

THE ROAD WELL TRAVELLED

How drug users took on HIV

Julie Bates played a leading role in Australia's early response to HIV/AIDS and has spent the past three decades working to improve the legal and human rights of marginalised people, specifically sex workers, injecting drug users and people living with HIV/AIDS. Julie was a foundation member of ADIC (the AIDS Drug Information Collective, the forerunner to NUAA) and was the first coordinator of NUAA. Today, Julie heads up Urban Realists, which provides advice and support to the sex industry. In this interview with User's News editor Gideon Warhaft, Julie talks about the early days of HIV in Australia, specifically its impact on injecting drug users.

User's News: When did you first get involved in drug user issues? What year are we talking about?

Julie Bates: Way back in the early 1970s. At the time, I had a pretty successful career as a law clerk in one of Melbourne's preeminent criminal law firms. The illegality of the sex industry at the time and, of course of drugs, kept our firm very busy. As a law firm that was known for representing the 'goodies' against the 'baddies' the firm went on to represent complainants (the goodies) in the 1975 Parliamentary Inquiry into the Victorian Police Force, known as the *Beach Inquiry*. A number of our clients, including dealers and users, gave evidence to the Inquiry. One of my duties was to take their statements, which would then be presented to the Inquiry.

I had been raised to believe that the police were there to protect people, that they were honest and trustworthy. Suddenly this belief was being challenged. I was listening to people talking about having drugs and guns planted in their homes, even in the bedrooms of their children, about being bashed into submission and admitting to things they hadn't done and having those statements turn up as evidence against them.

It was later that I became aware of the need for advocacy for both drug users and sex workers in the health and social welfare areas, especially primary health care and methadone maintenance. All of this sharpened my sense of social justice and led me, along with others, on a path

towards social and structural change that would really benefit people. And not just about the prevention of life threatening illnesses but also in a more general sense. Being a member of several of the affected communities certainly helped.

UN: People assume that it was HIV that got users politically engaged to set up their own organisations and lobby for needle and syringe programs and so on. Is this true?

JB: It certainly upped the ante, but there was a growing number of disgruntled people unhappy with limited access to treatment and methadone programs, and with the stigma and discrimination which affected their daily lives. There was little or no respect, compassion or dignity towards drug users. Just getting regular access to new injecting equipment was fraught with difficulties.

At some point in the early '80s, the political became personal for some like myself and the personal became political for others like Alan Winchester, the inaugural President of NUAA. For Alan, who had been a social worker and had previously worked with homeless people living with mental illness, his passion for the marginalised was rekindled when he saw himself as one of them. Waiting at the end of a very long queue to get on a methadone program and then seemingly trading his dignity to stay on the program, his fight then became political as he fought for not only his own rights, but also for fair, equitable and non-judgmental treatment for anyone on a methadone program. What we did not see at the time but what was just around the corner and would change our lives forever, was HIV.

HIV was the catalyst that brought many people together and helped forge the necessary alliances that supported all of our initiatives. Members of other affected communities, sex workers and gay men, were already engaged in their own struggles for social justice and law reform and together we were able to strengthen our alliances with politicians, health care professionals, bureaucrats, social researchers and even the media.

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Once HIV was added to the equation, the first two drug groups to emerge were known as Injector Services and ADIC [the AIDS Drug Information Collective]. Injector Services was made up of people primarily committed to an abstinence-based philosophy with the support of Narcotics Anonymous, while ADIC took a pragmatic approach to reducing harms and getting the “don’t share” message out to users. ADIC’s membership was comprised of users, social workers, nurses, policemen, nuns, sex workers, researchers, educators and the good doctor himself, Alex Wodak [then, as now, the Director of Drug and Alcohol at Sydney’s St Vincent’s Hospital]. Some of us were gay, straight, transgender or somewhere in between and on occasion described by media commentators as a “bunch of misfits, junkies, poofers and whores”. Only a few of us, however, held the exalted position of identifying with all four categories! As disparate a group as we were, we all had one thing in common: the belief that injecting drug users deserved to be treated with dignity and compassion and had the right to accurate information, clean equipment and non-judgmental support that would help protect themselves from HIV.

UN: What was the availability of injecting equipment before that?

JB: There were no NSPs as we know them today, with primary and secondary outlets in a variety of community and health care settings. The only access to injecting equipment was through a small number of pharmacies, but you had to brace yourself for a hostile reception when going in to buy them. It was not illegal to buy needles and syringes but it was really frowned upon. There were only a few pharmacies that were in any way ‘user friendly’.

Some of the dealers somehow managed to get boxes of syringes that seemed to come off the back of trucks. Without knowing it, street level dealers who were mostly users themselves were actually doing peer education of sorts by giving out, or in some cases selling, equipment along with the drugs.

This was before we’d even heard of HIV — it was all about reducing other damage caused by used equipment.

In those days people would have to sharpen their needles on matchboxes and glass, and clean them as best they could. People would store their equipment in places where others were unlikely to find them before the owner’s next hit. Because of the limited supply, users often suffered from abscesses at the injecting sites, and some contracted endocarditis and other infections, all because of the need to reuse and share equipment so many times. So even before HIV was identified, users understood the need to not share injecting equipment, but their practices were determined by the lack of availability of new equipment.

I always laugh when I hear people say it’s part of the ritual, that users like to share their injecting equipment. It just doesn’t make sense. In fact, it’s complete bullshit. Users don’t want to share now, nor did they in the past — they only do it when there isn’t any choice.

UN: It seems that when HIV was eventually identified there were three distinct groups: drug users, sex workers and gay men, and that these three groups worked very closely together. These days they work largely independently of one another. Why were they originally together and why was it important that they went their own way?

JB: Some of us naturally gravitated towards each other. I think this was because we shared the perception of being at the margins of society. Regardless of our sexual identity, employment in the sex industry or drug use we saw benefits in sharing our collective experience, knowledge and skills. Underlying this was the shared sense of personal and social calamity.

I also think in those days, and perhaps even still today, gay men who also injected drugs and maybe worked in the sex industry found it a whole lot more comfortable being around this broader group. Identifying as a drug user or sex worker within the gay community was often frowned upon. Segments of the gay community were not

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kindly disposed towards their own kind who injected drugs or received payment for sex.

For gay men, of course, the laws had changed, and while their lifestyle was no longer criminalised, they still faced enormous obstacles in achieving equal rights. Aspects of the sex industry, and of course drug use, were still penalised, and everyone still suffered enormous stigma and discrimination. In the early days of the first NSPs you could be arrested on route to taking a used fit back to the exchange and the cops could — and did — analyse the contents. This was used as evidence in charging you with a drug related offence — being in possession of used injecting equipment. This law was finally repealed sometime in the mid '80s as it hindered HIV education and did nothing to take used syringes out of circulation.

Turning to the second part of your question, why it was important that the groups went their own way, it was not so much the importance of why we went our own way, which was largely a natural progression, but that in many ways we are still intrinsically tied together, if not always harmoniously. Over time there has been greater competition for HIV dollars and that early sense of foreboding and mutual support, particularly when our friends and colleagues were literally dying before our eyes, has disappeared thanks largely to anti-retroviral treatment.

UN: So rather than a strategic decision to get together, it was more a case of so much overlap?

JB: That's right, but this overlap was nothing new. Sex workers and gay men, for instance, had been involved in feminist politics and gay rights from the late 1960s and had linked arms in the first gay street protests that gave birth to Mardi Gras. An early Mardi Gras poster depicts a sex worker rights activist on roller skates beside Paul Young, who was one of the first gay men to publicly announce that he had HIV. In fact, Paul is famous, or in some quarters infamous, for his statement at the time with words to the effect: "I am a gay man, have been a junkie and whore, and I don't know how I got this bloody virus. But it doesn't really matter... what really matters is

the care and treatment provided, and it's not in who you are but the safety or otherwise of what you do."

UN: Was it clearly known back then that you could contract HIV from sharing injecting equipment?

JB: When it was recognised that the Human Immunodeficiency Virus (HIV) caused AIDS it soon followed that the virus was transmitted by body fluids including blood and blood products. It was then immediately clear that transmission could occur via shared injecting equipment, although there had been speculation all along that this was the case. The trick was to get the message out to the thousands and thousands of people who injected, of whom only a fraction could be easily identified at methadone clinics or other health and welfare services. The evidence told us that the majority of people who injected drugs were occasional or one off users and were never going to be reached in those environments. They did not identify as people with a 'drug problem'.

In those days there was great debate about whether one should submit to being tested for HIV or not, particularly as there was no treatment. What was the point of knowing your antibody status when there was little or nothing you could do? Added to this was the stigma and discrimination one faced in both health care settings and society generally. We must not forget that AIDS was originally called GRIDIS [Gay Related Immune Deficiency Syndrome] and there was even a theory that it was transmitted by gay men sniffing amyl nitrate. If HIV had first been identified in using communities, I am sure we would have seen an equally hideous acronym blaming users and their lifestyle for spreading AIDS. This would come later, of course, though without the acronym.

UN: Do you think that the needle and syringe program was the biggest single outcome to make HIV rates so low amongst injecting drug users?

JB: Undoubtedly, but peer education and user community development was no poor second cousin and ultimately a combination of many things was necessary to prevent

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the spread of HIV. The introduction of the first NSPs required leadership from people in authority, such as Alex Wodak. In opening the first NSP, not only was Alex having to deal with breaking the law but also with his own staff at Rankin Court [a methadone clinic in inner Sydney]. They had an expectation that clients would stop using illicit drugs and return 'clean' urines in exchange for a continued place on the program. Alex's pragmatic harm reduction approach, of course, was new and scary to most even in the drug treatment field. They had relied on a 'us and them' approach and a strict formula for behaviour. This new-fangled harm reduction approach seemed to be at odds with their expectations. If you can imagine it, clients would go in through door C to get their dose of 'done, come out through door B and ring on door A to get their fits, all within ten metres of each other. It was clear to everyone, without the need for urinalysis, just who on the program was breaking the rules. But the biggest rule breaker of all, of course, was Alex, who knew the risks to users were too great and he could not stand idly by and let the virus move into the injecting drug using population without a fight. Alex understood that you can kick a drug habit, but not HIV, and based his HIV prevention practices on that simple understanding.

UN: Do you think that understanding came from all these alliances?

JB: Yes it did. I think it emboldened Alex particularly to continue to support the development of a user organisation because he was seeing people with lived experience and peer based knowledge who were courageous in their public presentations, acknowledging their own drug using history but having a lot more to offer. People such as Marion Watson and Jude Byrne, formidable individuals particularly at the speaker's podium at HIV Conferences. These women were frank and powerful in their self-disclosure and in so doing they helped to dismantle some of the myths surrounding drug use, and drug users, and helped forge user organisations and challenged the traditional AOD services and treatment regimes. Alex also

saw people with using histories being capable of leadership, writing funding submissions, chairing and presenting at meetings and conferences.

The stereotypes around drug use and drug users were being dismantled with the evidence that users could be found in every environment, could come from every walk of life.

UN: How do you feel about your part in this and is there a danger of complacency in the future?

JB: I am proud to be part of Australia's early responses to HIV but I would rather it not have happened and that the 6,000 or so Australians who have died of AIDS related causes were still alive today. As the song goes, it has been a long and winding road, but I was far from alone on this journey. Having come from a legal background, I could see the injustices and the fact that if people were maintained in a 'us and them' holding pattern, users had more to lose than their dignity and freedoms — people's lives were literally on the line. Action needed to be taken, but we did not think how fabulous we were or how we were going to stop a plague. We just got on with it.

You see, we really did not know how bad it was going to get, the merciless suffering and loss we were going to witness and how many friends we were going to lose. We would be at a funeral grieving a lost friend or colleague one day and back at our desks the next; such was the urgency we all felt in the work we were doing. Not a lot of time for grieving. We learned from and supported each other, and provided a shoulder to cry on as we went. In that process, of course we finally got money out of the government to fund a user organisation, but let us never forget that out of the 6,000 people, mostly gay men, who have died of AIDS, a large number were our early foot soldiers in HIV prevention and care. They did not survive their own battle, but they paved the way to make the world a better place for others at risk of getting or already living with HIV.