



Speak Easy Podcast – Season 1, Episode 9 – with Carla Treloar, Annie Madden and Jenny Kelsall

CARLA: Well a big hello, welcome back to the wonderful place that we know as the Speak Easy Lounge and today we have the irrepressible Jen Kelsall from Harm Reduction Victoria and in fact, this is the first Speak Easy where we've all been in the same place, so that's very exciting.

ANNIE: Actually in the same room rather than down the line from wherever.

CARLA: Annie, do you want to tell us more about Jen and her history?

ANNIE: I will, so for those who don't know, Jen Kelsall is the CEO of Harm Reduction Victoria or HR VIC, as it's often known as. HR Vic is the state-wide peer based organisation here in Victoria and Jenny is a highly respected advocate in the Australian drug users' movement and rightly so. That is due to her many years of hard work in the sector and leading by example and being a strong and consistent representative for people who use drugs in Victoria and across Australia. Now as you can imagine, that's not an easy job by any stretch of the imagination, particularly given how people who use drugs are depicted and thought about and treated in society, so it is quite significant that Jen has been such a long standing advocate in this area and we are really, really pleased and privileged to have this opportunity to talk to Jen in the Speak Easy, so a very warm welcome.

JENNY: Lovely to be here and thank you for your very kind words Annie.

ANNIE: You know, we've known each other for a long time and it really is a genuine pleasure to have you as our ... actually our first guest from a drug user organisation in Australia and I think it's entirely appropriate that it would be Jen, because as I say, you are a long standing member of the movement in Australia and highly respected. So I'm just going to kick it off with a slightly more personal background edge for people who don't know so much about you or maybe know you and might learn something new about you. So you originally hail from the land of the long white cloud as they say, where I recently had a little sojourn, so New Zealand of course. Can you tell us a little bit more about when you migrated across the ditch into Australia and how you got involved in drug user organisations?

JENNY: Well I was part of a mass exodus from New Zealand, it's really quite an historic event that many, many Kiwis left the land of the long white cloud during the era of a particularly unpleasant Prime Minister Muldoon, so I was part of that sort of exodus. I stumbled into injecting drug use after my arrival in Australia. I met the love of my life and he happened to be a long term user of opiates and I guess I would have followed him to the other end of the earth, so it was very much part of that love affair I think initially, not that I want to hold him responsible, it's not about blame, it was just that it was actually the point of access. As far as working in the sector though, I stumbled into that, it really was quite by chance. I had an

academic background and I fondly imagined when I became pregnant with my first child at some ridiculously young age, I think I was 19.

CARLA: Oh my god.

JENNY: That I was ... that life was just going to continue as before I'd enrolled to finish my Masters thesis, but I'd have a baby as well. I'd already been doing tutoring and a bit of lecturing in literature in New Zealand, so I had quite an extensive research background even at that stage, but my first daughter was born with spina bifida, and so my academic career was put on hold and I never ever got to go back to it in the way that I'd always imagined. And so fast forward 10 or so years and I happened to stumble into a person who I'm aware whose name is not so widely recognised anymore, but Professor Nick Crofts and it was at that particular point in time, 1990, that Nick had just returned from the States where HIV was you know the sort of buzz word and he had been working at the CDC, so he'd come back to Australia with all of these ideas and he managed to land a massive grant. Even by hindsight, within its sort of historic context, it was an enormous amount of money given that it was his first funding sort of opportunity and it was Nick who partly I think due to his experiences in the States, but part of the model that he wanted to implement for this ... it was a longitudinal cohort study of current injectors to look at HIV prevalence and incidence. Part of his model was to employ peers to do the recruitment and he figured that follow up rates would have to be better if the research respondents were members of the interviewer's social networks and he was right. I think it was because of that, that we did have such a high follow up rate and we were actually funded to follow people over a 5-year period, interviewing them every 6 months or so. So it just happened that it was at that point that the test for hepatitis C first became available, so even though it hadn't been part of the original design, the longitudinal study, Nick just co-opted it into the mix, so we were actually testing leading people ourselves, so we were trained as phlebotomists and so that made the whole issue of testing a lot more appealing to people that we could actually do it in their own homes. We were trained to do pre and post-test counselling, so we could deliver the results. And so we actually had access to the first generation of PCR testing, which by hindsight, were very crude. We wouldn't give an individual result until I think it was about the third PCR test, the level of accuracy just wasn't ...

CARLA: I didn't know that.

JENNY: It was considered appropriate for research purposes, but as far as individual results ...

CARLA: For diagnostics it wasn't.

JENNY: We would give them, but it was always within the context that we needed to do another one to provide a sort of a heightened sort of level of confidence in terms of accuracy. I was interested to read myself described the other day, as a pioneer of harm reduction.

ANNIE: Entirely accurate ...

JENNY: I'm aware obviously of the passing years that I've become something of a dinosaur, but it was actually Jacquie Richmond who mentioned the other day when I was doing an interview with her, "so you have been here from the beginning?" And it hadn't actually occurred to me before, but I was around at the very start of the hepatitis C story in those very early years when ...

ANNIE: Not many people can say that.

JENNY: Yeah, when the test first became available.

CARLA: And so how did you move from that into drug user organisations?

JENNY: I guess that's been a fairly sort of gradual process. Because of the work that I was doing with the Burnet Institute, I developed relationships with members of ... it was VIVAIDS back then and from time to time, for VIVAIDS I was co-opted to sort of perform specific tasks and they were always things that I loved to do. I got to design I think the first overdose workshop and that program sort of still exists today. I mean obviously it's evolved and it's been amended in many ways, but it was the original design from all those years ago. It was around about 2000 I think and I was on the Board of VIVAIDS on several occasions, so I guess it was ...

ANNIE: A natural progression?

JENNY: It was and just natural sort of friendships and I guess just natural allies that in terms of the work that I was involved in at Burnet. VIVAIDS still ran a needle and syringe program in Smith Street back then and so often I would use space there to interview someone. There was quite a close relationship between Nick's research and the local drug user organisation.

ANNIE: And that was the Centre for Harm Reduction?

JENNY: Yeah.

ANNIE: Was it called that then?

JENNY: No it wasn't, it was called the Epi and Social Research Unit way back then and then he established the Centre for Harm Reduction as a spin-off from that, yeah.

CARLA: So with that huge view of the past, as much as things change, something's stay the same right, so from your point of view Jenny, what are the key things for drug user organisations or drug users on the agenda today?

JENNY: As opposed to back then?

CARLA: Yeah.

JENNY: Well look I think the first comment I would make is that it's absolutely essential that we remain current and relevant to here and now and that I think parts of what we do within the operations of our drug user organisations, we do because we've done them historically and I think some of those things can easily become anachronisms. I actually think that one of the driving forces of this organisation is actually Dance Wise, which is a completely discreet and different community from the cohorts that we've worked with traditionally and as you would well know, the dance party community does not associate strongly with injecting drug use as much as there is injecting going on within it, it's fairly sort of secretive. But I do think and it's ironic, because when I first actually came to work at Harm Reduction Victoria, which is close to 10 years ago, at that stage Dance Wise was almost like a separate entity. There was such a cultural cringe on the part of Dance Wise in the face of injecting drug use, that they really didn't like the association with HRV and they would do quite a bit to distance themselves from HRV as the parent organisation and so one of the things I most ... if you like proud, but also I think I've been instrumental in is, integrating Dance Wise within the organisation and so now I don't think there is any distance or much distance there at all that Dance Wise is well integrated within the organisation as a whole and I think that it has gone from strength to strength. I mean just in sheer numbers, its' grown exponentially. The team when I first came to work here was maybe half a dozen. The target set by the health department has always been 12 to 15 events a year ...

ANNIE: Are they peer education type outreach type events?

JENNY: Well what they do at events, yes they are there to provide harm reduction information and education about safer drug use and safe partying. It's not part of the health department funding and service agreement, but part of Dance Wise and an integral part of Dance Wise has always been the operation of what they call their "Chill Out Space" and so it's a space ... they work very closely with the first aiders and the medics, the medical teams who are there and often their most ardent supporters. A lot of them, the medical teams and first aid teams, simply will not work an event unless Dance Wise has also been engaged. It's so helpful for them to have Dance Wise there to refer to for clients who may no longer need medical intervention, but they're certainly not able to return to the party. Their duties are just so sort of relieved by their ability to be able to refer people into Dance Wise's safe hands and safe keeping and Dance Wise over the years has become ... it hasn't just grown in terms of quantity, the quality of the service it provides, it's become extremely professional and streamlined and so they're monitoring and runs rings around the standard medical sort of monitoring. During the last summer, you are probably aware that there were several deaths at dance parties and interestingly, the Minister for Health in Victoria, Foley, actually stated in public that Dance Wise was the reason that there hadn't been any deaths in Victoria, which was huge for us that for once you know, we are seen as the solution rather than the problem. Having said that, Dance Wise still operates on a shoe string and the bigger it gets, the harder it is to sort of keep that shoe string from snapping. The team of volunteers is now 60 strong, it used to be 6 to 10 and the team meet fortnightly and they all show up, like the whole building is ...

CARLA: Full of people, we are here at HRV, it's not a huge place ...

JENNY: Yeah exactly and so they really are an extraordinary group of young people. They're not just committed Annie, they are so focused and some of them, their knowledge of the drugs that have currency is encyclopaedic. Like they know more about novel psychoactives anyone else I've ever spoken to and they really do have their finger on the pulse and I mean, they have sort of opened my eyes to ... in many ways to the fact that we live in a very, changing and different world. A lot of them only buy their drugs on line, they simply don't deal with ... the buying and selling happens in very different ways and it's not just sometimes, this is how it happens and I think that this is something that distinguishes us from some of our sister organisations, the drug user orgs in other states, that we have this particular program that doesn't just keep us in touch with the world we live in. It is the injection of youth and energy and vitality and given the nature of this community, they do tend to be ... I mean it's a gross generalisation, but a lot of the team members are highly trained professionals, a lot of them are still at school, but in the team there are doctors and pharmacists and lawyers and engineers, they're a pretty impressive bunch. They are also mad sort of LSD takers [laughs], but you know, they are a very skilled ... it's a very skilled population to be drawing from and their combined sort of talents and their combined sort of brain power, whenever they're brainstorming an issue, you know it really is an extraordinary discussion. I'm usually here in my office and I hear just because of the noise [laughs].

CARLA: And it is a different thing, you know taking a bit of a side way step for a moment, you know the ... it's not the usual group that drug user organisations can typically recruit in as volunteers. You know, I was just struggling to think of any other organisation that has the range of professionals that you just talked about Jen as part of its kind of core membership and workforce in the peer volunteer capacity anyway. You know, it creates a different profile opportunity for Harm Reduction Victoria to say, "look it's not just these (in inverted commas) fringe dwellers that we are talking about, it's a broad society that we're talking to and working with ...

JENNY: Absolutely Carla. So I think we haven't begun to tap into the potentials here and what is ... what does fill me with joy is to see Dance Wise as part of this organisation that the team members wear that badge with pride now and that there's no sort of distancing themselves from it and that they do see that we are all part of a harm reduction sort of team. And that yes, you know there are differences, but yes, there's also huge commonalities that harm reduction works in their community just as it works in other communities of people who use drugs. So I think that's been a really healthy cultural exchange on both sides. I think that it's given our more historical perspectives a bit of a new lease of life. I mean, it's also that we're living in an age of poly-drug use and that those clearly defined categories are no longer very indicative of reality ...

ANNIE: Or if they ever really were. I mean, we've always struggled I think haven't we to kind of get that message across that it really has been unusual for someone to just use one substance. They may have a favourite or a primary drug of choice so to speak, but this is another level again.

JENNY: And just that concept, the drug of choice, I think is almost anachronistic that it is the patterns of drug use that we observe are so much more opportunistic and it really is whatever is on offer and I mean, it never ceases to amaze me that it does extend as far as a committed opiate user settling for methamphetamine if that's all that's available. That sort of ... that used to be a fairly sort of clearly defined sort of grouping of preference, but even that one has gone you know what I mean? And people sort of come and go across those divides quite sort of seamlessly, so I think it is also indicative of that, that we're seeing ... it's not just that this organisation has brought these sort of separate cultures closer together. I think that in itself is indicative of the world that we live in, that there is more overlap and that people are sort of picking and choosing quite a sort of an often an exotic cocktail of different drugs and it could include anything from injecting and different means of administration that might include injecting of some substances and not others.

ANNIE: And so Jen, I mean sort of leading on from that I guess, Harm Reduction Victoria along with a lot of other peer based organisations in Australia have traditionally found primary sources of funding if you like in sort of blood borne virus prevention and you know testing treatment, those sorts of areas, but I guess with what you've said around Dance Wise changing drug use patterns and also sitting alongside the fact that HIV rates continue to be predominantly very low amongst people who inject drugs, the new hepatitis C treatments, they are saying potentially hepatitis C elimination as a serious public health threat in 10 years or whatever, what do you ... how do you see the future of drug user organisations with all that said I guess?

JENNY: Look I do think that Dance Wise is the future of this organisation and I've thought that for a while now that it probably is the future for a whole lot of reasons. Look I think there will always be a part for prevention, you know it seems so obvious to me, it's a no brainer and I guess I would like to see an even closer integration of say a program like Dance Wise in the other work that we do. We certainly have included BBV prevention training for the Dance Wise team which never use to happen and the Dance Wise team provide training around novel psychoactive substances, so there's much more sort of integration and crossover within the staff team and a lot of the health promotion team who do most of the BBV prevention and treatment stuff, that a lot of them actually attend the events. So I actually see that there is a potential for them to come together in a way that it hasn't historically. I do think we just need to continue the fight. I've remained very sceptical of these new hep C treatments. I'm very happy to be proved wrong as much as I have been. I remember I used to drive Margaret Hellard mad you know, "are they really as good, they can't be, it's too good to be true".

ANNIE: "It can't be possible" [laughs]

CARLA: We're talking to her on Thursday, we'll ask her again, how's that.

JENNY: But I do think that ... I'm very conscious, I guess because I have got a bit of a research background that most of what we know about the new treatments are based on the trials, so I think that, yes this is the first generation of results and experiences of treatment, but I think the story's a lot more complex and the one we've been sold to date and even in this first ... the flood gates have opened and this first tide of people who have received the new treatments, the stories have been varied and we're certainly aware of numerous people for whom experience of the new treatment wasn't a walk in the park and I think the fact that it's been sold as such, so non-toxic and so non-invasive that for the people who didn't have that experience, it was made worse. I think each and every one of them said to me at some time, "what's wrong with me, everyone else is ..."

CARLA: Flying through it ... yeah.

JENNY: Exactly, "so how come I'm not?" And particularly in clusters of people who were sort of doing it, friends you know doing it round about the same time and there would be ... well I'm thinking of one group in particular where there were three or four of them and three of them were ... they were transforming in front of our eyes. They started to sort of glow and the other one was just going in the opposite direction and every time we saw him, he just looked worse and worse and worse and that was his response. It's like, "What's wrong with me?"

ANNIE: And major issues potentially if couples are going through treatment together and one's doing really well and the other one isn't and there's not a great deal of support now around these new treatments, how does all that get coped with?

JENNY: All of those more socio psychological considerations that were just sheer necessity with the previous Interferon based treatments, they've literally disappeared from the agenda. You know, the Victorian Health Department has been very proactive in facilitating a series of treatment readiness meetings, you know across the whole sector. It's they're all there, all the usual suspects, but it's virtually impossible to get any, any discussion onto the agenda around models of peer and certainly any suggestion of the need for peer base support. It's all just gone and it is just the same old story that it's just not needed any more, that the drugs are so non-toxic that people are just not going to need any additional support. We're lucky to have this ... we need this time, we need every minute of this time to start this process, because so many of our community are light years away from considering treatment. I'm one of them. I've never seriously considered treatment. I know in that bell curve modelling, I'm one of the laggards, but how do we get to the laggards and how do we engage people who just decided a long time ago that treatment wasn't for them and so the mention of hep C treatment, they don't prick their ears up and start listening. In fact, the opposite happens, it's like, "No, I'm not interested" and there's so much information to be undone. The one thing that everyone knows, is that there's a horror story about someone trying to survive the rigors of Interferon.

CARLA: I think another thing to be undone is what people believe themselves to be. There was a great paper just published earlier this month by Ben Cowie's team from Victoria, looking at what proportion ... using modelling, getting data from labs over a 10-year period, so what proportion of people who have received an antibody test have gone onto have follow up tests? 60% or 58% or something like that, have not had the follow up test, so I think there's a whole lot of people out there who have had really poor testing and repeat antibody testing over and over again, no confirmatory testing and so that's a piece of work that needs to be done to get people good quality testing. So we'll put the link on the website for the podcast and I'll send it to you Jen, because it's just ... we've heard this time and time again in interviews

of people saying, “I thought I was positive and then something finally happened and I got the next test and I wasn’t”.

ANNIE: And similarly the Australian NSP study has shown every time poor repeated antibody testing, much poorer levels of confirmatory testing and that’s particularly among people who inject drugs, so there’s some good data gathering to say, “this is a real issue”.

JENNY: And that was certainly ... I remember part of my experience of the healthy liver clinic all those years ago was such a nice task to be able to tell someone, “well no, you don’t actually have hep C” and often it would have been something that someone had been living with, with 10 plus years.

CARLA: Or thought they were living with?

JENNY: Exactly, exactly.

CARLA: This terrible burden.

ANNIE: And made decisions, possibly big ones, based on that?

JENNY: Absolutely. So no, it’s great that Ben’s actually published hard data to confirm.

CARLA: Yeah, so we need to get it out there. That’s been one of the things that I’ve always admired about you Jen is that real connection between your research interests and experience and the work that Harm Reduction Victoria are doing and I think I’ve said this to you before, one of the first things I read when I started my job in this sector, was your peer education chapter and it just lifted veils from my eyes. Like, “Oh my god, this is how the world can work” and I think that as you mentioned, Nick Croft’s taking ... building into his work, that this is the only way we can get this work done properly and efficiently and expertly and to respect the people at the end of the chain as well, is to have peer workers involved. So what do you see as the ... why a collaboration between research and frontline stuff is important and what’s next on your agenda for that?

JENNY: Well I have been delighted at the initial steps that have happened between us already, Carla and Annie. I just think this is almost like a wish list sort of situation that I do ... and I guess it is very personal, though I’ve always had an interest and a love of research that it’s just an opportunity to sort of bring the two together and I guess because I have had the good fortune to work on both sides of the fence if you like, I just see how just interconnected they are and that one sort of can feed off the other in a really constructive sort of way. It’s my great sort of frustration and sorrow almost and when I was answering that initial survey and when it came to questions about the barriers ...

ANNIE: The community engagement and research is that when those moments come where peer educators, people working in drug organisations do engage with certain pieces of research, they’re really like those, to use an American term, those “Aha” moments, like people really enjoy it and really engage with it and it’s a revelation. It’s like, “Oh my god, this is so great” and then they use it, they use it a lot, in their work, in their planning of things, in their presentations, you know it does happen, but it’s how you make that happen on an ongoing basis isn’t it.

CARLA: It’s also the responsibility on the researcher’s side you know that summary I gave you of Ben Cowie’s paper, like I don’t understand the modelling in it either, but I understand it enough to be able to give you that one or two sentence thing and that’s our responsibility to get better at that to do it and now some journals ask you to write the three or five points highlights you

know, but often they're written in this kind of ways that you'd go, "huh, what does that mean? I don't know." So I think there's still a lot of work for us to think not just about the academic audiences that we're writing for, but talking it you know.

JENNY: Do you know much about this "Lives of Substance" model?

CARLA: Yeah.

JENNY: So this Oxford model. I didn't even realise it was a model and ...

CARLA: Yeah we spoke with Suzanne about it for a podcast that's coming up just at the launch of the website.

JENNY: Great, right and so I've been on that advisory group and so I do see that as a sort of worthy attempt to get research out of the hallowed sort of halls of academia and into a more accessible place. I just think it's just a great title, apart from anything else, it's just a fabulous title.

ANNIE: It could be taken in so many ways too.

JENNY: You know, I think those sorts of titles can speak volumes and you know, I just like the sort of suggestion in it that we are talking about people and lives of some significance.

CARLA: And that are full and multi-faceted.

JENNY: Absolutely.

CARLA: Full of joy and love and trying things.

ANNIE: Exactly, like everyone else's lives out there you know, which is not often thought of. So Jen, we've covered and traversed wild amounts of ground in this, so we probably need to start wrapping up. Probably just quickly, is there anything in terms of what is coming up next for Harm Reduction Victoria, new campaigns, new programs, anything else you would like to know about through this podcast that we haven't touched on?

JENNY: Well look, we do see this Victorian Parliamentary enquiry, I don't know how much you know about it?

CARLA: No, I don't know.

JENNY: It's just Victorian. I remember when it was Steph, one of the Dance Wise coordinators told me about it, my response was, "as if" and she said, "no, it's happening".

CARLA: What's the enquiry in to?

JENNY: So it's into illicit drug use in Victoria, so the terms of reference are massive and but it does include policing. There are some more specific parts ... I mean, I just think it's way too big, way too big and we've been working on a special edition of our magazine just focusing on the enquiry. As much as it's a sort of pretty dry topic for our sort of loyal readers and members, we just figured we had to make a feature of it and to try to sort of engage people and to sort of ... not just to know about it, but to actually make submissions and we're offering to help people write them or they can speak them to us and we can put them together. I'm hopeful that this parliamentary enquiry will involve a shift in the political sort of thinking around pill testing, particularly with Caldicott on site and he does want ... I mean one of the handbrakes of course is the limitations of reagent testing and Caldicott is now advocating for way more sophisticated testing on site.

ANNIE: So this is David Caldicott who's an emergency doctor in the ACT hospital system and who's been a very public strong advocate for pill testing?

JENNY: Yeah and he's a very ... whatever you think of David, he's a very charismatic individual and I think for that reason as well as many others, he is a powerful champion for pill testing, just that he has the credibility of being a doctor.

CARLA: It's worth having a look at him on Twitter actually, there's stuff he's posting. It's really interesting discussion around the issues.

ANNIE: Any other quick issues out of that enquiry that you really are hoping for?

JENNY: Well look, it is an opportunity to raise a lot of things. Certainly we will make the most of the opportunity. It's hard to know where to stop, you know whether we should focus on two or three key issues or whether to ...

ANNIE: It's become a bit of a scatter.

JENNY: A massive sort of myriad of issues and we still haven't really made that decision. We are covering everything in this edition of the magazine.

ANNIE: And when will that be out Jen?

JENNY: In a month or so and the forum as well I think, will hopefully be another way of sort of engaging people. Look, I am hopeful since ... I do think since Dance Wise has been referred to as a solution to a problem and the problem of deaths within this culture is a big plus for us and I do think ... I'm hopeful that this parliamentary enquiry will help to further validate Dance Wise and to sort of enable us to resource it properly, because at the moment it's resourced primarily by the goodwill of the volunteers involved.

ANNIE: I guess that's a nice positive place to end the podcast. As I said earlier, we've covered a huge amount of ground and it's really fascinating, some great stuff that you know is really good to put on the record for like history as well, you know the things that people ... you know that get forgotten and that are really important, but also a really nice vision to new things and the future and I think it speaks volumes of your leadership Jen and the strength of the organisation that you've been able to provide us with such a rich and amazing interview. So thank you so much for your time.

CARLA: Alright, signing out.

ANNIE: Bye.

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