

Life+ Peer navigation for people newly diagnosed with HIV

Queensland Positive People

CHRISTOPHER HOWARD: A little bit about our organisation. The historical role of peers in the HIV response, so for those of you who don't know what HIV is, it's the human immune deficiency virus that causes AIDS, or AIDS acquired deficiency syndrome. We're going to talk about the contemporary role of peers in the response, the peer navigation model that we developed. We'll hear from Tiko in particular around his perspectives as a peer navigator and we'll look at peer navigation from now and beyond. A little bit about us as an organisation, so we were founded in 1989, essentially to support people living with HIV across the State of Queensland. Our vision as an organisation is to help improve the health and wellbeing of those people living with HIV across Queensland and encourage individuals to be informed and empowered and to lead lives free from stigma and discrimination. Our mission as an organisation is to provide a comprehensive range of services that meet the health and wellbeing needs of individuals living with HIV and ensuring these are delivered in accordance with internationally recognised best practice and peer navigation model which I'll talk about, is actually one of those. I mentioned that the model was made possible through a number of different funding sources and is adapted from an internationally recognised best practice model that is provided in Canada. I just want to talk a little bit around the historical context of the role of peers in the HIV/AIDS response, so for some of you in the room who might remember in the early '80s the emergence of AIDS in particular, it required a very significant involvement from the community, the people living with HIV and those that were dying from the virus were actually the carers, they were the educators, they were the advocates, they were the

activists providing social, emotional or practical support to their friends, their colleagues, their loved ones and it was done primarily from a position of volunteerism. Those individuals were really not paid for that work, there was a lot of stigma, a lot of fear, a lot of ignorance around HIV and AIDS. It required a community driven response. I don't know if you know the Ottawa charter that was developed in 1986? Following on from that was a principle that was endorsed globally, which referred to the greater involvement of people living with HIV and essentially, this evolved over time to not only greater involvement, but really a meaningful involvement of people living with HIV. Essentially utilising their lived experiences, their personal experiences to inform the broader HIV response, and that was founded on some key principles about local responses to HIV, that policies and programs were tailored and responsive and there was a focus on self-determination and personal empowerment. This is a diagrammatic... I'm sorry it's a very busy view, but it's actually the GIPA model. The key principles are the branches of the tree and the leaves form the actions, the recommended actions. So if anyone wants the link to that to have a look at it closer in depth I'd encourage you to come and see me. But it's a really fascinating model to implement in practice.

NEW SPEAKER: Could you just tell us what GIPA stands for?

CHRISTOPHER HOWARD: It stands for the greater involvement of people living with HIV and AIDS and MIPA stands for meaningful involvement of people living with AIDS. I just wanted to turn our attention towards looking at how HIV has changed over the years. So in 1983, the HIV virus was identified by a number of clinicians and then basically until 1996, there wasn't any effective treatment for the management of HIV and a lot of people unfortunately succumbed to the virus and died. But in 1996, there was some ground breaking clinical evidence as a result of extensive trials that demonstrated that triple combination therapy, so that's the utilisation of a number of different therapies was very effective in suppressing the replication of virus in the body. What we did see was the number of people that were living with HIV started to increase and the number of people dying from HIV declined. Then very rapidly over the

past few years we've seen significant advances in treatment and there was some major milestones and I won't go through them, but they're essentially here on the slide. Really, the take home message from this slide is that there was resounding evidence that early intervention or early treatment following a diagnosis of HIV not only prevented disease progression in an individual, but also prevented onward progression sorry, onward transmission of HIV. So there were two key elements which it's now known as TASP, or treatment as prevention. That's the prevention of disease progression of a person living with HIV and the prevention of onward transmission. In 2013, the United Nations AIDS Committee part of the World Health Organisation on the basis of treatment as prevention developed some modelling to basically say by 2020 if they had 90 per cent of people that actually knew they had HIV, that was their target and that 90 per cent of those people that knew they had HIV that were actually treated and then 90 per cent of those people that were treated for their HIV had undetectable virus. That is, that the medication suppressed the virus so it was not infectious, that they could virtually see the elimination of HIV by 2020. What that essentially informed was some strategic focuses. There was the global United Nations' AIDS targets of 90, 90, 90 and then there were strategic objectives embedded in Australia as 7th National HIV Strategy, which is currently being reviewed for 2018 and also, the Queensland HIV action plan. So these principles became embedded as strategic objectives in all these levels of planning. As an organisation committed to the health and wellbeing of people living with HIV, we identified there were a number of ways we could respond to support those strategic targets, but also support the health and wellbeing of the PLHIV population, so we developed two distinctive programmes, one of which is a peer testing clinic. This is where peers in our community test those most at risk of HIV for HIV and other STIs and we have a clinic in Brisbane and one on the Gold Coast and we also developed the Life + program which was about addressing the other 90 per cent. 90 per cent of people living with HIV would be on treatment and 90 per cent of those people would have undetectable viral load. I'm very happy to say that the model that we submitted to the department in 2015 which was looking at an integrated suite of programs was actually funded and that the department for

the first time recognised that a PLHIV peerbased organisation was best placed to respond to the holistic needs of people living with HIV across Queensland. So some of the other services that we provide in addition to peer navigation is complex case management for individuals living with HIV, health education information and resources and stigma and discrimination. So the broader goals of the program are actually listed on this slide, but I think most of the goals are achievable through the peer navigation program and a particular focus for us is preventing HIV disease progression in PLHIV and improving the overall quality of life of our peers. I talked a little bit earlier around how peers have always been central to the HIV response and primarily in the role of volunteerism. This slide here just models where peers now fit within the broader response to HIV. So we work in the peer navigation program alongside health professionals to help people newly diagnosed with HIV to synthesise that diagnosis into their lives by the provision of an early intervention model for individuals following a diagnosis. As is the process for any program development, there's a very logical sequential flow, but I really wanted just to highlight that individuals living with HIV were at every step along the way of this process and engaged in the focus testing and the development, in the delivery. So PLHIV were involved at every point. I'm now going to hand over to Tiko to talk a little bit about the model and the lived experience.

SATRIO NINDO ISTIKO: Thank you, Chris. If you look at this picture, the white person in the middle is newly diagnosed and you can imagine how complex and overwhelming it is once you are diagnosed with HIV to navigate the HIV care and treatment. What we did is we did a needs analysis result to identify the information and support needed for that person and the result of that analysis are basically one, about information, people need not only information about diagnosis, treatment and navigating HIV care, but they also want information about disclosure, about legal rights and responsibility and other topics. In regards to support, they want someone who can provide emotional and social support and can help to put their diagnosis into perspective and help to ease their fear and anxiety of becoming an HIV positive person. What's really interesting is that apparently they want this information and support to come

from a trained PLHIV peer worker and they want to meet this peer worker in a face to face setting and they want it right from the get go, since day one of diagnosis. So what we did is created this model in which client is at the centre of our model and then we have three integral parts starting from the peer support, in which in this part the peer navigator will use their lived experience as an HIV positive person to provide that emotional and social support and in the navigating health system part, the peer navigator will help them to build trust with the doctors how to access treatment through the pharmacies and how to understand their lab results and through the peer navigation, the peer navigator will deliver education by using educational modules. These education modules basically are categorised into two categories. The first is the core modules and the second is elective modules. For all clients they have to go through the core modules, in which they will talk about HIV one on one. They understand the virus and then the treatment and they're navigating the health system, but when it comes to the elective modules they get to select which topic they want to discuss and that's because in delivering this educational modules it is based on the adult learning theory. Now the intervention itself is very highly structured. It's 15 hours for a client and that can range from 4 to 8 weeks and it's very flexible in terms of setting. The peer navigator can go to the doctor's appointment with the client or meet at a coffee shop and what's important is towards the end of the engagement the peer navigator will assess whether the client is actually confident to manage that diagnosis and whether there are other issues that need to be referred to a case manager. Now because we need to provide a very good quality, safe and culturally appropriate services, we have peer navigators all across Queensland. Mostly they are in Brisbane, but we also have in other regions, as well. We have females, we have heterosexuals, there are peer navigators from Africa, Aboriginal and Asian backgrounds and they also have other lived experience from mental health issues, alcohol and drugs and also homelessness, so that we can address that intersectionality issues within the clients. When we provide training and then we provide the skills development and also ongoing supervision to make sure that the service that we provide is safe and is of good quality. So for me, how do I work within this model? For me, being a peer navigator

is about empowerment. I empower the clients and I empower myself, so I have to bore you poor people about a little story about myself, in which I came to Australia last year as an international student to study Master degree in health management and I was diagnosed just one month after I got into Australia and then I have to navigate the Australian HIV care which is so simple to understand and that's an understatement! Of course, unfortunately there's people that helped me to understand that and how to better manage my diagnosis and in June, I applied for the job to become a peer navigator to work with people who don't have access to Medicare. Now what we have to understand is prior to that, I'm just a consumer, I'm a consumer with a very complex issue just like any other consumer, but starting as a peer navigator, this consumer can provide services to other consumer, and after working a while, I discover even more complex issue with my home country in which there's a persecution towards the Indonesia LGBTIs and I apply to become a refugee here in Australia and so since December, I'm basically an asylum seeker, but thankfully with my job as a peer navigator and my study I keep on going and I find myself now as a team leader of this peer navigation team and right now, I'm presenting in front of you all, not only as a peer navigator team leader, but also as a gay HIV positive asylum seeker.

APPLAUSE

Thank you. I months ago about people who don't have access to Medicare, in which apparently there's another term, Medicare ineligible, because obviously we need more terms. Medicare ineligible is people who basically have a working visa, student visa, working holiday visa or holiday visa, they can't access the Medicare and therefore, they cannot access the HIV treatment and the HIV treatment itself, it will cost about \$1,000 to \$1,500 a month. That's the first regimen that the doctors prescribe, so we have to find other ways for these people to access treatment. If you look at the building blocks on the top, that's the story that we want all people living with HIV to go through. They got diagnosed, they are linked to the care, and they retain their linkage to the care. They're committed to the treatment and then they achieve that final suppression or undetectable viral load in which their blood the volume of the virus is really low. But for Medicare ineligible, they have access to navigate that various

access to treatment. It's really difficult, it's not straightforward and then there's a financial barriers that I mentioned and then there's a low health literacy, because it's not easy to understand a health care system in a foreign country and also, they have to navigate complex migration system, because a lot of them wants to become permanent resident, but to become permanent resident if you're HIV positive you fail the health requirements and you have to waive the health requirements. Very complex. Basically, up until now I've supported 10 Medicare ineligible clients out of 76 peer navigation clients and most of them are males, most of them come from Asian countries and most of them hold student visa, but what I consider as a big achievement for the peer navigation program is that all of them started training within 3 months and that's the goal of our programs and we're very proud of that, because we've been working hard to achieve this and we get amazing feedback like people saying they're really confident now in managing their HIV. That rarely happens, it's like we're giving a fast track process to people to achieve that level. And so I guess the benefits of being a peer navigator for me, it's all about empowerment, like I said. I as an asylum seeker get to develop my skill, apply what I studied about quality improvement, people management, program evaluations and this is the skills that Australia needs and I get to contribute to the Australian society in general and PLHIV specific and I'm proud of that. So to discuss more about the outcomes and challenges, please welcome Chris. (APPLAUSE).

CHRISTOPHER HOWARD: Thank you Tiko and thank you very much for sharing your very personal story. Just going to touch quickly, since the peer navigation program has been up and running, as Tiko indicated we've had 76 clients, 10 of which have been female and the balance male. Interestingly, the demographic there for the age range aligns with, of course, the epidemiological data from Queensland Health. It's a very concerning fact for us as a PLHIV organisation that we continue to see the rate of diagnosis amongst Aboriginal and Torres Strait Islanders increase and that's represented in this slide that ten of the people that we've supported since the peer navigation program has developed have been Aboriginal and Torres Strait Islanders. We just want to talk a little bit

CHRISTOPHER HOWARD: I want to talk a little bit around the challenges. I didn't necessarily want to paint the implementation and operation of this program as being plain sailing. We've certainly had our challenges in employing peers to work in the role. Some of those challenges have been peer navigators working within their scope of practice and stepping outside of that doing, as you can appreciate, peers work in this role for altruistic reasons and they're really wanting to help their peers. They sometimes go a little bit far, so some boundary violations have occurred. We have had peer navigators through lived experience that bring great strength to their role that have a prior history of drug and alcohol misuse. We have seen some peer navigators triggered and relapsed. So the need for intensive support, ongoing supervision and the retention in alcohol and other drug programs or mental health programs are really critical to ensure the health and wellbeing of our peer navigators. Supervision and support is challenging for your geographically dispersed team of peer navigators right across this State and... I did correct this misspelling, but it's actually casual employees, but casual employs, each engagement with a peer navigator is 3 hours, so we pay them at a casual rate, but under the award it actually can be quite expensive, so that's an ongoing challenge. Technology use, also. All our peer navigators are armed with mobile phones and mobile tablets and for some peer navigators it's been a real challenge in terms of utilising that technology and also data entry. We capture quite a lot of data. We're partnered with the University of Queensland for an evaluation of this project so that does require the inputting of data, as well as our reporting to Queensland Health. Basically, future plans for peer navigation, so we're extending the program to those at risk of falling out of care. So what our care managers identify as some of the clients they're working with are at high risk of falling out or disengaging in care and they identify as significant value that a peer navigator can provide for a time limited period, so we're extending the program to that. Strengthening the capacity of all peer navigators to work with Medicare ineligible PLHIVs, so Tiko will be developing module training for all peer navigators given that Medicare ineligible peer navigators, Medicare ineligible PLHIV are across the State, and the thing that's probably stood out for me in the development of this program is that one size doesn't fit all.

I think in recognition of that is tailoring and adapting the program more specifically to meet the needs of Aboriginal and Torres Strait Islander people. We talked about this as being an early and brief intervention model. That just doesn't work for some Aboriginal and Torres Strait Islander identifying people, so we acknowledge that we really need to work with the community to adapt the model in a more suitable way. What I can sort of say and it's not on this slide, is that we have been successful in securing funding for Townsville to implement a further innovation which is a HIV, STI peer tester as well as peer navigator position which will sit within the health service within the Townsville region, so it's a pilot project. It has been funded, but yet to be implemented. Take home message is really from here, is that peers have always been central to the HIV/AIDS response, as I said earlier today and we have a vital role to play to support the global achievement of those targets. We as individuals within the community, we're here to empower and support our peers and peer navigation really does that in a really proactive and constructive way and the model continues to adapt to the changing needs of our consumers essentially and to our other key stakeholders. Basically, questions, if we have time.

NEW SPEAKER: We most certainly have time. Tiko, would you like to join Chris. Does anyone have a question, I'll bring the microphone to you? Steve down the back.

NEW SPEAKER: Chris and Tiko, thank you for a very educational presentation and obviously the innovation to establish a peer network needs to be congratulated and continued. I actually am HIVpositive and have been since 1983 and during the 80s and 90s we undertook a major public education program and worked across multiple sectors then and there was a degree of success, although the program didn't actually focus on Aboriginal and Torres Strait Islanders and was lacking in that respect. I'm wondering, is there room today for a more prolific or higher profile public education program? Because we are seeing certainly in North Queensland some rise particularly in STIs and certainly HIV Indigenous communities. I'm wondering what, if any strategies, you or others might be planning to raise the bar in terms of public education?

CHRISTOPHER HOWARD: Thanks, Steve. So the question was really what are we doing as an organisation to raise the profile of HIV, particularly in Aboriginal and Torres Strait Islander communities. Would that be a fair?

NEW SPEAKER: STIs?

CHRISTOPHER HOWARD: Our role primarily as an NGO is really to work with people already living with HIV. In terms of the prevention space, the government has funded other organisations to work in that area and in particular with the amount of money the minister's committed to the Aboriginal and Torres Strait Islander health strategy for the north, \$15 billion, it's really hopeful that there's something very constructive that comes out of that. We're very keen to partner where we can. We have an Aboriginal and Torres Strait Islander peer navigator in Cairns that currently provides outreach support to Townsville and as I said, we're very keen to continue to develop and adapt the model to ensure that it's more appropriately meets the needs. I think the thing that as an early intervention model, the idea of peer navigation is to help people synthesise the diagnosis into their lives and prevent the risks of falling out of care and we do know that Aboriginal and Torres Strait Islanders are at greater risk of falling out of care. That's why this program, but we understand there are real complexities in engaging in the community and needing to be sensitive to the individual needs.

NEW SPEAKER: Do we have any other questions? We've got one, two and three. Just to let you know, the lovely Helen checked and unfortunately there's nothing we can do about the dripping sound, so apologies if that's distracting.

NEW SPEAKER: Thanks for the presentation, it was wonderful. I'm interested in the peer navigator model as it's adapted to other kinds of diseases and conditions and the one thing that I'd like to ask, I've got a lot of questions, but the one thing I'll ask about is what do you do about the boundary breaches, where the peer navigator and perhaps they've gone outside the scope of their practice. How is that handled and what have been your main issues with that?

CHRISTOPHER HOWARD: So the question was peer navigation adapted to other health care. There are two questions. One relates to peer navigation within other health care settings.

NEW SPEAKER: Mainly the second part, boundary violations.

CHRISTOPHER HOWARD: They're lots of fun! I'll pass back to Tiko.

SATRIO NINDO ISTIKO: I just repeat the question. The question is how do we handle whether there's a breach of boundary from the peer navigators themselves? There are a couple of layers, just like any other quality improvement strategy, you cannot depend on just one method, so one is that we provide formal supervision every two months, so that's to talk about a lot of things, including engagement with clients and then there's an informal feedback that I always give to the peer navigators every time I see a warning sign. That can be from the report that they just wrote and if I sense there's a gut feeling that it's just not right, I always tell me peer navigators that I'm going to be open and honest about it and then we're going to have a discussion about it. Then also, I always encourage the peer navigators to plan and then seek approval and then act. So if they're kind of thinking about a strategy that they want to utilise to engage with the client and they're not sure, how they may be overtly confident about it, have a check with me first. Talk to me and see what plan do you have and then we discuss that, so that's how I mitigate the boundaries. But when it already happen, you don't punish, you don't use punishment as a centre of the philosophy of managing breach of boundaries. But instead, it's about open and honest discussion with client as the centre. So we have to get a clear information about what happened to the client and then we need to be clear about what exactly, how the peer navigator responds to that and then we created a plan of action from that information.

CHRISTOPHER HOWARD: Thanks, Tiko. I might just add that where people have relapsed back into drug and alcohol use, basically we support those individuals to engage in a treatment program. They step aside from their role until such time as they're stabilised and we're also cautious about how we link those people, so we don't link those peer navigators necessarily to people that may trigger some of

those behaviours. It's a really important and our board as you can appreciate, wanting to ensure that risk is managed. Some of those other challenges where we have peer navigators in rural and regional communities are that socialise and sexualise in those environments through social media and other mechanisms, so we provide very clear guidance and support around that. As always with any other ethical or boundary issue, we always encourage them to seek guidance and support be open. In terms of adapting peer navigation to other health care settings, look I believe it's done quite widely within the mental health sector and in HIV it is done in the UK, in Canada and in San Francisco, I believe.

NEW SPEAKER: Thank you, Chris. We are fast running out of time. Two people have indicated they have a question, ask them to ask their questions and if you can respond briefly to both of them, that would be great.

NEW SPEAKER: I guess I was interested in the opportunity especially for your volunteers, your peer navigators to transition over into doing that support work in other areas?

NEW SPEAKER: We've got one more up the front.

CHRISTOPHER HOWARD: Certainly the board are very keen to explore the expansion, for example, peer navigation for injecting drug users for example. It may be for sex workers, for other marginalised and at-risk groups to help support those individuals to engage in care.

NEW SPEAKER: I was just wondering if you had incorporated within your peer navigation models those that are suffering from hearing voices, which is associated with paranoia and claiming the HIV as an external factor coming from such thing as the devil instead of understanding it's a human acquired causal? What are you incorporating within your peer navigation models towards assisting these people, because I don't see them in mental health units at the moment?

CHRISTOPHER HOWARD: That's a very complex question, but essentially we really work with an individual around exactly where they're at as an individual. For exam-

ple, we've talked very specifically about a very protreatment approach, but as an organisation of people living with HIV, we respect an individual's choice to choose whether they engage in treatment or not and similarly, that relates to how they perceive the acquisition of HIV and so forth. Where we identify there may be other ongoing issues for that individual, it may sit outside this scope of practice of the peer navigator, so we'd be keen to explore how we might work with that individual about providing other supports through case management program. We want to ensure that what we're providing, peer navigators are safe in the work they're doing and we respect the duty of care to ensure we're providing the best support to PLHIV.

NEW SPEAKER: Thank you. Can we thank Chris and Tiko for their presentation and also for their courage in sharing their own lives and experience. Thank you.