

'Some are here and some are missing': Movements, crisis and normal times

By Darryl O'Donnell

This is a transcript of a keynote address by AFAO CEO, Adjunct Associate Professor Darryl O'Donnell on 11 April 2018, at the Health in Difference Conference. Speakers were invited to provide a personal reflection on our histories as lesbian, gay, bisexual, transgender and intersex communities, with Darryl's reflection offered as a gay man.

It is hard to know where to start, or perhaps more to the point, where *it* starts. But it seems to me that it starts with *a feeling*. Something unrecognised, subtle at first. Vague and at the edges of awareness. A sense of *not-rightness*. Something deep in us. Fundamental to us. But actually, and this is where it's confusing, not in us. In *other* people, in the world around us.

Something is not right. It becomes clearer. A sense of difference between us and our world. Our life, our *selves*, our health, now, seemingly, in difference.

And an awareness of this grows. We look around us for others in whom we can recognise ourselves. We search. We find. We talk. We explore.

And we have that moment where we cry, overcome with the joy and relief of finding others like us. Their journeys – different to our own – but the same.

We question what we thought we knew and come to new conclusions. We find

empathy for others – those who have been where we were, and maybe are still there, or are yet to come.

And the will to act grows. What we have found becomes a way of life. It is political. An act of disobedience. We have embraced difference. We pull away from the centre and push toward new places where we hope that the weight of values, conviction and effort will create something better.

At least it was for me. That is how I remember it. A personal experience of coming out and finding others and a collective experience of together trying to create change. That was my experience as a student on campus. It was my experience of the first Health in Difference conference held in 1996, just a few kilometres away on Oxford Street, and 22 years ago. And it is my experience of being part of our communities' response to HIV.

That response goes back a decade further than I do. To stories of strange cancers among gay men. To deaths that could not be explained. And to growing fear as the toll grew and it became clear that something was killing us.

At the beginning, gay men and others in our community mobilised. We found information from wherever we could. Wrote articles in our newspapers and magazines. Published flyers and pamphlets. Gathered in meeting halls.

Formed teams to provide care – sometimes 24 hours a day – for those becoming ill and to be with our loved ones as they died. Raised funds. When it seemed like this thing might be transmissible, we tried to work out how. We coined the term safe sex. Committees formed. AIDS Action Committees in each state and territory. Later to become AIDS Councils. Created by us and of us.

It was an act of making sense of an emerging horror. Of doing whatever could be done. What else *could* we do? Well, that's the interesting thing. It seems today only natural that we should have organised as we did, but there are few other health responses that centre on community in quite the same way as HIV.

The community mobilisation around HIV emerged from older paths – not from nowhere. It was a response by our communities drawing from our political organising as a gay liberation movement, from the women's movement and from the trade union movement. Its organising occurred through the nascent architecture of our community at that time. Through our newspapers. Through our organisations. It was Mardi Gras that provided the funding for ACON's first work, not government.

And through conferences like this one. My own organisation has its origins as

the Australian AIDS Action Committee, created by state and territory AIDS action committees at the Ninth National Conference of Lesbians and Homosexual Men. This was August 1983, just a month after Australia's first AIDS death. Our first job was to meet with the Federal Minister for Health at Parliament House to discuss how Australia should respond to AIDS. Quite an astonishing thing: at a time when we were still criminalised in many states we were talking with government about what to do.

Public panic and hysteria grew. This was the AIDS crisis, a descriptor for the period used ubiquitously and without hyperbole. So grave was the threat that Australia's 1988 Green Paper on HIV/AIDS was tabled in every Australian parliament. It laid the policy architecture for how Australia would respond. It rejected quarantine – something unimaginable today, but possible then. It rejected segregation. It embraced human rights. It embraced the dignity of all people, including people with HIV and AIDS. And it embraced community.

Many communities. Our communities came together with others in rich ways - with sex workers, people who use drugs, culturally and linguistically diverse communities, Aboriginal and Torres Strait Islander communities and communities of all people with HIV - and those coalitions endure.

The foundational principle that emerged from the Green Paper, and that rests at the heart of each of Australia's seven successive *National HIV Strategies* – and soon its eighth – is this: *that those most affected are best placed to respond*. It is a simple idea. It posits that those closest to the epidemic care most about it, are most deeply connected to it, most motivated to minimise its burden, to reach others, and most expert in finding a way through it. It recognised the centrality of lived experience long before that term was in use.

And it is deeply controversial. It challenges orthodoxy. It challenges elites. It challenges doctors, researchers, governments and experts whose paternalistic commentaries and prescriptions for what *ought to be* so usually have sway. It is quite adult. It

starts from *what is*. From the wonderful richness and messiness of lives lived fully. It trusts people to make the best judgements they can in the context of their own lives and guides and supports them with the best of collective effort and community spirit.

By the early 1990s elite resistance to this controversial idea was at its peak, with AFAO at loggerheads with the AMA as doctors declared that the gays had hijacked the AIDS debate. What debate? We were, they said, unreasonably dictating terms in the response.

Damned right.

Our communities demanded the right not to be victims but to be people living with HIV/AIDS. Demanded the right to be part of decision-making about our lives and our futures. To be at the table. And damn it, when it matters most, to be at the head of that table making sure everyone understands that there can be no effective response to HIV/AIDS without us.

We demanded the right to be treated with respect in clinical care, to be partners with our doctors, where our questions are answered and where we make decisions on our own terms, not at a doctor's order.

We demanded the right to speak about sex – about fucking – in our language, with our imagery, not with the sanitised censorship of a high-school textbook.

We demanded immediate access to life-saving treatment when so many were dying and, ultimately, we got it. D-Day was 6 June 1991. 'D' was for deaths, drugs, delays and deadlines. The image of ACT UP members – the late Bill Hathaway and others from the AIDS Coalition to Unleash Power – standing in a row outside Parliament House with red flares lit in distress is one of the defining images of our communities' history. Inside, an activist abseiled to the floor of the chamber as the Health Minister spoke. In Melbourne, the Queen Victoria Gardens were made into a cemetery, with flowers from the garden beds ripped out and replaced with wooden crosses. And we won. Australia's therapeutic goods regulator was reviewed, and drug access was improved. Yet we didn't win. In 1994,

more than 1,000 of us died. In just one year. That's where the title of this talk comes from. A song, that goes: "All the people I was kissing, some are here, and some are missing. In our 1990s."

This was part of my coming out. I found the very best of community - wonderful people – at a time of crisis. Not for all of us. Not everywhere. But in the community I found, there were so many who were living with HIV at a time before effective treatment, when HIV was fatal. And I got active. It was my way of holding on to the precious thing I'd found.

Being agents in our own response to HIV is the ultimate story of the epidemic. It is not universal. And it is not perfect. We are not perfect. And thank goodness for that. But it is real. The early 100% condom culture gave way by the early 1990s to a recognition we were working out how to stay safe without condoms. Gay men in relationships were sometimes agreeing to not use condoms if they were both negative or both positive. It was hard to talk about because the condom culture we created was so strong. But we were evolving.

This was also the time people first spoke of post-AIDS. The idea - so confronting and controversial at the time - that HIV was one issue in our lives and for many of us, not the only issue. It was surreal and painful to hear for those still in the thick of the epidemic. And yet somehow, it was real. The fog of the epidemic was thinning. There were other things that mattered. Space was opening for old things to become visible again and for new things to emerge.

In the early 2000s many AIDS councils were responding to this changing context. To fully respond to HIV, we would also need to respond to the other issues that create vulnerability to it - alcohol and drugs, mental health, STIs, poverty, homelessness and violence. But it was more than that - perhaps, just perhaps - those issues and many others mattered too, in their own right.

By 2007, our communities were back at Parliament House for the conception of another organisation: our partner organisation, bunk buddy and friend, the National LGBTI Health Alliance - whose 10th birthday we celebrate at this

conference. I won't chart the history since that time because so much of it is laid out before you in the content of this program and in the stories we'll share together in coming days. But it is a great journey.

I said at the beginning that it starts with a feeling. So, what is my feeling as I end. I feel hope. How can we not when we reflect on our journey? I've recounted one journey today - my own, and the story I have drawn from our communities' responses to HIV and its evolution as I have experienced it. From movement, through crisis and now normal times. Well, not normal. Definitely not *normal*. But normal in the sense that we are no longer in crisis. Our collective experience is no longer dominated by the trauma of a brutal epidemic. In normal times, we get to look around and to look ahead – to look to where the possibilities lie, to what is new to us, what is important to us - whether it's HIV, ageing, disability, closing the gap, our bodies, our genders or our souls - and I look forward to doing so with you over the coming three days.

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