

M *EANINGFUL*

I *NVOLVEMENT OF*

P *EOPLE LIVING WITH AND*

A *FFECTED BY HIV*

MIPA REPORT & ACTION PLAN

2018 - 2019



Western Australian
AIDS COUNCIL

What is MIPA?

The Western Australian AIDS Council has a long and proud history in its commitment to and promotion of the meaningful involvement of people living with and affected by HIV.

Be it at Board level, the substantive HIV Positive Peer Education role, campaign design and involvement and focus groups, the organisation continues to adapt and evolve in providing the means and opportunity to ensure continued commitment to the two core MIPA principles:

- 1. Advocating for the meaningful involvement of people living with HIV and affected communities in all aspects of the HIV response.**
- 2. Fostering active and meaningful involvement of people living with HIV and affected communities in all of our activities.**

“As a Board member of POWA and on the Board of NAPWHA, I was happy to be involved with the MIPA working group. I found the WA AIDS Council to be open with the procedure. It was a great mixture of people or the working party of both professional and people living with HIV. Even the group of people with HIV were very diverse with MSM, women and IDU. This was very important to me to have as much diversity as possible. It was very easy to follow with each program broken down, and then able to comment. We were kept up to date with the changes at the next meeting. Overall I felt it to be an open and honest process”.

- Diane Lloyd, NAPWHA & POWA Board Member





Chairperson's Message

Asanka Gunasekera

It is with great pleasure that I present this Meaningful Involvement of PLHIV and Affected Communities (MIPA) Audit Report and Action Plan to Community.

Clause 3.1(1) of WAAC's Constitution outlines our objectives. Everything WAAC does, and hopes to do, emanates from this essential text. In the first line, the words "in partnership with our community" appear. Thus, "partnership" is central to everything. For WAAC, the HIV Positive Community has (and will) always be a key partner. To honor the lived experience of HIV Positive people and to recognize their continuing and vital contribution, WAAC completed its first MIPA Audit in 2017/2018.

The Report follows an extensive organisation-wide audit of WAAC's programs and services to investigate how HIV Positive people contribute to the work of the agency and what we can do to more meaningfully involve them.

A consultative committee made up of Board Members, People Living with HIV, staff and key stakeholders painstakingly reviewed every aspect of the WAAC business against the extensive MIPA criteria. From the M Clinic, Freedom Centre, PLHIV Peer Support, NSEP, Inclusive Education WA, and Bequest Programs to Case Management & Counselling, no corner of WAAC's operations was spared MIPA's investigative reach.

Over the course of 12 months, honest and robust deliberations occurred at a series of 10 meetings held at the WAAC Boardroom. A broad spectrum of perspectives, experiences and ideas provided integrity to a complex but necessary conversation.

In a difficult year that saw weather events, office damage and closure, a competitive tender and organisation restructure, the MIPA audit charged ahead, such was WAAC's commitment to it. The result is an important piece of work that will serve to comprehensively hard-wire the agency's engagement with HIV Positive and affected communities to its enduring pursuit of healthy, inclusive and safe communities.

On behalf of the Board, I thank all those involved with this inaugural project.

The MIPA Working Group

The Western Australian AIDS Council acknowledges the commitment of all members of the working group, their contribution, their time, their tenacity, support, understanding and value to the MIPA audit process.

Community Representatives

Ryan Oliver (Positive Organisation WA Chair – POWA)
Diane Lloyd (NAPWHA & POWA)
Roger Sykes
Kristal
Graeme
Dr Belinda Wozencroft
Michele Kosky AM

WA AIDS Council Representatives

Asanka Gunsekera (WA AIDS Council Chair)
Lisa Tomney (Manager, Clinical Services)
Mark Reid (HIV Positive Peer Education Officer)
Matt Bacon (Health Promotion Officer)
Michael Birch (HIV Positive Board Representative)



HIV Positive Peer Mentor Program

Living with HIV has changed over the past decade. With modern treatment and support, HIV positive people are leading healthy and active lives. Learning to live with meaning and successfully does not have to be overwhelming, and no one needs to be isolated or alone.

The WA AIDS Council Peer Mentoring Service provides the most current HIV information, answering questions and offering support to people living with HIV. The role of a Peer Mentor is to support a person living with HIV to gain knowledge and develop HIV self-management strategies, and to help build resilience by providing the important information and encouragement needed to achieve their identified goals.

Peer Mentors are trained and educated on the current health issues surrounding HIV/AIDS, STI's, self-care, disease progression, co-morbidities, HIV and ageing and well-being. Through a series of supportive discussions, Peer Mentors use everyday language instead of jargon or medical terminology to make topics easier to understand.

The WA AIDS Council is fortunate to have a comprehensive team of social workers who work with PLHIV regarding complex mental health, alcohol and other drug dependency, homelessness, poverty, partner and family violence. The Mentors role is to step in and provide any additional psychosocial support that a client may wish for.

"Since the project first began and we started to get referrals for people to be matched with the trained mentors, I have received incredibly positive responses from both the mentors and the mentees about the development of some strong relationships that have been of benefit to both people. The shared learning, support and the chance to connect with another person with HIV has already proved to be an invaluable tool for people involved. I am excited about the future of this program based on what it is already achieving"

- Mark Reid, HIV Positive Peer Education Officer

"Being a gay HIV positive man and having lived a fulfilled life of 80 years, the last 28 years have been lonely since my partner succumbed to AIDS. Loneliness can eat at you, causing the darkness of depression that's hard to continue living with. When I heard about the HIV Positive Peer Mentor Program, I felt that it was exactly what I needed, as I knew I was very close to falling once again into the darkness.

I enquired, and within a couple of weeks, I was linked up with a HIV Positive Mentor. The Mentor and I met at a coffee shop to get to know one another and to build on the mentor/mentee relationship. It's now been three months since we met, we chat with lots of laughter over our stories and life in general, and my mentor is great for any problem solving, encouragement and motivation. The dark hole has eased, all due to the friendship formed through the company of my mentor.

Thanks to the WA AIDS Council for access to such a great peer program and to my mentor for their support, I can continue to live as an ageing HIV positive man who's now looking ahead to the next 10 years of my life."

- Mentee

Key Audit Areas

HIV Positive Peer Education Program

Provision of individual peer support, and a suite of workshops, forums and social networking opportunities for PLHIV

SHAPE Outreach and Case Management Programs

Comprehensive Case Management services for PLHIV who are experiencing complex and challenging issues in their lives which is compromising their health and well-being

Counselling

Therapeutic counselling services for PLHIV and affected, and all people from the LGBTIQ+ communities

Health Promotion

A broad range of health promotion activities, targeting key population including Gay/MSM, Mobile & CaLD communities, Youth, Aboriginal & Torres Strait Islanders, Needle & Syringe Exchange Program and Freedom Centre

M Clinic

Peer Led sexual health screening clinic for gay and homosexually active men

Organisational Development

Training & Development, Media & Communications, Fundraising, Volunteer Program, IT & Facilities, Policy

Bequests

Funds to provide white goods, dental & optical support, and annual PLHIV organisation funding support



Ryan Oliver, POWA Chair

It was a pleasure to be a part of the WA AIDS Council MIPA Audit.

Through the course of the year we were given an overview of each part of the organisation of which frank conversation was had.

The process was lengthy, robust and thankfully all on the panel had a good sense of humor to carry us through!

Meaningful Involvement of PLHIV and Affected communities (MIPA) is an important part of any organisation which provides services to PLHIV, to be providing the services which reflect the needs of the community.

This calls for both a commitment from the organisation such as this audit and the implementation of the action plan and PLHIV working together for the greater good.

The Audit

Throughout 2018, the MIPA working group has convened regularly to analyse and evaluate the organisations self-assessment audit, to acknowledge where WAAC is applying the MIPA principles, and where improvements can be made.

Our Strengths

- HIV Positive Board Representative, formally co-opted, now nominated and elected by the membership
- An HIV Positive Peer Educator substantive employment position, which has been in place for 25+ years
- Since its inception, the WA AIDS Council has provided annual funding contributions to the 'Positive Leadership Development Institute', so that Western Australians living with HIV can benefit from this opportunity
- The development of the 'HIV Positive Peer Mentor' program. People living with HIV provide volunteer psychosocial support for other people living with HIV who are isolated, vulnerable, lonely or ageing with HIV
- Commitment and contribution to PLHIV research, including, Latrobe POZQoL, HIV Futures, Partner Study, Opposites Attract, RISE
- Continued support for the positive voice in WA, via previous funding and administrative support for PLWHA WA, HAPAN, WA Representatives at NAPWHA, and now current support and an established memorandum of understanding with Positive Organisation WA(POWA)
- HIV Positive and affected populations focus groups
- "Sharing The Journey" series of on-camera interviews featuring a diversity a people living with HIV. The interviews are a feature of all training and development campaigns and projects.
- "This is What HIV Looks Like in 2017" billboard and media campaign, featuring 5 people living with HIV.

Our Action Plan

Principle 1:

Advocating for the meaningful involvement of people living with HIV and affected communities in all aspects of the HIV response.

Actions for Improvement:

Health Promotion

- Investigate and implement opportunities for increasing PLHIV representation on steering/reference groups in which Health Promotion are invited to participate in (YEP, SHQ, Headspace)
- Provide opportunities to develop PLHIV ambassadors to assist in the development of projects and provide personal perspectives
- PrEP, TasP and U=U have not been comprehensively introduced in some aspects of Health Promotion e.g. School Education. Messaging needs to be transitioned from the more subtle, to distinct language
- Better focus on female perspectives discussed in 'Sharing the Journey' to be included in educational programs
- Continue to actively seek and maximize opportunities and roles for PLHIV to be involved in campaigns
- Programs aim to educate marginalised populations about HIV prevention. Health Promotion need to actively seek PLHIV from these populations to serve these communities. Health Promotion to work closely with Clinical Services to best engage PLHIV who want to contribute to specific education projects

SHAPE & Case Management

- Engage with all possible research and evaluation that PLHIV can contribute to, particularly regarding PLHIV who experience complex and challenging bio-psychosocial issues. E.g. PozQoL, RISE, Futures, Most Significant Change
- Explore new and innovative mechanisms for feedback
- Further develop opportunities for PLHIV involvement at a service experience level, e.g. Personal Perspective at meetings, forums,

M Clinic

- Continue to develop and expand involvement of PLHIV as important providers of information and knowledge through reference and focus groups about the services provided through the clinic
- Consider opportunities for dedicated HIV Positive Peer Education through M Clinic site

Bequests

- Removal of 'Retreats' from Bequest Policy, as funding levels are not sufficient to facilitate this from of activity.

Principle 2:

Fostering active and meaningful involvement of people living with HIV and affected communities in all of our activities.

Health Promotion & Organisational Development

- Continue to seek the interest of PLHIV for involvement in projects, employment and volunteering
- Develop consumer reference groups inclusive of PLHIV across all program areas

SHAPE & Case Management and HIV Positive Peer Support

- With a shared objective of collaborations that provide better health and well-being outcomes for PLHIV, The WA AIDS Council will continue to provide opportunity for cooperative events with POWA, and to review the established MOU on an annual basis.

Bequests

- Organisational Development and Fundraising to actively seek bequests/donations to continue providing this form of financial support (in addition to the HIV Emergency Relief Fund)





Michele Kosky, AM

Being part of the MIPA working group was extremely gratifying for someone committed to patient and consumer participation in the health sector.

The WA AIDS Council should be congratulated for undertaking this comprehensive audit of the meaningful involvement of people with HIV at all stages, and every level of the policies and operations of WAAC.

It is a model that could be effectively adopted by many other non-government organisations in the health sector. The administration of the working group was excellent in terms of meetings and papers, there was robust discussion and respectful disagreement, and it was a privilege to be part of such a diverse and committed bunch of people.

I am hoping that all the changes suggested are adopted, and that this model sets an example for a wide range of health providers.



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