**Transcript “Disability, Sexuality and HIV” Women on Line, 2018**

**Program Name**: Disability, Sexuality and HIV

**Producer:** Hope Mathumbu

**Broadcast:** <https://www.3cr.org.au/womenontheline>

**Hope: Welcome to Women On The Line, one of Community Radio's national women’s current affairs programs, produced at 3CR Community Radio in Melbourne and broadcast nationally on the Community Radio Network.**

**I'm your host Hope Mathumbu. Women on the Line acknowledges this program is produced and presented on the sovereign lands of the Wurundjeri people of the Kulin Nation. We acknowledge elders past, present and becoming, as well as the owners of the land you are hearing us from.**

**Hope: “Effective responses to HIV have also been based on protecting the human rights of the most vulnerable and marginalised groups – gay, lesbian, bisexual, transgender, queer (GLBTQ) communities, women, young people, sex workers, people who inject drugs, migrants, and people from culturally and linguistically diverse (CALD) backgrounds; however, one group has been left behind. Why aren’t people with disabilities included?”**

**These are the words from an article: ‘HIV *and Sexuality: why are people with disabilities left behind?*’ featured in HIV Australia, a publication by the Australian Federation of AIDS Organisations. In this show, I speak with one of the two authors, Suzanne, an HIV and disability advocate with a background as a healthcare professional in different local and international health contexts. Let's hear from Suzanne:**

**Suzanne:** I've been living with HIV for 26 years and I’ve been active in the HIV sector and positive people's peer organisations at a Victorian, Australian and international level. I’ve worked in the health sector for more than 30 years in Australia and but also African and England. Now I work in the disability sector, where few people know my HIV status. I have sat for eight years on a disability reference group. I also volunteer as a community visitor with the Office of the Public Advocate, monitoring the welfare of disabled residents in group homes.

I have a fairly unique perspective as an HIV-positive woman healthcare professional, now working in disability and as an ally to the disabled community. Sometimes this means I am the only voice in the HIV community on some issues, and especially on disability and HIV

**Hope:** **December 1st is World AIDS Day and December 3rd is International Day for people living with a disability. Can you tell us a bit about the two way relationship between HIV and disability?**

**Suzanne:** Firstly, everyone knows that if HIV is not treated, people develop AIDS, including disability. So they remember the severe wasting and debility. They remember blindness from CMV (cytomegalovirus)

People could become deaf from the antibiotics which we used. Um, HIV in the brain caused dementia. Nowadays, most (HIV)positive people are well, productive and getting on with with their lives. But there are also many older positive people who are ageing and starting to develop disability. Because many of the early HIV treatments did not cross over into the brain, some are starting to develop HIV-related dementia - what we call HAND….H-A-N-D….HIV-associated Neurocognitive  Disorder. Alzheimers Australia have developed some really great resources online.

Secondly, having a disability can put a person at higher risk of contracting HIV, other BBVs and STIs (Blood-Borne Viruses and Sexually Transmissible Infections). So imagine you’re a young person with a disability, but you don’t get any sexuality education or HIV prevention information, because there is no accessible information. Your parents want to protect you from having sex. ‘Cause they think it’s better for you to be ignorant instead rather than risk you learning about your sexuality and safe, respectful sexual relationships. Imagine if you are young disabled person, who is questioning your sexuality or gender, or you come from a different culture or language background. Who would you turn to for information ?

Some kinds of disability may pre-dispose, put people at risk- so cognitive disabilities or mental health issues or psychosocial disability….say for instance, bipolar disorder … could mean that people engage in risky sexual practices or injecting drug practices.

**Hope: HIV in Australia and various other western nations looks very different to HIV in low income countries in Africa or parts of Asia for example. Can you tell us a bit about some of these differences and how people living with HIV and people with a disability are affected in those contexts?**

**Suzanne:** In Australia and most Western nations, the HIV community is mainly gay men, or men who have sex with men (MSM) some gender-diverse folk. It’s probably maybe about 10% heterosexual, and positive women about 10%. But you know, HIV is now a chronic illness, because we have effective HIV treatments.

In contrast, it’s mostly a heterosexual epidemic in low income countries, where about 90% of the world’s positive people live. There are more positive people, but not all, who can access first line combination treatment. But when that treatment fails , very few positive people can access the newer, better and more costly treatments. So it does mean that positive people in low-income countries are more at risk of developing disability because they can’t access appropriate treatment

In these countries, the HIV epidemic is also driven by social, economic and cultural factors…so lacking access to education, health services..lacking an income and sustainable livelihoods…..These also fuel gender inequality.

All of these threats and challenges that put people at risk of HIV are even greater for people with disabilities, especially the issue of gender–based violence.

Let’s remember that forced sex increases the risk of HIV infection because of trauma to the genital tract, or to the rectum. Women with HIV are at higher risk also of sexual violence. But women and girls with disabilities experience even higher levels of sexual violence and abuse. In fact, UNAIDS has identified violence and sexual abuse as the number two reason that puts people with disabilities at the risk of HIV. Women and girls, who are deaf, who cannot speak, or who have intellectual disability are particularly targeted because they cannot tell anyone, and they’re not considered to be reliable witnesses. So if you think world-wide, the movement against violence against women, this is an issue that crosses all cultures and boundaries.

The other thing that’s a big difference is the quality of the healthcare services. You know, in Australia, we have fabulous HIV services. People self-select to work in HIV. It’s shifted so we now work in a shared care model between HIV services and the GPs. However, in low income countries, UNAIDS has identified stigma and discrimination in healthcare settings as the major cause of people with disabilities being at risk of HIV infection, and not receiving also appropriate treatments, if they do become HIV-positive.

Part of this is that healthcare workers are not trained to work with people with disabilities. That’s both in resource-poor settings and also western countries, like Australia. You know, if we talk about the four pillars of primary health care – curative services, preventative services, health promotion…the health sector is fine with that. The weakest link is actually rehabilitation and supporting people with disability.

In terms of sexual and reproductive health services, tremendous progress has been made for women living with HIV. We can now prevent babies being born with HIV. Mothers are more likelt to be able to access treatment. So the idea that women with HIV shouldn’t have kids because the kids are going to be infected, and the mothers are going to die anyway, so why bother?.....So the prevention of mother-to-child transmission and the rollout of antiretrovirals to mothers is huge progress.

The same cannot be said for women with disabilities. They are still deemed that they can’t take care of their kids. They’ll make poor mothers. They don’t have any reasonable livelihoods, to look after the kids….So there is a real issue in the wider community and healthcare settings against women with disabilities having children. Whether people with disabilities have HIV or not, they have the right to the same healthcare – the same range, quality and standard of healthcare – as anyone else in Article 25 of the UN Convention for the Rights of People with Disabilities…and this includes sexual and reproductive health services. Under Article 23, people with disabilities also have the right to marry, and have a family, and decide on the number and spacing of their kids. And the access to age-appropriate information, reproductive and family planning education.

**Hope:** **On Community radio around Australia, you are listening to Women On The Line. You were just listening to Suzanne, an HIV and disability advocate with a background as a healthcare professional in different local and international health contexts. We were discussing the relationship between disability, sexuality and HIV.**

**And don't forget to also tune into 3CR's exciting lineup of advocates, artists and radical disabled activists for 3CR's dedicated 12-hour broadcast as part of International Day of People with a Disability on Monday, 3 December. These programs can be downloaded from:** [**https://www.3cr.org.au/disabilityday2018**](https://www.3cr.org.au/disabilityday2018)

**If you're just tuning in, we are now heading into the second half of my conversation with Suzanne, an HIV and disability advocate, discussing the relationship between disability, sexuality and HIV.**

**Hope: In terms of the Australian context, we have seen a lot of progress being made in terms of treatment and the prevention of new infections. But how are people with a disability considered, if at all, in these conversations?**

**Suzanne:** I became HIV-positive before the advent in 1996 of effective combination therapy . The progress in HIV prevention and treatment has been enormous, but people with disabilities are still left behind.

We’ve been very lucky in Australia to be able to access the full range of HIV treatments through the pharmaceutical Benefits Scheme. HIV+ mothers can have babies that are HIV-negative. Then there’s the breakthrough research showing that positive people taking treatment, who have achieved at least three months of undetectable virus in their blood cannot infect their sexual partners.

This is known as U = U, which means that Undetectable virus equals Untransmissible (sexually). This is a huge breakthrough for combating the stigma and discrimination about people with HIV. Another intervention is PrEP, Pre-Exposure Prophylaxis, so prevention. So someone who is HIV-negative can avoid HIV infection by taking daily HIV medication, in the same way that women take the oral contraceptive pill to prevent pregnancy.

However, HIV and STI prevention and education has ignored the fact that disabled Australians are.. surprise ! ..sexually active like anyone else, and that some are also LGBTIQ and gender diverse.

For example, there has been no peer education program in the Deaf community, or for the Deaf LGBTIQ community since the early 1990s. Consider all of the advances that have happened since then.

I know of a Deaf HIV-positive gay man, who refuses to use an Auslan interpreter when he attends the HIV clinic, because he’s afraid is HIV status might be disclosed by the interpreter. Incidentally, we see the same problem for positive people from CALD (Culturally and Linguistically Diverse) backgrounds, who refuse interpreters because of disclosure issues.

So these are some of the examples for the continued need for community engagement. Unfortunately, because HIV is mainly managed through medical interventions, through just taking pills, we’ve kind of lost those community development approaches.

Australia was the first country in the world to have a National HIV strategy, in partnerships with affected communities – people living with HIV, the gay community, people who injected drugs, sex workers.

Previously, there have been links between Australia’s positive community and disabled peoples organisations (the DPOs). NAPWHA ,which is our National Association of People Living with HIV Australia, used to be a member of the peak body AFDO, the Australian Federation of Disability Organisations. But NAPWHA withdrew from AFDO round about 2012 because positive people are staying well. They’re not getting sick and they’re not developing disabilities.

Another issue for me is none of Australia’s national strategies for HIV, Sexually Transmitted Infections , Hep B, Hep C or the Aboriginal-Torres Strait Islander Blood-Borne Virus and STI strategy – None of them make any mention of disability in the guiding principle of access and equity.

I am really disappointed that NAPWHA and state positive organisations have not pushed for the recognition and inclusion of people with disabilities, within the key target populations. The five strategies I spoke about all expired in 2017,and new strategies are currently being drafted. There have been isolated voices like mine,in the HIV sector, who have call for disability to be included, but really, this is the time the disabled community to step up and make their voices heard, and demand their inclusion in their new strategies.

The disabled community and the positive community live in silos. People with disabilities have probably also been prioritizing the NDIS – the need for transport, for housing, for education, for jobs, for income. The ability to express your sexuality like anyone else is part of what makes you human. So this is the time for the disabled community to actually lobby to be included in the new strategies. I would really hope that positive people’s organisations will also be their allies and support them in these demands.

**Hope: And what about on an international level? I mean, it was four years ago now that Melbourne hosted the International AIDS Conference. Where those conversations being had then, and where are they at now?**

**Suzanne:** Australia was very proud to host the 20th IAC (International AIDS Conference) in 2014. It was partly also recognition of Australia’s leadership in HIV responses. I worked with AFDO and international disability activists, local disability and human rights organisations to set up the Disability Networking Zone in the Global Village.

In the conference proper, there were unprecedented number of oral presentations and posters focussing on disability, and these can still be downloaded from the 2014 program.

However, the Melbourne motto was “No-one left behind” and people with disabilities were not specifically mentioned as a key population. It was only the former High Court Justice, the wonderful Honourable Michael Kirby who in his opening speech, who apologised that he was not a disabled person facing HIV. He had known and it was hoped, and urged, that a voice would be given on that occasion in the opening plenary, to such a speaker so that truly no one would be left behind. And he hoped that such voices would be raised in Melbourne, loud and clear. While the disability focus continued in 2016 in Durban, but it didn’t seem to feature very highly in the Amsterdam conference this year.

There is a dissonance between the International AIDS Conference, which is actually run by the International AIDS Society, who are the doctors. These are the clinicians, the medical researchers, the scientists. And that’s how the International AIDS Conference started off. Later on, there was the introduction of the social scientists, and positive people and affected communities. But basically, the International AIDS Conference is a scientific and medical conference.

UNAIDS, on the other hand, identified in its GAP report in 2014, that people with disabilities as one of the populations left behind. The real difference is that UNAIDS is the umbrella HIV agency that co-ordinates the relevant HIV responses from all the different UN organisations – whether that’s the World Health Organisation, the Development programs, the economic programs, like the International Monetary Fund.

So UNAIDS actually, I would trust UNAIDS maybe can bring along this issue. I think when the AIDS Conference goes to San Francisco in two years time, in 2020, that the disability rights movement there, which is really strong will force this issue there, the need to include people with disabilities in HIV responses. And I would hope that Australian and other international disability organisations are going to take this up, and that Australia positive organisations and the Australian HIV sector will support this at San Francisco, ‘cause for sure there’s going to be a big Australian contingent there.

We’ve already talked about how Australia’s leadership in terms of its national strategies and its approaches of harm minimisation. And also exemplifying the new paradigm that HIV really forced on us, in that you have to link HIV prevention with care. You can’t use the traditional strategy of infectious disease control – isolation, detention, quarantine, criminalisation. That does not work for people with HIV and the virus. So yeah, Australia has actually been really great as a role model, how we prevent through caring, not preventing through what I call punishment.

So Australia has provided strategic leadership in its HIV services, in its HIV and international development programs, such as funding NGOs (non-government organisations), strengthening health services, capacity-building through partnering Australian peer organisations – positive people, people who inject drugs, sex workers – with their counterparts in the Asia-Pacific, and especially in Papua New Guinea, our nearest neighbour. I am not sure whether Australia has supported Papua New Guinea’s health and HIV programs be more inclusive of people with disabilities. Likewise I don’t know that the disability programs that Australia has been supporting in Papua New Guinea have been inclusive of HIV, STIs and Blood-Borne Viruses.

There is much to learn from Africa. We often think that learnings are always from the North to the South, from the industrialised wealthy countries to the lower income/resource. However, there has been much to learn from Africa. The Durban International Conference in 2000 was groundbreaking. There was a local coalition of South African civil groups o get cheaper treatments. It was the very first time that the West faced the reality of the devastation of families and communities by AIDS. So Durban marked the beginning of global networks of clinicians, researchers, peers and activists working together. I think it’s also probable that Africa is leading the way. Disabled people’s organisations are bringing change, making HIV services more inclusive.

I would hope to see partnerships between positive people, people with disabilities and their organisations. But the major barriers are they need to see past the myths and stereotypes they believe about each other, and stop seeing each other as competition for scarce resources, and instead build bridges to work together on the challenges they face in common.

I think Australia cannot also afford to rest on its laurels. Australia is a weird combination of both developed contexts, but also if you consider our regional and remote areas of Australia, that’s like living in the Third World. You know, to the north, we have Papua New Guinea , our nearest neighbour, so Australia needs to be able to include strategies, resources and services, not only for our well-developed and served populations in the cities, but also in our remote locations and our neighbours in the Pacific, especially PNG.

**Hope: Where can people go to find out more information or access services in disability as well as sexual and reproductive health?**

**Suzanne:** The Royal Women’s Hospital is THE go to place for Victoria women with HIV and Victorian women with disabilities for their obstetric care and probably their gynaecological care. They are the centres of excellence.

There are probably clearer pathways for people with HIV, especially women with HIV, to access information and services for sexual and reproductive health. However, I am not sure whether the same pathways are so clear for people with disabilities and what kind of accessible services there are in places, like Family Planning Victoria or Marie Stopes clinic.

Positive people have often found, often you just need to find the right provider for you. It might be that people with disabilities, women with disabilities face the same issues. They, look, they might prefer to ask their peers or peer organisations, you know the DPOs , and ask around where have they found, or are there other people who have found individual healthcare providers or services which have best met their needs. As we said before, you know, healthcare providers and mainstream services have not received really comprehensive training in supporting people with disabilities. But maybe you can find some individual, who is personally motivated, and has developed particular expertise, in supporting people with particular impairments. So if you don’t get satisfaction in your mainstream sexual and reproductive health services, then ask around in your own disability community, as to who they would recommend.

And just a final point for what you can do personally, for people with HIV and people with disabilities….if a friend or family member discloses to you they’re HIV-positive, do not ask them “How did you get it?” It is the rudest question anyone can ask, and it’s none of your business, not even healthcare workers. Not even a question that positive people ask each other. If you have a friend or family member who has HIV or has a disability, and they want to become parents, don’t judge them. Instead think about where they can get information, how can you support them to reach their goals and be the best parents they can be.

**Hope: We've come to the end of my conversation with Suzanne, an HIV and disability advocate with a background as a healthcare professional in different local and international health contexts. We were discussing the relationship between disability, sexuality and HIV. This show is dedicated to and acknowledges the work of the late Dr Paul Chappell, a South African-based disability and sexuality academic and activist.**

**And that’s all for Women On The Line today.**

**Women on the Line is a Community Radio national women’s current affairs program. It’s produced and presented by a range of women broadcasters from 3CR in Melbourne, and broadcast across Australia on the Community Radio Network. We greatly appreciate financial support from the Community Broadcasting Foundation. We welcome your comments or thoughts on today's show, so send us an email to womenontheline@gmail.com or phone 3CR on 03 9419 8377. Women on the Line programs can be downloaded from our website** [**www.3cr.org.au/womenontheline**](http://www.3cr.org.au/womenontheline)

**The theme music for Women on the Line is “Slideshow at Free University” by Le Tigre. I’m Hope Mathumbu, and I hope you can tune in again next time.**