - 2:07)
And the way it affects our lives are very different. The way it's presented throughout our lives are very different as well. And I think that's one of the big things that we'll be covering this evening is just how diverse the concept of disability is and how it means something radically different to each person.

[CJ] (2:07 - 3:01)
Yep. So when I was preparing for this show, I was sort of looking at, you know, as I usually do, you look up the definitions. We have a bit of a laugh sometimes because some definitions are ridiculous.

My favourite thing about looking at the World Health Organization's statement on disability, the first bit just says disability is part of being human. And I appreciate that because dehumanization of people with disabilities is not an uncommon thing. So I love that opening sentence right there.

And about, well, they say about 1.3 billion people in the world at any one time has a disability, whether it's permanent or temporary, which is about 16%, or one in six, to put it in perspective. So if you're in a room with 10 people, at least one person, if not two, will have a disability of some sort at that time.

[Grant] (3:01 - 3:08)
And people can acquire a disability at any point in life as well, which kind of makes it a rather unique topic.

[CJ] (3:08 - 3:32)
Correct. Because a lot of other things you're sort of born into, like you're born in a certain country, you're born into a certain religion, you're born, say, Aboriginal or not. But with disability, you can be born with a disability, but not everyone is born with a disability.

So, and there's different challenges with being born disabled versus acquiring a disability as well. And then whether your disability is visible or not.

[Grant] (3:32 - 3:55)
100%. I actually kind of think it's funny. There was a, I wish I could remember her name.

There was a comedian I saw on Instagram. And they were talking about how the LGBTQIA+ community can often have an agenda, whereas the disability community doesn't have an agenda. But that's actually not right.

[CJ] (3:55 - 3:55)
No.

[Grant] (3:55 - 4:02)
Because if anything, we do have an agenda because we know how limiting society can be when it comes to disabilities.

[grab voice] (4:03 - 4:21)
Okay. I am disabled. Yeah.

You're going to be okay. Actually, fun fact, the disability community is the only minority that we will all join at some point in our lives.

[CJ] (4:23 - 5:08)
Tonight, we have some amazing guests with us. Two people who have disabilities and have very different disabilities. So we're going to hear two very different voices.

We have Kath Duncan, who uses she/her pronouns. Writer, researcher, super freak with a background in electronic journalism. Kath has written news, unusual features, live comedy, nude disability and amputee fetish performance.

Kath has degrees in arts communication, sound extension, a BA in honours in creative writing, a master's in writing. Kath produced her own one-woman show, High Heartbreak, in 2016. Led the Australian Research Council project, The Last Avant-Garde.

Kath's also won the 2020 Creative Australia Ros Bower Award for community arts and cultural development. Welcome, Kath.

[Kath] (5:08 - 5:11)
Yeah. Hi. It's really hard to hear a lot of stuff about yourself.

[CJ] (5:12 - 6:02)
It is. We've got Jasper here. Jasper's pronouns are he/him.

He's a 36-year-old gay trans man and is deafblind and has a bunch of mental health issues. Was raised by a single mum who was a Jehovah's Witness and posed significant barriers to exploring and finding language for his own identity. Jasper grew up in Adelaide but became increasingly isolated, which was having a huge impact on his mental health.

So moved to Melbourne to have more access to support and community. Has had some amazing opportunities to connect with Deafblind community in Melbourne now. Works part-time with DeafBlind Victoria and has also started seeking more opportunities to connect with the queer community.

Jasper says he's usually a lot more open about being gay than about being trans and still has a lot of fears about how open to be, both because of physical safety and fear of rejection, which is really reasonable and that's how a lot of us feel in the queer community. So welcome, Jasper.

[Jasper] (6:06 - 6:11)
Hi, thank you for having me and giving me an opportunity to share my experiences.

[CJ] (6:12 - 7:21)
Well, it's wonderful to have you here, Jasper. And people may be perplexed at this point because I've just introduced Jasper and said how Jasper's deafblind and then Jasper's just spoken into the microphone and that is Jasper's voice that you're hearing. So we do have an interpreter here that is using deafblind fingerspelling on Jasper's hand.

So there are different degrees of deafblindness. So not everyone is like fully deaf and fully blind, which means they can't see or hear anything. And not everyone that's deafblind can't speak, the same as not everyone that's deaf cannot speak.

So some people have what we call a deaf voice, which is a little bit of a different sounding voice. And some people have a voice that you would expect to hear coming out of anybody else that has no disability or impairment at all. So one of the things we do with deafblind community and blind community is we describe ourselves when we introduce ourselves.

So my name is CJ. I am a woman with long brown hair and today I'm wearing a long blue dress with short sleeves and it has lots of different colours across the middle and the bottom of the dress.

[Grant] (7:21 - 7:39)
I'm Grant. I have no hair on my head. I'm bald with a fairly large beard that goes down to the centre of my chest and I'm wearing a dark green top, beige coloured shorts and I have a lot of traditional tattoos covering my body.

[CJ] (7:39 - 7:42)
And Jasper, if you'd like to describe yourself.

[Jasper] (7:45 - 8:10)
I'm Jasper. I've got a little bit more hair than Grant. By the sounds of it, a less impressive beard.

I'm wearing sunnies and because I'm still very concerned about COVID safety, a face mask and rainbow earrings, a white t-shirt with a big red heart on the front that says "hug a homo".

[CJ] (8:11 - 8:15)
And Kath, would you like to describe yourself for us?

[Kath] (8:15 - 8:39)
Yes. First, I'm an iced latte fiend. So this sound, that's me. *ice clinking in glass*
It's a very full latte. It's super gorgeous. I'm in my early 60s.

I'm short and round. I've got curly hair that's always a weird colour. At the moment, it's sort of pinky purple.

I'm wearing sunglasses inside as well because it's kind of bright in here. Great views from here actually. It's all kind of like trees.

[CJ] (8:40 - 8:41)
This is why we call this studio The Tree House.

[Kath] (8:42 - 8:47)
Oh, get out. Oh, sorry about that with the ice latte. I will try and keep it just to a low burble.

[CJ] (8:48 - 10:19)
And we also have Silent Jack in the studio who many of you know exists. Silent Jack won't be describing himself. Silent Jack is also a middle-aged man with sort of salt and pepper black-grey hair and a matching beard, but it's a short beard.

And he's wearing a red t-shirt with Save Ferris written in black writing, big bold capital letters and a pair of very boring black pants compared to their t-shirt. So now that we've done our visual descriptions, one of the other things I'd like to share is DeafBlind Communication. When I was doing my Diploma of Auslan, I was taught that at that time, there were 12 different types of DeafBlind Communication or Deaf and/or DeafBlind Communication.

So there's Auslan, which is our Australian sign language, but there's also Tactile or Hand-Over-Hand Auslan, which is where you're still signing Auslan, but the person that you're communicating with has their hands on top of yours so they can feel the signs if they don't have the vision to see the signs. There is tactile fingerspelling, which is what Jasper and his interpreter are using at the moment. I'm not going to remember all 12.

The other one, which was more so used before sign language was more formalised, I believe, and someone can correct me if I'm wrong, you can email me and tell me off, is Family Sign Language, where families would have their own sign amongst their own family group. So yeah, that's the multitude of ways that we can communicate with blind, deaf and DeafBlind people.

[Grant] (10:20 - 10:35)
And what you'll be hearing initially is there will be pauses for the translation when this first goes to air, but as the episode goes on, we will be cutting those out, which is why the responses will get faster as we move through the show.

[CJ] (10:35 - 10:51)
So we'd just like to give you a feel of what it's like to be in a room working with an interpreter. And yeah, it's just so you can appreciate how easy it is to communicate and put these things in place where we can open up access and communications. And that's really important.

It's part of why we're here.

[Grant] (10:51 - 10:57)
Talking about the way disability affects everyone very, very differently.

[SONG] (11:19 - 11:35)
I'm Deaf by Sean Forbes
(13:43)
END SONG

[Grant] (13:46 - 14:05)
Welcome back to diHARD Diversity, inclusion, the hard topics Jasper, what are some of the unique issues that you are met with when it comes to navigating the DeafBlind community as well as your queer identity?

[Jasper] (14:06 - 15:55)
I find because the DeafBlind community is mostly an older community a lot of concepts can be new to people in the DeafBlind community or they've been, even some of the younger ones have been quite sheltered and so sometimes I'm not really sure if I'm comfortable talking about my queer identity or how to raise the topic. Having a Jehovah's Witness mum it added a lot of challenges to explore my identity and even find the words to express anything about my identity Always having very low vision was like, well, I know girls wear dresses and I'm being forced to wear dresses and I don't like it But not being able to look at boys or look at men's clothes if we walk past them in the shops and so at the age of about 10 I was like, "so mum, what do boys wear?"

And then trying to explore that was really difficult for me and I faced a lot of judgment and so then I just tried to go quiet and fit in and I didn't hear of the word transgender until I was about 21 then I was just like, holy shit there's actually people who exist who share how I've been feeling since I was a kid. There's actually a word for this. There's actually a process where I can do something to match who I know I am.

[CJ] (15:55 - 15:59)
Wow, that's amazing That must have been so exciting for you

[Jasper] (15:59 - 16:00)
Yeah, it was

[Grant] (16:00 - 16:26)
I know for me, I grew up in a very religious family and I was sent through what was called a conversion therapy program and it's taken me a long time to build a good relationship with my family since going through that. How has your identity affected relationships, be it family or friends that you grew up with?

[Jasper] (16:27 - 16:56)
With family, I had a lot of concerns about openly coming out. It took me a year after coming out in all my social settings as trans before telling my mum. It took her quite a while to stop dead naming me and mum's known since 2011. Just over two years ago was the first time she introduced me to someone as her son and I told her how happy that made me feel

[Grant] (16:56 - 17:07)
It's rare for that to actually happen within some religious community group so it's so heartwarming to hear that your mum introduced you as her son

[grab voice] (17:07 - 17:12)
So shines a good deed in a weary world

[Grant] (17:12 - 17:22)
Were you ever concerned about how coming out as both trans would intersect with your DeafBlind identity?

[Jasper] (17:22 - 18:00)
Well maybe something I should have explained about myself earlier I grew up blind but then I started losing my hearing as a young adult so I didn't realise that that exact intersection would be a thing I'm not sure if this is going a little bit off track Being trans comes with, for some people who need to take that route can come with a lot of medical expenses and as someone with disabilities I have less access to earning money Fortunately I have a job now but there was a long time where I didn't

[CJ] (18:00 - 18:21)
And we need to point out as well that the job that you have is within the DeafBlind community so whilst it's wonderful you have a job it's because the DeafBlind community created jobs for their own rather than you being able to go and get a mainstream job which you would be equally qualified to do if people were patient and accommodating of your DeafBlindness

[Jasper] (18:21 - 18:41)
Absolutely, I mean the only other paid job I've ever had was in a factory that was set up specifically for people with disabilities and it was a terrible working environment and I definitely wasn't saving much money when I was working there because I was only getting $6 an hour

[CJ] (18:41 - 18:43)
That's appalling, seriously

[Jasper] (18:44 - 18:50)
And then I got fired because I put in too many complaints about sexual harassment including from supervisors

[CJ] (18:50 - 18:55)
That's just foul

[Grant]
Yeah

[CJ]
I'm not surprised sadly but it's foul

[Grant] (18:56 - 19:09)
I'm not 100% sure on the statistics but I know there is a huge issue with sexual harassment and the disability community Do you know much about?

[CJ] (19:09 - 20:30)
I don't know the stats but especially with people who have communication differences so people with intellectual disability that are less verbal, non-verbal or use less advanced language or people who are Deaf or DeafBlind and use some form of alternate communication, there's a perception amongst many in those workplaces that they can't report so therefore there's a high, high level of abuse and I as a clinician have looked after quite a few people. Even inappropriate comments that are, and things that are written, that have somehow gotten back to those people and someone has intellectual delay for example, so therefore they didn't understand it or that never happened they just thought it did. Their memory's poor, whatever it is So there's a lot of scope for people with disabilities of all kinds to be taken advantage of in the workplace I'm just interested Jasper and please don't talk about this if you don't want to but from the point of view you said that the workplace for people specifically with disabilities that you worked at. They're perceived to be getting a gift because they've got a job at all but no one would want to work in those circumstances So are you comfortable to share some things about the workplace?

[Jasper] (20:30 - 20:51)
Yeah, when I started because they made assumptions of your value based on your disability and so they would just decide a pay rate and my contract said that within 13 weeks of starting my productivity would be assessed for appropriate pay.

[grab voice] (20:52 - 21:03)
You shall be paid and paid well My army cannot win a war without your weapons. You should continue their making. Our victory depends on the efforts of the small folk.

[Jasper] (21:03 - 21:27)
So when it was nearly 13 weeks I went to the manager and I was like “so what's happening about my assessment?” And he said “when the assessors do their rounds”. They did the assessment about 16 months later, a week before they fired me. So I never found out what I should have been getting paid.

[CJ]
And were you paid in the interim though?
(21:27 - 21:31)
You were just paid like a minimum wage which you mentioned was six dollars an hour

[Jasper] (21:31 - 21:34)
Yeah I was just paid that the whole time I was there

[CJ] (21:34 - 21:43)
I don't even know what to say to that to be honest I can't even say like I'm appalled or anything because I don't think there's a word that expresses my feeling about that

[Grant] (21:44 - 22:30)
And I think that's why within the disability community there has been such vocal support to close down these disability supported work environments. Because in a way they're stipulating that the person with disability has less worth and less value so they're getting paid well and it's unfortunately illegal, sorry still legal within Australia because of the disability, to pay such a low rate, which would not happen in any other industry. So what was it like going into your job now with that being your original reference point of work?

[Jasper] (22:31 - 22:34)
I was very anxious when I started

[grab voice] (22:34 - 22:36)
Nobody should have to go to work thinking

[grab voice] (22:37 - 22:47)
Oh this is the place that I might die today That's what a hospital is for. An office is for not dying.

[Jasper] (22:47 - 23:34)
I mean I think I still have imposter syndrome I still walk into the office and I think how does anybody think I'm capable of doing this? But it is an indescribably different workplace It is a very supportive environment Yes I've had a lot of work stress, but the team is amazing We all look out for each other We're all there for each other It being led by DeafBlind people means access needs come first. There's a lot of, a lot of empathy and care and respect from everyone in the team towards each other

[CJ] (23:34 - 24:18)
I would definitely say A) Jasper I'm thrilled that you're in a so much better working environment and my wish for the future and my hope is that mainstream work environments hire as many disabled people under the same you know good conditions It shouldn't have to be just a disability-led organisation but it's great that we have them anyway Yeah and definitely that if people ask you to sit on committees or give your advice or share your experience you are well within your rights to go yes and as an expert in this particular field I have a fee And you'd be surprised how many people will actually pay the fee, it's only they don't pay it if they can get away with not paying it

[Grant] (24:18 - 24:23)
I think we may have a short break and join us after this song

[SONG] (25:06 - 25:11)
Limp by Fiona Apple
(26:12)
END SONG

[grab voice] (26:16 - 26:18)
They're just people, James.

[grab voice](26:18 - 26:26)
They're just people exactly like us.

[GRANT]
So Jasper, with disability affecting everyone differently how do you find society disabling?

[Jasper] (26:27 - 27:24)
That's an interesting question and you're right, it's so different for everyone For me, a lot of it is people's attitudes I mean, you think about the physical access and for me a lot of that is needing somewhere that I can communicate so somewhere quiet or having someone with me who can support with communication but so many people are impatient or they see me with a comm guide or an interpreter and just think I'm not going to bother interacting with that guy.

[CJ]
Yup

[Jasper}
For me as well, so many things have moved to high tech and everything being done on phone apps so wanting to meet people, make new friends, go on dates, find a fuck buddy, whatever, so much of it is social media and dating apps

[Grant] (27:24 - 27:48)
Especially within the queer community, a lot is about online interactions and interactions within quite loud environments such as pubs, clubs where drinking is involved and I can imagine that's a barrier that has some unique presentations for you personally

[Jasper] (27:48 - 27:54)
Absolutely and I want to be in environments where drinking is involved but I want that to be accessible

[Grant] (27:55 - 28:01)
In what ways do you feel you close yourself off when you are entering those environments?

[Jasper] (28:01 - 28:29)
I tend to try and seek a quiet little corner sometimes or the seating out the front where I can vape with my beer and only like talk to one or two people at a time But it's also really hard to access times that I can go into those environments because of all the systemic garbage of having to fight for extra support to have someone to go with me

[CJ] (28:29 - 28:32)
Yeah it's something we were talking about earlier is the systemic garbage

[grab voice] (28:33 - 28:38)
That's politics baby, get what you can out of someone then crush them

[CJ] (28:38 - 29:14)
I was just going to raise actually like when Jasper mentioned finding a fuck buddy and I think whenever disabled people talk about fucking everyone goes *gasp!* because it's like we don't fuck. And let me tell you as a fetishist and a long-term lover of sex, we fuck a lot, well some of us do depending on if fucking is your proclivity or not. But it's something I always like to raise about how people are received and you know finding fuck buddies or people to be intimate with when you have a disability like what challenges people face because it's just a really or what responses you face Jasper would you like to talk to this?

[Jasper] (29:14 - 29:46)
I've been talking to comm guides recently trying to prepare for this. How do we navigate a situation where there is potential flirting? And one of the things I keep thinking is if someone sees that they have to communicate through another person to come and have a drink and a chat are they going to want to bother? I just want to be clear when it comes to the physical intimacy part of it there won't be an interpreter or a comm guide in the room with us

[CJ] (29:46 - 29:47)
That's not a fetish?

[Jasper] (29:48 - 29:49)
I don't know

[CJ] (29:49 - 30:12)
You might need to find a kinky comm-guide I think that the concept of like adding a third person into the mix and you know physical challenge and then having the intimacy arm and seeing how it all worked you know I just think that's amazing because it's just an extra dimension to your communication and your engagement that you didn't have before and wouldn't get with someone else

[Kath] (30:12 - 30:22)
But to be fair not everyone wants that sort of communication. I mean there's nothing wrong with a fast and furious session somewhere where not much is exchanged

[CJ] (30:22 - 30:23)
Yeah absolutely.

[Kath] (30:24 - 30:42)
The points that Jasper is raising around connections through disability and you know and the fetish life or sex or easy sex and all that, these are still really really in our face It was easier before the pandemic. I'm sorry I'm just going to come out with it

[CJ] (30:42 - 30:44)
it was It was. It was a lot easier to pick people up.

[Kath] (30:44 - 30:44)
Yeah

[CJ] (30:44 - 31:04)
But it was easier to pick people up 20 years ago you know when I was dating and hooking up There weren't phones. So people had the ability to communicate in many different ways You could read body language You didn't even have to say anything You just knew someone was flirting with you Although I was a bit oblivious, I was a bit hopeless at that, but my friends would go "they're into you" I'm like "Really? Cool!"

[Kath] (31:05 - 31:24)
I remember dances here in Melbourne and elsewhere Dances where you would go, flirt, hang around, you know I don't get this online thing I mean I've been doing it for 20 years or something but gave up say the last 10 years or so, or something like that, but I only ever met sociopaths, boars and liars online

[CJ] (31:24 - 31:28)
So from a sexual point of view when you're hooking up,

[Kath] (31:28 - 31:28)
Yeah and so

[CJ] (31:28 - 31:29)
In person

[Kath] (31:29 - 31:45)
When people say “oh we met online” it's just so great I'm like "How did that possibly happen?" I'm sorry but either I'm totally hopeless at online dating which is possible I'm not good at everything or the sociopaths, boars and liars are just abounding

[CJ] (31:45 - 31:52)
Look the golden ticket can often just be to a Willy Wanker and that's just really challenging and that's just the way it is.

[grab voice] (31:52 - 31:55)
Possible my dear lady that's absurd, unthinkable!

[grab voice] (31:55 - 31:55)
Why?

[grab voice] (31:56 - 31:58)
because that pipe doesn't go to the marshmallow room, it goes to the fudge room.

[Grant] (31:58 - 32:05)
I find the biggest challenge with online is as soon as people know I've got a disability they want me to explain it to them

[Kath] (32:05 - 32:06)
Yeah right

[CJ] (32:06 - 32:13)
Or it's fetishised The fetishisation it's like oh "oh what's your disease? That's kinky." Or missing bits or whatever.

[Kath] (32:13 - 32:30)
I don't mind a bit of disability fetish I find it a really interesting field to explore and I'm much happier with that than say someone who wants oh I don't know I can't you know all the other fetishes that people can have it's my sort of one of my preferred kind of fetishes and I quite like exploring

[CJ] (32:30 - 32:33)
As long as I think though it's if it's I think respect is the big thing though

[Kath] (32:33 - 32:36)
Oh come on in a basic hook-up how much respect?

[Grant] (32:36 - 32:38)
How much respect is in a basic hook-up anyway?

[Kath] (32:38 - 32:46)
diddly diddly diddly come on

[CJ]
Fair

[Kath]
You know I mean why are we applying these different standards? yes some people will get hurt there's no doubt about it

[CJ] (32:46 - 32:48)
Yeah but in a hook-up that could, no in a hook-up that can happen anyway

[Kath] (32:48 - 32:49)
Yeah exactly

[CJ] (32:49 - 32:50)
He never writes, he never calls

[Grant] (32:51 - 33:27)
Quite often people with disability can be fetishised. Sometimes it comes out in a positive way. Other times it's come out in a negative way. I know for me personally I've had a few hook-ups where they have fetishised my disability and it's been very negative where they're touching and grabbing me and because I've got such a problem with chronic pain and nerve damage when I'm touched or kind of limbs are moved in a certain way it can be excruciatingly painful for me and that is the negative side

[CJ] (33:27 - 33:29)
And that's it like you don't find that a turn on, like they're about to break your ankle or something?

[Grant] (33:29 - 33:41)
No not at all. But on the flip side some people fetishise disability but they do it in a positive way where it's actually empowering. Have you ever encountered that Kath?

[Kath] (33:44 - 33:50)
I've probably encountered it more than any other Australian living or dead would be mine

[Grant] (33:51 - 33:52)
Do tell

[Kath] (33:52 - 34:27)
It was the early days of the web and it was a school friend site and I thought oh you know and I just sort of pinged a few things in yeah I'm looking for talking to people women who blah blah blah and the next day I opened my mailbox or whatever you call it and there was like 60-70 messages a lot of them from guys and I thought "What's this?" And I opened them and read them and I'm thinking wow they've got this, just because I've said I'm an amputee. And I realised that all these different messages from all these guys wanting to know this ridiculous stuff like the length of my arm and leg stumps and all this crap and I mean I just was like, "What?"

[CJ] (34:27 - 34:30)
Well they want to know how well you're hung in the arm and leg department

[Kath] (34:30 - 35:15)
Yeah, so I pinged a couple of them that weren't complete neanderthals just going sorry I asked for a woman who dot dot, something friendly something or other from this that and the other so what are you doing here? And they explained that there was this fetish around amputees So because I was always a freelance media maker I got onto a friend of mine who was also a filmmaker and I said look I reckon there's this great documentary in this bunch of fetishists and this bunch of amputees are going to be at this big convention in Chicago in 1998 and I think we should be there with a camera crew And and we got funded blah blah blah we went A lot of it I found no more negative or weird than if you're seeking to pick up somebody somewhere for some reason.

[CJ] (35:15 - 35:16)
Yeah it's just another fetish

[Kath] (35:16 - 35:22)
Yeah well and it's also the same rules apply as in: Who are you? Who do you know?

[CJ] (35:22 - 35:23)
How safe are you? Do you like what I like?

[Kath] (35:23 - 36:04)
Yeah I don't think it's any different. So you know when people talk about 'oh we're so victimized' I'm like wellllllll, I don't think so I definitely think some some of us are more vulnerable than others and I think everyone who knows their vulnerabilities you know should take that with them when they go sexuality shopping or you know however you want to call it But in terms of like sexuality I feel that it's fine to experiment I think some of the problems come from this heteronormative notion which I've bucked all my life which is that you have sex with the person that's nice you're then meant to stay together when I look at those sort of things

[CJ] (36:04 - 36:06)
No, no just say no.

[Kath] (36:06 - 36:07)
Yeah

[CJ] (36:07 - 36:15)
Hell freaking no! Some people you just bang and it's like absolute fireworks

[Kath]
Exactly! And it's beautiful!

[CJ]
and then they can get the fuck out because there's nothing else to talk about

[Kath] (36:15 - 36:17)
and there is nothing wrong with that

[CJ] (36:18 - 36:24)
No, because we are physical beings

[Kath}
Yeah

[CJ]
with physical urges and needs

[Kath]
Yeah

[CJ]
and we're supposed to enjoy things

[Kath] (36:24 - 36:26)
It doesn't have to be a relationship

[CJ] (36:26 - 36:38)
Jasper you mentioned to me personally that a lot of the dating apps and things are very inaccessible to use you know we all have needs and fucking is awesome so and hooking up is awesome so how do you navigate that?

[Jasper] (36:39 - 37:02)
I've had a few friends suggest I have a go at queer speed dating. I'm really curious about it but I also find the idea quite intimidating and overwhelming. Like quick chats with lots of people. But also the word speed in that just doesn't suggest accessibility.

[Grant]
Can slow dating be a thing?

[Kath] (37:02 - 37:06)
Good idea I've never heard of slow dating

[Grant] (37:06 - 37:08)
I've never heard of slow dating

[CJ] (37:08 - 37:12)
Where you get like instead of three minutes a person you get like 20 minutes or something

[Kath] (37:12 - 37:12)
Yeah

[CJ] (37:13 - 37:26)
and you might… and you know what that would force people to sit in uncomfortable pauses too

[Kath]
Yeah

[CJ]
because sometimes you may have nothing to say but you just have to wait out the 20 minutes. But it would be good. It would be great. Because it would just teach people communication full stop.

[Kath] (37:26 - 37:27)
It's an interesting concept.

[Grant] (37:28 - 37:35)
Have you found that there are community groups that you communicate better with on a day-to-day basis?

[Jasper] (37:35 - 37:43)
I've really only mixed with the Deafblind community and so I'm starting to look for opportunities to meet more people.

[SONG] (37:48 - 37:50)
Someone You Loved by Lewis Capaldi
(40:32)
END SONG

[Grant] (40:39 - 41:02)
Welcome back to diHARD. Diversity, inclusion, the hard topics. How difficult is it to find supports that understand you both as a person but also your queer identity?

Do you find that it can be challenging to find someone who you can communicate freely to interpret what you're saying?

[Jasper] (41:02 - 41:41)
I have to say my current support team is absolutely amazing. I'm really lucky. I can be really open with all of my commguides that I currently have.

I might sometimes choose to organize certain activities on a day that I have a certain commguide just because I feel like that particular thing matches how we work together. Sometimes I will request specific interpreters for certain things. The trouble is wanting to go to things that fall on a time when I can't get support.

[CJ] (41:42 - 41:56)
Yeah, I was wondering about how you navigate spontaneity because part of friendships and social engagement often can be spontaneous activities. So do you actually get the opportunity to be spontaneous?

[Jasper] (41:57 - 42:35)
I tend to have to plan ahead a lot for social things. I'll be in a social situation and want to say, how about we do this? Or I want to say, I'd love to hang out for longer if you don't have anything else happening.

But I have to be aware of when my support ends. Sometimes it's okay, a couple of extra hours if my commguide hasn't maxed out the amount of time they're able to work and they are available. But often I have to go, oh, okay, next time we catch up, how about we do this?

[CJ] (42:35 - 43:05)
Do you have some other way you can communicate without a commguide? I have a Deafblind friend who has a braille reader on their phone. So when they came to my house, I communicated with Tactile Auslan, but then my family couldn't.

But then she sat with one of my kids and communicated through their phones that way. Do you have a way that you communicate that would work where you wouldn't need a commguide if the other person, of course, is willing, which is another factor again?

[Jasper] (43:05 - 43:08)
I am a technophobe.

[grab voice] (43:08 - 43:13)
You've got to stop it somehow. Turn everything off.

[Jasper] (43:14 - 43:41)
Um, I need access to some training to be able to do something like that. If we're somewhere really quiet one-on-one, I, with my hearing aids, can hear some speech. But also then if we're out, I can't just say to my commguide, it's okay, you need to finish.

I'm going to hang out with this person for longer because I can't then get myself home.

[Grant] (43:41 - 43:44)
Is adequate funding an issue that you run into?

[Jasper] (43:45 - 44:25)
Yes, I'm currently having some problems I'm trying to sort out with the NDIS. First, my support coordinator has been trying to push for more support and the NDIS said no. She's been trying to push for them to actually recognize my mental health issues, which is like very long-term chronic mental illness, as part of my disability.

And they said no. Their argument for everything they've knocked back, including more accessible housing, came down to my needs not being value for money.

[Grant] (44:25 - 44:43)
It always annoys me with the NDIS, how someone you've never met is essentially determining how much support you need and particularly the term value for money. How fatiguing do you find it advocating for yourself to get more than the bare minimum?

[Jasper] (44:44 - 44:44)
It's exhausting.

[CJ] (44:45 - 44:49)
Yeah, I don't think there's much more he can say. We all feel the same, really.

[grab voice] (44:49 - 44:54)
I'm tired.

I'm always tired. People think I'm hung over.

[grab voice] (44:54 - 44:56)
Oh, you trying one on last night?

[grab voice] (44:56 - 44:58)
No, there's just my body trying to stay alive.

[CJ] (44:58 - 45:53)
Just to go onto a slightly different topic, Jasper, you mentioned before about there being very few young DeafBlind people in the DeafBlind community. I don't know that there's not many DeafBlind young people.

It's just that there aren't many coming to like DBV or to the events. Do you think it's actually that there's not a lot of DeafBlind people around because there are more medical technologies that are thrust upon people with disabilities to, in inverted commas, fix them? And therefore the community is getting smaller.

I know having been involved with the community that we have lost some younger people who have passed away because of their other medical conditions. Why do you think that maybe there aren't as many young DeafBlind people sort of coming to the events or is it just the community is really small? Do you know why?

[Jasper] (45:54 - 46:53)
I think partly it's that some genetic conditions that cause DeafBlindness present later in life or progress further later in life. I do think it's probably partly also the people getting fixed by tech bullshit. I don't know if it's also just lack of awareness about the DeafBlind community existing so people don't connect with us.

DBV does try to do, we do a lot of work to raise awareness and I feel like that is making a difference in the community. We've presented in schools as well. We've also for the last couple of years had a stall at the Deaf Festival and often some genetic conditions, people will start out deaf and then their vision will reduce as time goes on and so that's another place where they get to find out who we are.

[CJ] (46:53 - 47:22)
And I think my last question is how have you found navigating the queer community with respect to your DeafBlindness? Because it's such a big part of who you are. It's an integral part of your identity and a lot of your social and particularly intimate engagements are going to be within the queer community.

So how do you find the community either responds or probably more so reacts to your DeafBlindness? Like do you find them welcoming to you at their events?

[Jasper] (47:22 - 48:10)
It's been mixed. I have recently started looking for more opportunities to connect with the queer community. Since moving to Melbourne, I've gone to Pride March every year.

I've marched with a few different groups. One of those times, I really didn't feel much part of the group I was marching with but other times with other groups, people have come up to have chats with me and it's been a lot more inclusive. A comm guide told me about a queer social group that is, the first one's happening soon, for people with disabilities and they're hoping that will be a regular thing.

So I'm planning to check that out and see if that's a space I feel comfortable in.

[CJ] (48:10 - 48:37)
But I also feel like as a disabled queer person myself that it's nice that the groups are being created or formed for us as a group but also just to be able to be part of the mainstream queer community as a person in my own right. I think that's really important as well and I was just wondering when you said you've marched with some groups and you felt

comfortable and they've been inclusive, have the relationships with those groups continued beyond Pride March?

[Jasper] (48:37 - 48:52)
With one group, I kept in touch with a few people afterwards. Two people from that group I'm meeting up with one day next week for lunch and then, if the weather's not horrible, a walk around the Botanical Gardens.

[CJ] (48:52 - 49:02)
Well we hope for the not horrible weather because that's another thing that a lot of people with disabilities struggle with is temperature change. Extreme heat or extreme cold or even moderate heat or moderate cold.

[grab voice] (49:03 - 49:13)
It's hot, damn hot, real hot. Hot as this is my shorts, I can cook things in it. Little crutch pot cooking.

What do you think it's going to be like tonight? It's going to be hot and wet. That's nice if you're with a lady but it ain't no good if you're in the jungle.

[Grant] (49:14 - 49:23)
To wrap things up, if there was a key negative perception that people have about being deafblind and you'd like to kind of address that, what would that be?

[Jasper] (49:24 - 49:27)
Ah great, you're making me pick just one.

[CJ] (49:28 - 49:35)
No, you can pick more than one. What things? We'll pluralise. Just smash those perceptions for us Jasper.

[Jasper] (49:37 - 50:14)
I think being treated as if we're either children or just don't have the capacity to run our own lives and make our own decisions and have our own views and values. We can do those things. Maybe to varying degrees for some people but that's the same throughout the whole community.

I think we've all, whether it's an additional disability, mental health issue which kind of comes under the disability umbrella anyway, amount of life experiences we've had. But yeah, we can do those things.

[CJ] (50:14 - 50:26)
Yeah and just people in general have different strengths and weaknesses. I'm really good at some things and really lousy at others and that's just the way it is. It doesn't mean you're not capable.

It's just something might not be a strength.

[Grant] (50:26 - 50:44)
Again, it's that idea that our capacity is being determined by people other than ourselves and that is just something that we need to move away from as a society because it's very self-limiting and it puts people in boxes that they don't belong in.

[CJ] (50:45 - 51:12)
And it's about not being heard. We're actually speaking and you say to someone directly, no, I can do that myself or I actually can't do that and I need support for that thing. And they go, oh yes, yes and they haven't acknowledged a word you've said and then that's a value judgment on our capacity to actually make those statements about ourselves.

So yes, it's challenging and an ongoing quest. I like to call it a quest because it makes it sound more fun.

[Grant] (51:14 - 51:18)
As you said earlier, sometimes you've got to smile because otherwise you'll cry.

[CJ] (51:18 - 51:20)
Correct. And they're not happy tears always.

[Jasper] (51:21 - 51:31)
Absolutely. My doctor says I'm her naughtiest patient because some of my humour can be very dark and I'm just like, that's how I cope with shit.

[Grant] (51:32 - 51:35)
You are very welcome here then.

[CJ] (51:35 - 51:38)
Yes, I was about to say and that Jasper makes me proud to know you.

[Jasper] (51:39 - 51:40)
Thank you.

[Grant] (51:41 - 51:43)
All right. Thank you all for joining us.

[CJ] (51:44 - 51:50)
We will be back next week with our live show. We are going to be at your mercy. So go hard or go harder.

[Grant] (51:52 - 51:52)
Have a great week.

[SONG] (54:07 - 54:13)
Go by Maduk, Lachi