

**A New HIV Deal For WA = Perth Sexual Health Clinic & Community Hub!**

**A Discussion Paper!**  
**“Modernising, Moving On & Putting Health Consumers First in Western Australia!”**

**#Destigmatisation #CapacityBuilding #EasyAccess**



**A New HIV Deal for WA = A New Decade in a New Century & A New Perth Sexual Health Centre will Destigmatise Health Care, Allow Whole of Sector Capacity Building & Provide Easy Access to BBV/STI Treatment/Prevention with A Community Hub to Prioritise Equity & Fairness in Advocacy & Peer Support & Leadership!**

**December 2019**



**Western Australia**



# **A New HIV Deal For WA = Perth Sexual Health Clinic & Community Hub!**

## **Introduction.**

This Discussion Paper has been written by Grassroots People Living with HIV (PLHIVs) in WA to improve Consumer Health Outcomes for People Living with HIV & help deliver a New & Improved, Consolidated Sexual Health Service for Western Australia.

A World Class One Stop Shop Perth Sexual Health Clinic & Community Hub for Advocacy & Peer Support Groups, that includes every demographic from S100 prescribers for HIV, Sexuality Gender Diverse (SGD) Health, Pharmacy & Travel Medicine for Domestic, Tourist & FIFO Workers, would replace the current model of service delivery.

The Current RPH Sexual Health Clinic has a very good reputation for providing HIV Health Care & Prep but are limited by inadequate funding. An Ageing HIV Population suggests that an increase in demand for services will be inevitable. The stress that may be placed on the current system, may lead to a reduction in the quality of care that is being provided now and this is of concern for Consumers, who value the service.

Ending the current fragmented NGO policy development & Service delivery with a modernised evaluable needs analysis & assessment framework will allow the needs of Health Consumers to be front and centre. This would provide smart governance and a better spend of existing health budgets.

The Perth Sexual Health Hub could be achieved by consolidating the current HIV, BBV, STI, Sexual & Gender Diverse and NGO Boutique Health Clinics, be managed within the Health Department and/or attached to a Main Hospital in the CBD area, close to public transport. This would also allow for greater accountability, modernised programming with measurable targets & continuity of services that put WA Health Consumer Needs First.

Waste prevention strategies & state of the art evaluation techniques are needed to allow Service Providers & Funders to know if the stated outcomes of BBV & STI Prevention Programs are being achieved & the WA HIV Strategy Aims, implemented as per the plan!

An article, "Australia has a target of virtually eliminate HIV transmission by 2022" by Kate Emery in "Grim Reaper is Not Dead" in the West Australian 27 December 2019 is a timely reminder that HIV/AIDS & Sexual Health targets have not been realised. There is cause to be cautiously optimistic given the Media "PR" Reports highlighting the looming potential of HIV Vaccines or even a Cure & it is clear that the Epidemiology of HIV may undergo significant change thus the time is right to end all procrastination and develop New Strategies to update the current last century models of BBV & STI Service Delivery and Advocacy.

The Perth Sexual Health Clinic and Community Hub approach is an Opportunity to create a Professional Advocate, located in the Community Hub, to protect the interests of Sexual & Gender Diverse People and BBV/STI Consumers, including those in Aged Care & Hospital Settings. Especially vulnerable & isolated frail patients need to have an Advocate, that has statutory authority to act on their behalf, as has been highlighted in Evidence given to the Royal Commission on Aged Care.

There have been many Warnings from the PLHIV Community that there is currently no coherent or reassuring HIV Ageing Policy to inform service delivery for the complex health needs of People growing Older with HIV on low incomes. This need is illustrated in the following quote;

"With an ageing people living with HIV and AIDS population, both medical practitioners and health policymakers must understand the risks this growing vulnerable population faces... We hope that the findings in this study will contribute

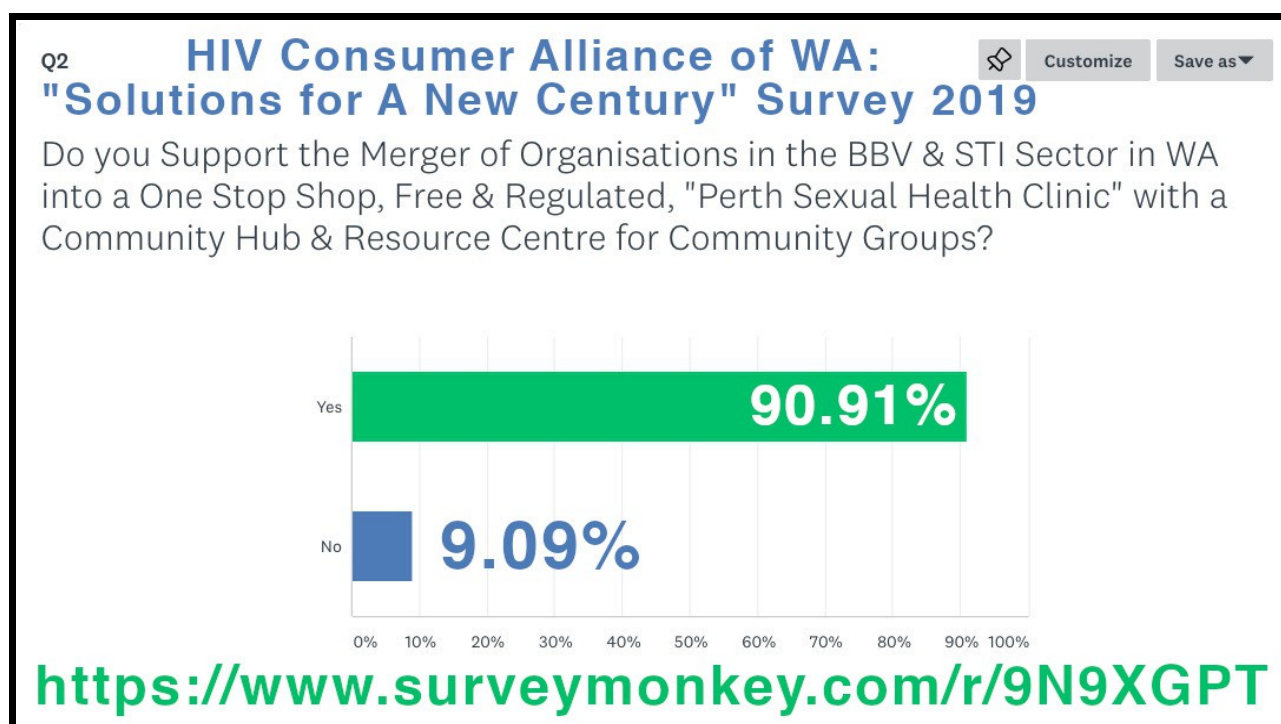
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to a growing body of literature which will help our healthcare systems prepare for a rapidly increasing population of ageing people living with HIV and AIDS.” Michael Carter, 27 December 2019 from: <https://www.aidsmap.com/news/dec-2019/older-people-living-hiv-have-increased-risk-chronic-diseases-associated-ageing>

The current Multi Agency “NGO” Approach has allowed the development of programs & funding for services that are essential to PLHIV health and wellbeing, yet these have been terminated, sometimes without notice, with changes of policy & management style, and no Meaningful Consultation with effected Grassroots Consumers.

Reassurance and Consistency for Ageing Long Term Survivor PLHIVs, who live with significant compromised health, due to side effects of medication and early participation in the Treatment Trials that led to today’s ART programs, is needed as a human right. There is currently little or no help for PLHIV currently navigating the stressful and complicated Aged Care System. A Professional Advocacy Service in the Proposed Community Hub will help PLHIV & SGD to ensure dignity and respect are maintained in old age. It is doubtful whether these health consequences and the many long term side effects will disappear with any cure or vaccine hence People Living with HIV/AIDS will still be with us requiring Health Care and this needs to be planned for.

Bringing all BBV & STIs into “A World Class One Stop Shop Perth Sexual Health Clinic & Community Hub for Advocacy & Peer Support Groups” will also assist to eliminate Stigma around BBV & STI and more broadly Sexual Health which will increase efficacy of BBV & STI Prevention and normalisation of Treatments. HIV should be treated as any other STI which will lead to HIV Decriminalisation. Individual Health Outcomes will be measurably improved by early diagnosis and increased treatment of all BBV & STIs, thereby leading Western Australia towards achieving the target of eliminating HIV transmission by 2022.



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### DeStigmatisation

Stigma is a process of producing and reproducing inequitable power relations, where negative attitudes towards a group of people, on the basis of particular attributes such as their HIV status, gender, sexuality or behaviour, are created and sustained to legitimise dominant groups in society. Discrimination is a manifestation of stigma. Discrimination is any form of arbitrary distinction, exclusion or restriction, whether by action or omission, based on a stigmatised attribute.

From: The NGO HIV/AIDS Code of Practice

HIV Stigma occurs when someone is seen in a negative way because of their HIV+ Status & Discrimination happens when a PLHIV is treated in a negative way because of their HIV Status. Stigma and discrimination can make health problems worse and act as barriers that stop a person from getting the help they need.

“Findings from this synthesis indicate that HIV-related stigma is a global social phenomenon for people with HIV that manifests within multiple social spheres, including health care environments. The qualitative literature identifies a number of strategies used within health care settings - some rooted in institutional practices, others shaped by personal perceptions held by practitioners - that could subsequently be stigmatising or discriminatory for people with HIV”. From: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4557823/>

This is a serious issue for PLHIV who can be discriminated against by missing out on job opportunities or housing & being bullied in social settings. Stigma increases the risk of PLHIV becoming Victims of Assault & Domestic Violence. Stigma can also mean PLHIV don't seek medical treatment when they need it. A definition of Stigma can be seen in the following quote:

“The concept of stigma is the process of perceiving a characteristic of another, as deviant from the social expectations that are held by the majority. Stigma arises in various spheres of life... and throughout various interactions we might have with the broader community, such as in the workplace or health services”. From: <https://www.aasw.asn.au/document/item/6780>

HIV Specialist Researchers have developed a large body of work that outlines the effect of Stigma as a significant factor in Health Care Settings. For example In “Barriers and facilitators to patient retention” by Yehia et al state that “Retention in HIV care improves survival and reduces the risk of HIV transmission to others”. The following quote describes further the way Stigma causes PLHIV anxiety in Health Care Settings.

Stigma was a barrier in the high tertile for patients not retained in care and a barrier in the medium tertile for those retained in care. Uncertainty about how the public would respond to their status made some patients anxious and affected their ability to attend appointments. Attempting to avoid disclosure in the waiting room, laboratory, and pharmacy created additional obstacles for these participants and discouraged regular clinic attendance. From: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4485864/>

Social Isolation as a direct result of Stigma and Discrimination is known to lead to poorer health outcomes for PLHIV. From a public health perspective, adherence to treatment is an optimal goal for HIV Health Care Providers and so providing WA with a World Class Sexual Health Hub, designed around the elimination of stigma, would be a sign of a system committed to best practice in health care service delivery. The Australian Federation of AIDS Organisations (AFAO) recognises the significance of Stigma in the following way.

“HIV-related stigma and discrimination is a source of significant harm in the lives of individuals, causing both a decline in wellbeing and quality of life and in physical

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wellbeing (social isolation is correlated with poorer adherence to HIV treatment). At a population level, stigma and discrimination present a barrier to people presenting for regular testing, engaging with health care providers regarding risk behaviours, and sustaining contact with health care and treatment adherence. These factors in turn pose a risk to our public health goals of reducing HIV transmission... there has been limited investment to date in innovative activities to address stigma and discrimination.” From: <https://www.afao.org.au/our-work/hiv-blueprint/community-led-efforts-stigma-discrimination/>

Stigma is a major problem in Perth that takes on a greater significance due to the interdependent and overlapping relationships that exist in all small communities. To be treated negatively by others, to be discriminated against, and to be made to feel less than a full member of a peer group, especially those from minority demographics where the effect of stigma is concentrated, is an extraordinary burden for a person in a small community to carry.

One of the tangible benefits from the National Association of People with HIV/AIDS (NAPWHA) that does help the development of HIV policy in Western Australia is their development of theoretical frameworks & discussion papers. In the following quote NAPWHA highlights the fact that a lack of “a whole of sector approach” undermines targets to eliminate Stigma and HIV transmission.

“There is currently not a whole-of-sector approach to these issues, nor a comprehensive framework for jurisdictions that will enable the development of consistent, culturally competent responses to reducing stigma and discrimination and supporting resilience jurisdictions and at all levels of the HIV partnership response to drive progress on addressing these concerns.” From: <https://napwha.org.au/stigma-and-discrimination/>

The development of theoretical frameworks to reduce Stigma by NGO Peak Bodies and Peer Support Groups, over many years, have failed to implement the Strategies or Educational Campaigns, required to change attitudes and beliefs relating to Stigma that have been recommended. For example,

“HIV-related stigma continues to negatively impact the health and well-being of people living with HIV, with deleterious effects on their care, treatment and quality of life. A growing body of qualitative research has documented the relationship between HIV-related stigma and health” From: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4557823/>

There have not been any comprehensive or memorable anti-discrimination measures run to reduce HIV Stigma in Western Australia. A Perth Sexual Health Clinic with a Community Hub, Linked to the Health Department would allow for a “whole of sector” approach to managing stigma & health care with measurable outcomes to ensure value for program funders. More importantly isn't, as the following quote details, addressing the inherent failings of the current last century “not whole of sector” approaches and ensuring the development of new frameworks include the Meaningful Involvement of Grassroots People with HIV/AIDS, a moral and legal imperative?

“The health care profession has an ethical duty to avoid engaging in stigmatizing behaviors and a legal duty not to discriminate. To provide maximally effective and ethical HIV testing and care, health care personnels also need to recognize and take into account the realities faced by people living with HIV.” From: <https://journalofethics.ama-assn.org/article/hiv-stigma-and-discrimination-persist-even-health-care/2009-12>

People Living with HIV/AIDS in WA were among the pioneers that stood up against Stigma



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& developed the Prevention Strategies that were central to Australia's successful HIV response. A One Stop Shop, Perth Sexual Health Clinic & Community Hub for Advocacy & Peer Support Groups, as it is put forward by members of the PLHIV Community, is “a whole of sector approach” that the WA State Health Department can utilise, in conjunction with meaningful engagement of grassroots Consumers, (MIPA) to eliminate Stigma in every context and to minimise all BBV & STI transmissions.

A Perth Sexual Health Clinic & Community Hub is an opportunity to provide a modern Australian Leading Medical Practice that can share it's expertise with Health Care Services in regional areas & be the “whole of sector” Hub at which real strategies & materials to measurably reduce stigma can be produced & disseminated throughout Western Australia.

A Hospital linked Clinic will also remove the fear & anxiety related to Stigma from referrals for Complex Treatments. Having a “whole of sector” Stigma Free Practice in the one building will make access to Peer Support and Rehabilitation Programs easier and may reduce the burden on the criminal justice system by preventing crime.

Absorbing all BBV & STIs and their attached Health Boutiques into a Sexual Health Hub will provide the state of the art clinic facilities with comprehensive Sexuality and Gender Diverse Medicine that the WA LGBTI Health Strategy recommends, as described in the following quote.

“Services and resources are centrally located in a ‘one-stop shop’... a peer-led multidisciplinary health clinic for trans and gender diverse adults and support for tailored and appropriate interventions to support LGBTI populations at high-risk of illicit drug related harms such as methamphetamine-related harm.” From: Western Australian LGBTI Health Strategy 2019–2024 p 27.

Including ALL Ages LGBTI Health in a Perth Sexual Hub will lead to the further de-stigmatisation of Sexuality & Gender in the Health Care setting, allowing for improved access for Transgender Medicine, Counselling with ALL Ages links to Emergency Care for ALL Ages LGBTI SGD in Crisis Situations, thus preventing risk of suicide!

HIV needs to be Normalised as treatable along with other STIs. The Perth Sexual Health Clinic & Community Hub setting will help lead to less stigma and self stigmatisation by HIV clients & this approach will start to help the community and politicians moving towards legislating the decriminalisation of HIV, when it is no longer seen as a threat.

A Community Hub would help increase the critical mass of participation for groups which state they lack the capacity to provide services or support for their stakeholders and members. Some Organisations & Peers raise the issue of trickle down toxicity. A New Hub for Advocacy & Peer Support Groups would provide the opportunity to replace the toxic leadership that maintains self stigmatisation & discrimination in WA.

A properly regulated, transparent & accountable Hub would enable employment of “whole of sector” Multidisciplinary co-ordinating roles that would replace the existing toxic leadership & allow peers to work to redefine WA's PLHIV culture into a more cohesive, inclusive & compassionate environment to help end the situation of PLHIVs falling through the cracks and failing to access essential services and mental health supports.

Consolidating HIV Services & Advocacy into a New broader BBV & STI Hub will remove the Stigma of AIDS labelling leading to greater uptake of services. Anecdotal evidence from PLHIV Peer Support groups has long identified the pejorative AIDS Label of specialised HIV focused NGOs as a barrier stopping people doing surveys and attending AIDS Labeled Architecture. The unrelenting Stigma associated with being called a

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HIV/AIDS Carrier, or worse, and the constant risk of peer based breaches of confidentiality are potent sources of self stigmatisation that compare with the Grim Reaper Ad Campaign & researchers have identified as the reason for self selecting isolation.

Stigma in Health Care settings & Self Stigmatisation from the need to seek medical care relating to Sexual Activity is a problem in Rural and Regional Settings. People come to Perth for treatment because it's private and because they can avoid the Stigma associated with BBV & STI testing and treatment in small towns. A widely promoted, Perth Sexual Hub, would create equity between city and country by offering consultations & services via secure web app technologies, allowing People in small communities to avoid experiencing the stigma outlined in the following quote.

“Research suggests that health care workers often hold negative views of people with HIV... Prejudicial attitudes of health care workers... have been shown to have a negative impact on treatment adherence while satisfaction with a healthcare provider has been shown to increase medication and appointment adherence in adults with HIV. Research illustrates some of the ways in which stigmatising attitudes of healthcare workers are transformed into discriminatory practices and behaviours... lack of eye contact; clipped or brusque speech and differential precautions were all attributed to HIV-related stigma... They also found more overt forms of discrimination, such as blaming patients for their status, physical abuse and the denial of care, and that many of the patients reported being very upset and even emotionally scarred. Patients also reported experiencing substandard care, ranging from an inadequate time spent on their needs, to being left in extreme pain for an extended period of time.” From:

<https://www.aasw.asn.au/document/item/6780>

Western Australia needs a whole of sector approach that addresses Destigmatisation of all conditions. This will also ensure that the goal of the Western Australian HIV Strategy 2019–2023 to “Provide initiatives to assist PLWH to challenge and address incidences of stigma and discrimination” is carried out. People in Perth describe negative experiences navigating complex health care settings. There needs to be a High level importance placed on having a clear and simple health care solution to Sexual Healthcare in WA that provides certainty and reassurance for HIV Aged Care & a resetting of the HIV Culture and a New Century, Consumer First, Standard of Service delivery, without Stigma.

World AIDS Day 2018 #EndStigma

# HIV

## STIGMA leads to more HIV!

*HIV Stigma leads to more HIV infections because it stops people from getting tested, going on treatment, makes them less likely to be educated about their risk of infection & discourages those who are HIV+ from discussing their HIV status. Accessing medical care & Support is a big problem for people with HIV because the Medical System is itself a source of stigma. Organisations discriminate against consumers by failing to enforce confidentiality requirements and when Staff know breaches have no consequences then consumer's rights aren't likely to be respected.*

facebook.com/ConsumerAllianceWA

**HIV Consumer Alliance WA**

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## STIGMA stops COMPLAINTS!

*If the first thing that happens when a Consumer lodges a Complaint, their name and HIV status is revealed, the consequent irreversible damage done is devastating. Stigma creates the threat of confidentiality breaches which prevent legitimate Consumer complaints from being made and protects Organisational Reputations from the Scrutiny of the resolving complaint process!*

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### **Whole of Sector Capacity Building.**

Whole of Sector Capacity Building via A Perth Sexual Health Clinic & Community Hub is a complex systems approach to increase the productivity of WA's current BBV & STI Partnerships & Leadership. This is an Opportunity for a systemic "Move On" from meeting the Competing Needs of Outdated Single Organisations and their burden of Costly duplicated Administrations, with a structural reform package, refocusing health outcomes on Consumer Need First to "multiply health gains many times over" while providing a more efficient spend of existing health funding.

CAPACITY BUILDING is...An approach to the development of sustainable skills, organisational structures, resources and commitment to health improvement in health and other sectors, to prolong and multiply health gains many times over. Hawe et al: 1999

Five key action areas in capacity building: organisational change, workforce development, resource allocation, partnerships and leadership.

From: <https://yeah.org.au/wp-content/uploads/2014/07/A-Framework-for-Building-Capacity-to-Improve-Health.pdf>

Whole of Sector Capacity Building that involves smarter resource allocation can challenge existing entrenched cultural norms and mindsets, however, the long term benefit is increased productivity and for WA's AIDS Industry this is the chance to finally "Move On" from the Mind Sets of Factional Politicised Management Styles & the Toxic Leadership of the current PLHIV Community to a perspective that values inclusive healthy environments in Service Delivery.

System capacity building: Capacity building at this level involves multiple layers, complex power relationships, and involves policy development, inter-organisational planning, resource allocation, consultation and advocacy efforts. In a health promotion context, these decisions may be aimed at (but not limited to) supporting a healthy environment and are defined by the boundaries set by the systems. Mostly initiated by strong players such as government, vocal lobby groups, or powerful non-government organisations, this level of capacity building can challenge cultural norms, values, paradigms and mind sets. Decisions made at this level will affect whole populations, not specific communities. From:

[https://www.vichealth.vic.gov.au/~media/resourcecentre/publicationsandresources/general/capacity\\_building\\_factsheet.ashx](https://www.vichealth.vic.gov.au/~media/resourcecentre/publicationsandresources/general/capacity_building_factsheet.ashx)

Evaluable Whole of Sector Capacity Building processes will enable individuals and organisations to identify and develop the skills needed to do their jobs competently in a BBV Sector for which the Mission has changed through New Tools, including an existing cure for HepC and indications that HIV Cures & Vaccines are on the horizon.

Capacity building (or capacity development) is the process by which individuals and organisations obtain, improve, and retain the skills, knowledge, tools, equipment, and other resources needed to do their jobs competently. It allows individuals and organisations to perform at a greater capacity (larger scale, larger audience, larger impact, etc). "Capacity building" and "Capacity development" are often used interchangeably. Community capacity building often refers to strengthening the skills of people and communities, in small businesses and local grassroots movements, in order to achieve their goals and overcome particular issues that may cause exclusion. Organisational capacity building is used by NGOs and governments to guide their internal development and activities. From: [https://en.wikipedia.org/wiki/Capacity\\_building](https://en.wikipedia.org/wiki/Capacity_building)

Our View is a "Move On" to a broad and holistic view of capacity building with Future Service development focused on putting the Needs of Consumers First, away from



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Outdated Organisation's Shifting Mission Statements designed around Protecting, Retraining & Recycling Career Specialists.

The contemporary view of capacity-building goes beyond the conventional perception of training. The central concerns of environmental management and community building – to manage change, to resolve conflict, to manage institutional pluralism, to enhance coordination, to foster communication, and to ensure that data and information are shared – require a broad and holistic view of capacity development. This definition covers both institutional and community-based capacity-building. From: <https://learningforsustainability.net/capacity-building-empowerment/>

A Perth Sexual Health Clinic and Community Hub would be an opportunity for the Principle of Whole of Sector Capacity Building in Small Community to be implemented as a part of a reinvigoration of BBV & STI Partnerships & Leadership. The lack of real Capacity plus the inability of Old Models to attract a critical mass of membership, is an issue within the Peak Peer Led Organisations and HIV Support Groups in Western Australia who are no longer relevant in the new HIV landscape.

The fragmented nature of the current BBV & STI Sector leads to a ubiquitous competition with arguments between NGOs that results in Organisations Representing the Organisation First and putting the Needs of the Organisation before helping achieve better health outcomes for Consumers.

A Toxic Leadership Culture has driven the majority of grassroots PLHIV out of organised activities run by the Unsupervised Peer Led Groups & Associations, with the result that these have lost the capacity to meaningfully engage with PLHIV in WA. For example, how can a Group whose Board represents less than One Third of One Percent of PLHIV in WA really be considered legally proper to make Decisions & negotiate Health Contracts on behalf of the Majority of the PLHIV Community in WA?

A Best Practice Community Hub will allow capacity building to become central to organisational change, workplace development and the Principles of the Meaningful Involvement of Grassroots People with HIV/AIDS. (MIPA). Whole of Sector Capacity Building should not be considered the sole domain of HIV Career Specialists who don't empathise with those Consumers, who as a result of their Chronic Illness, live on low incomes and struggle with costs of living & maintaining good health and wellbeing.

Whole of Sector Capacity Building has been sought by many grassroots individuals and lobby groups in Western Australia but have met with little support. This Discussion Paper is proof there is Capacity among Grassroots PLHIV who need to be meaningfully involved in the decisions relating to health that are made in the State. There is currently no where in WA that provides a safe and affordable environment for Professional Level Mentor Training. This is where a Community Hub will play an important part in Health Promotion Programming & Whole of Sector Capacity Building.

A decades long HIV Social Structure has become entrenched in Western Australia that gives permission for PLHIVs to engage in open factional bullying & discrimination against other PLHIV at public events and meetings on the grounds of Employment Status, Marriage, Sexual Orientation, Gender Identity, Out HIV Status, Appearance, Religion and Ageism. The effect Organisational Culture in Health Settings has on individual health and wellbeing is described in the quote below.

It has been previously suggested that organisational culture is one of the factors influencing quality of care, health-care provider appraisals and patient satisfaction. The often-quoted definition of organisational culture is 'the invisible force behind the tangibles and observables in any organisation, a social energy that moves people to act. Culture is to an organisation what personality is to the individual—a hidden, yet unifying theme that provides meaning direction, and mobilisation'. From: <https://academic.oup.com/intqhc/article/27/1/37/1829356>

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A Regulated Professionally Managed Community Hub in a New Sexual Health Clinic will usher in a new era in a Whole of Sector Capacity Building Approach that places the values of Equality and Equity of Access for Consumers First! This will realise the true potential of the PLHIV Community that exists and reengage people who have fallen through the cracks.

With the HIV Population Ageing there needs to be a policy and service response that enables PLHIV to maintain their quality of life. Whole of Sector Outcomes need to be provided and Consumers already Living with the Disability of Chronic Illness should not be left alone to navigate the current confusing system which is known to be not friendly towards Ageing LGBT & PLHIV. Many Ageing HIV people are already living in isolation without access to Services or Peer Support Programs, which are not run by the Peak Peer Led PLHIV Body in WA.

An Inclusive Community Hub in an all ages friendly LGBT & PLHIV Health Service would enable a Community to form that would enable Peer to Peer Support Networks to develop that would be a start to reducing the chronic isolation that is leading to more complicated health care needs which require funding.

A Whole of Sector Capacity Building Model can ensure that a New Perth Sexual Health Clinic and Community Hub becomes the Leading Australian, Multi-purpose and Multi-Disciplinary Centre for Sexual Health & Community Development that leads to the empowerment of Individual Consumers to help end HIV Transmissions. When the AIDS Catastrophe happened, the Western Australian response was arguably the World Leader in HIV Health Promotion, Prevention & Support and A Sexual Hub that implements best Practice BBV & STI Treatment & Prevention plus an Australian First, A Comprehensive HIV Aged Care Policy, would quickly rise to a place of prestige in the Health Care Arena.

Making the Perth Sexual Health Clinic, a Hub for Travel Medicine, in a location close to WA's Premier Tourist Destination, the Central CBD, would contribute to destigmatisation & provide a method of extending the reach of Sexual Health Education Programs. With the Government's recent big increase in funding for Tourism, building the infrastructure to support the expected influx of visitors, as well as Australians returning from overseas, of a World Class Sexual Health Clinic will enhance the Tourist experience in WA. From a Capacity Build of Health Promotion Perspective, when Travellers attend to obtain pre or post travel health care the Sexual Health Hub's Staff can ensure that the opportunity provided to discuss the health risks of BBV & STI is taken advantage of.

We Welcome the WA Health Department's development of the first LGBTI Health Strategy, however, we hope that in future Strategy documents a more inclusive approach will be taken and that HIV+ LGBTI People will be named and have needs included, to prevent the Erasure of this demographic so that ALL healthcare needs, including LGBTI Intimate Partner Violence, are addressed, included and acted upon.

At its core, the Strategy asks for the WA health system to see people as individuals and to respond with humanity in addressing all physical and mental healthcare needs. From: <https://ww2.health.wa.gov.au/~media/Files/Corporate/general%20documents/Health%20Networks/PDF/LGBTI-Health-Strategy-2019-2024.pdf>

Alex Keuroghlian, below, demonstrates the Importance of integrating Primary Care and Behavioural Health for LGBT Patients, however, this is of benefit to all demographics. A Community Hub would not only be focused on Peer Support but could contain Allied Health Services such as Psychology, Aged Care & Nutrition to name a few hence we are calling for a One Stop Approach ends the exhausting traipsing all over the city and waiting hours in underfunded and understaffed Health Care Settings!

Having a Perth Sexual Health Clinic & Community Hub able to refer Consumers to "in house" psychological and other allied services with the ability to meet on the spot emergency need could prevent suicide attempts or self harm of LGBT people suffering

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from depression & anxiety. If all people, including PLHIV & LGBT with substance use concerns, are able to be helped sooner, then perhaps family conflict situations can also be prevented?

Review of the value of behavioural health integration for LGBT patients and how advancing behavioural health integration in primary care settings can improve patient access, engagement, and both physical and behavioural health outcomes.

LGBT people have disproportionately high prevalence of depression, anxiety, substance use disorders, and suicide attempts compared with the general population. In addition, LGBT people often have unique combined physical and behavioural health needs, including those of transgender people undergoing gender affirmation and special considerations for people living with HIV AIDS. Integration of behavioural health and primary care is therefore of particular importance as a clinical best practice for LGBT people. From: <https://targethiv.org/library/importance-behavioral-health-integration-lgbt-patients>

In an era when most LGBT Human Rights have been achieved in WA, it is time to mainstream the health needs of Sexual and Gender Diverse People in A Whole of Sector Capacity Building Perth Sexual Health Clinic that will serve to further reduce stigma while the Community Hub will be able to provide specific programming for LGBT as well as for all the other demographic groups such as Culturally and Linguistically Diverse People. (CALD).

One of the biggest concerns amongst the grassroots PLHIV Community is the awareness that Intimate Partner Violence (IPV) is an increasing health problem in the PLHIV & LGBT Communities. It is a concern that longstanding cultural and ideological taboos combine to aggressively bully into silence victims and advocates for prevention. Those who silence others, because, “we don’t want to make the community look bad” are effectively giving permission for perpetrators to carry out abuse. The right and proper response should be to adopt a mature, whole of sector approach and treat this issue as a priority Health Need.

Myths about domestic violence, like the AIDS myths pedalled by Grim Reapers, never help anyone. We know victims’ fear and shame stops them seeking help and if they do reach out many don’t know where to go or who to tell. Peer Volunteer Groups with the assistance of Professional Advocates in a Community Hub could add value to the Sexual Health Clinic by helping to develop world leading Gender Neutral Anti-Domestic Violence Resources, that would make a real difference to minimising harm in WA.

A health service with Non judgmental, Gender & Sexuality Neutral, IPV Pamphlets and Posters would be the ideal place for Victims to find someone to ask for help so that action can be taken to end bad situations and prevent negative health outcomes. A discrete properly Trained Health Worker, open to helping all Genders & Sexual Orientations and able to open the doors to emergency help would be a serious step in the right direction that would help address “one of our most serious health risks, affecting significant numbers within our communities”. From: <https://www.advocate.com/crime/2014/09/04/2-studies-prove-domestic-violence-lgbt-issue>

Many people who are suffering either don’t realise that they’re in a terrible situation or don’t know where to go or who to tell. They wonder who will listen, who will believe them. Myths about domestic violence, victims’ fear and shame, a silence that stems from a desire not to harm perceptions of the LGBT community — all these together contribute to making the problem invisible to others. From: <https://www.advocate.com/crime/2014/09/04/2-studies-prove-domestic-violence-lgbt-issue>

The following references, provide a background to the issue of LGBT Domestic Violence, including the impact on PLHIV, beginning with a study from Western Australia, and are proof that supports the claim there is a Hidden Health Care Crisis not being spoken about.

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These studies refute the myths that only straight women get battered, that men are never victims, and that women never batter — in other words, that domestic violence is not an LGBT issue. In fact, it is one of our most serious health risks, affecting significant numbers within our communities. From:

<https://www.advocate.com/crime/2014/09/04/2-studies-prove-domestic-violence-lgbt-issue>

### **LGBTQ Domestic Violence: A Hidden Health Care Crisis!**

- The silence surrounding the issue of same sex domestic violence is pervasive. The subject remains largely a taboo subject within lesbian and gay communities. Denial of the problem maintains the silence of victims and effectively condones the violence by allowing it to continue.
- It is unlikely that the heterosexual community will support efforts to address same sex domestic violence unless the lesbian and gay community acknowledges its existence and organises to address the problem. Regrettably, the reluctance of the lesbian and gay community to discuss and address same sex domestic violence is widely reported in the literature.
- Unless the silence created by heterosexism, homophobia and notions of privacy, is confronted, the problem of domestic violence in lesbian and gay relationships will remain closeted. Continued silence poses serious ramifications for lesbians and gay men caught in abusive relationships.
- Island & Letellier estimate that between 15-20% of gay and lesbian couples are affected by domestic violence and describe gay male domestic violence as "the third most severe health problem facing gay men today", trailing behind only AIDS and substance abuse. They estimate that approximately 500,000 gay men per year are battered by a violent partner.
- Some studies also suggest that the rate of violence is higher in same sex relationships. A 1985 study of 1109 lesbians by Gwat-Yong Lie and Sabrina Gentlewarrior reported that slightly more than half of the respondents indicated that they had been abused by a female partner. Coleman, in a 1990 study of 90 lesbians reported that 46.6% had experienced repeated acts of violence. Finally, Ristock's study of 113 lesbians reported that 41% said they had been abused in one or more relationships.]
- Arguably, these estimates substantially under represent the extent of the problem, due to the general reluctance to report or discuss incidents considered to be a 'private' matter between partners, and also because of the impact of a heterosexist and homophobic society which effectively maintains the silence of same sex domestic violence survivors. There exist barriers both within the lesbian and gay community and the wider community to disclosing same sex domestic violence, and both are inextricably linked to heterosexism and homophobia.
- Despite the absence of reliable statistics on the prevalence of same sex domestic violence, there is no doubt that the problem is extensive. If we are committed to non violent relationships generally, then the problem of same sex domestic violence must be acknowledged and addressed by both the lesbian and gay community and the wider community.



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- **A party who is abused may:**
- fear 'coming out' which may occur if s/he approaches family, the courts, or the police.
- feel that s/he is betraying the lesbian or gay community, which is already under attack, by 'accusing' a partner of violence.
- Feel that s/he is exposing his/her violent partner to a homophobic criminal justice system if s/he pursues legal solutions. This is a valid concern which needs to be discussed by the lesbian and gay community in terms of what responses to domestic violence should be supported and developed.
- feel that s/he has nowhere to turn for help and fears hostile responses from the police, courts, shelters, and therapists, because of homophobia.  
From: <http://classic.austlii.edu.au/au/journals/MurUEJL/1996/37.html>
- The CDC's National Intimate Partner and Sexual Violence Survey found for LGBTQ people: Forty-four percent of lesbians and sixty-one percent of bisexual women experience rape, physical violence, or stalking by an intimate partner, compared to thirty-five percent of heterosexual women. Twenty-six percent of gay men and thirty-seven percent of bisexual men experience rape, physical violence, or stalking by an intimate partner, compared to twenty-nine percent of heterosexual men. Forty-six percent of bisexual women have been raped, compared to seventeen percent of heterosexual women and thirteen percent of lesbians. Twenty-two percent of bisexual women have been raped by an intimate partner, compared to nine percent of heterosexual women. Forty percent of gay men and forty-seven percent of bisexual men have experienced sexual violence other than rape, compared to twenty-one percent of heterosexual men. From: <https://aumag.org/2019/08/28/justin-time-hiv-lgbtq-domestic-violence/>
- LGBT people face discrimination over domestic violence claims... Study finds serious issues with LGBT and HIV-affected people gaining access to emergency shelters and encountering 'hostile' or 'indifferent' police From: <https://www.theguardian.com/world/2016/oct/18/lgbt-hiv-affected-people-domestic-violence-study>
- As a mental health counsellor with the Violence Recovery Program in Boston, Jessica Newman says that because the default assumption is that people are straight, there can be an attitude within shelters that a gay person somehow "deserved" the violence. "Same-sex relationships are often demonised or marginalised," she said, "So some people's attitudes are 'it serves you right.'" But Newman, Lee, and Valentine all added that there are also internal factors that keep a cover of darkness over the issue of domestic violence in the gay community. **"There can be a fear of making the community look bad,"** said Newman. "Some people might have a real and legitimate fear of being looked down on, or not finding services through the police, judicial system, or a shelter. People don't want that negative image of the community out there." From: <https://www.theatlantic.com/health/archive/2013/11/a-same-sex-domestic-violence-epidemic-is-silent/281131/>
- The available evidence suggests intimate partner violence occurs in LGBTIQ relationships at similar levels to heterosexual relationships and the abuse similarly involves the use of power, coercion and control. However, heterosexism, homophobia, biphobia and transphobia are central to understanding how LGBTIQ people experience intimate partner violence .



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Heterosexism, homophobia, biphobia and transphobia also affect access to services and responses from service providers and the justice system. Several barriers have been identified for LGBTIQ people accessing services. These include discrimination (real or feared), lack of awareness and sensitivity to LGBTIQ issues, lack of recognition of intimate partner violence in LGBTIQ relationships and heteronormative understandings of gender and intimate partner violence. Building the capacity and knowledge of health care workers, domestic violence support services and the justice system through education and training is imperative in order to improve understandings and responses and prevent further violence in LGBTIQ communities. From:

<https://aifs.gov.au/cfca/publications/intimate-partner-violence-lgbtqi-communities>

- Sam does worry about the lack of discussion, both publicly and privately, about LGBT domestic abuse. Many of their friends were mutual and so when Sam finally escaped after several months, she lost them too. She says they did not believe her. It was a singularly lonely time, “A lot of that silence is about shame,” she says. “And about community – we are a close-knit community and when I admitted to a few close friends what was happening, I lost them because everybody knows everybody. My self-esteem has been shot to pieces,” she says. “It’s taken years to rebuild.” She adds: “It feels like a conspiracy of silence.” From:

<https://www.buzzfeednews.com/article/patrickstrudwick/this-is-domestic-abuse-when-lgbt>

- **There is a close link between Intimate Partner Violence (IPV) and HIV.**
- IPV can increase risk of HIV by limiting a person’s ability to negotiate safer sex and safer drug use and because the short- and long-term effects from IPV may lead people to engage in higher risk behaviours. IPV is common among people living with HIV, in part because IPV and HIV disproportionately affect some of the same populations. People living with HIV may experience more severe or more prolonged IPV than people who are HIV-negative and experiencing IPV. People living with HIV may be particularly vulnerable to IPV when they disclose their HIV status to their partner. Intimate partner violence can lead to poorer HIV care outcomes. HIV service providers can play a role in helping to prevent or respond to IPV. Likewise, those working with people who experience IPV can play a role in helping to prevent HIV and encouraging testing and treatment. From: <https://catie.ca/en/pif/fall-2019/link-between-intimate-partner-violence-and-hiv>

“We’re also seeing a real trend of gay men who are HIV-positive and their HIV status being used as a form of control,” says Harvey Barringer. “Either through threatening to reveal their HIV status or their partner withholding medication. This also occurs with partners of trans people withholding their hormone treatment. Even when LGBT people seek help from agencies that are supposed to support and protect those in need”, she adds, “many face further problematic assumptions”. From:

<https://www.buzzfeednews.com/article/patrickstrudwick/this-is-domestic-abuse-when-lgbt>

- Craft and Serovoich (2005: 785) report that of the HIV+ men participating in their study, 72.5 % had experienced psychological aggression from their male intimates, 45.1% were victims of physical assault, and 33.3 % had been sexually coerced. In New South Wales Australia, Dwyer (2004: 8) found that amongst a sample of clients from a generalist HIV/AIDS counselling service

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who reported same-sex domestic violence occurring in their relationships over a two year period, 70% of cases (including both men and women) involved emotional abuse, 59% of cases (including both men and women) involved physical abuse, and five cases (including both men and women) involved sexual assault. From: [https://research-repository.griffith.edu.au/bitstream/handle/10072/53248/86999\\_1.pdf](https://research-repository.griffith.edu.au/bitstream/handle/10072/53248/86999_1.pdf)

- All too often, we feel like we don't have a voice, must remain silent, don't cause trouble. Too many times offenders of abuse, assaults, harassment, racism, discrimination lead a double life, sweet, charming all the time hiding their true nature. All too often offenders are supported, promoted, defended by leaders of the community, their "cliques", their friends. Never wanting to hear a bad word about the people they call friends. Too often abusers, rapists, assaulter get away with their crimes in the gay community. Here we are in a New Year, a new decade... Time to start calling out those who don't deserve your love, your support or your friendship. Time to start cleaning up our community and supporting/protecting those who must deal with the consequences of the darker side of our society. From: Gary Page, Adelaide, 2020.

As the previous quotes demonstrates, ideologically based leadership that allows unpopular health issues to be ignored or be "swept under the carpet" serves as a petty punishment that "closes the door to the way out" for people in bad situations. Silence for Political Expediency ensures isolated people experiencing a problem, are forced to continue suffering in silence which worsens individual outcomes & across populations, increases the risk of preventable harm and associated Health Care costs to thousands of people. The LGBTI & HIV sectors needs to end the toxic leadership that censors community discussion because the explosion stated below is not just a Heterosexual Problem.

An "explosion" in family and domestic violence across WA is being driven by a toxic combination of soaring meth addiction rates and the end of the mining boom, one of the State's biggest charities has warned. From: <https://thwest.com.au/news/wa/hardship-meth-drive-rising-family-violence-ng-b88530573z>

One of the factors which undermines the authentic Whole of Sector Capacity Building Approach that is needed to deliver health care services and policy development in the LGBT & AIDS Industries, is the setting aside of the Principles Grassroots Meaningful Involvement of People with HIV/AIDS (MIPA) and re-imagining that MIPA conditions of funding can mean that Unrepresentative Influencers, Celebrities and/or HIV Career Specialists with Conflicts of Interest between Organisation vs PLHIV Community Needs, can represent Grassroots Need, while conspiring to lock Grassroots Consumers out of decision making processes and blocking access to Services for PLHIV who complain.

"As a result of the control, of Unrepresentative Influencers, Celebrities and/or HIV Career Specialists with Conflicts of Interest between Organisation vs PLHIV Community Needs, Grassroots PLHIV Consumers are delivered shallow, culturally sanitised misinformation that prevents meaningful and realistic discussion about health care from going on. Important Health Issues that should be discussed by the Community in Mature and Open ways are minimised or sabotaged by fights between Petty Controllers & Gatekeepers who perpetuate taboos & silence that maintains and encourages Stigmatisation". Mary-Jane Singleton, Convenor, HIV Consumer Alliance WA. <http://www.Facebook.com/ConsumerAllianceWA>

Celebrities are highly visible people whose actions and decisions are watched and often shared by wide audiences. Many celebrities have used their prominent social standing to offer medical advice or endorse health products. A celebrity endorsement is familiar as a value adding exercise in Health Promotion Campaigns to promote health care services. There is a danger that high profile influencers are used by HIV Career Specialists to push

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factional political agendas & deliver ideological propaganda to manipulate the public's health-related knowledge, attitudes and beliefs, rather than delivering unbiased health information.

When discussions are controlled by Conflicted HIV Career Specialists no Accountability is ever taken for Strategy failures or Errors that lead to unintended negative side effects and it is common for predictions of the future to creating unrealistic expectations when projecting estimates of health outcomes. An example of this can be seen in relation to the Management of the Meth Crisis which is described in the following way;

WHEN AIDS drugs arrived in the 1990's, gay men's sexual health agencies began prioritising HIV management over prevention. Once compassionate responders sidelined proven prevention policies in favour of a zealous PC ideology that softened messages around "safer sex" and hard drugs and erased personal responsibility from the equation, in turn facilitating and accelerating HIV infection and crystal meth use and boosting demand for their lucratively-funded services. Ultimately they unwittingly spawned today's 'chemsex' culture that has afflicted gay communities throughout the West, destroyed tens of thousands of lives... From: <http://lifeormeth.com/#/aids-inc-uncovered/4520785349>

Peer Support Programs conducted by PLHIV Organisations could have the capacity to act as informal diversion programs for PLHIV whose isolation makes them at risk of using MethAmphetamine as a self medication to deal with chronic illness & depression/anxiety.

The Community Hub at a Perth Sexual Health Clinic would have the capacity to provide the space for a new kind of peer led support group, run by Co-ordinators rather than Presidents and with a simple health focus and mission that seems beyond the capacity of HIV Organisations run via factional politics.

The current multi agency Boutique Clinic approach, fosters inter-organisation competition, clutters the prevention landscape, reduces HIV treatment education services for Consumers, increases the duplication of services, adds the burden of expensive Administration & Non Core Expense costs, while undermining the Efficacy, Effectiveness and Evaluability of BBV & STI Preventative & Health Care messages.

A Perth Sexual Health Clinic & Community Hub will consolidate existing Health Boutiques which will offer a better service and this will benefit all Consumers and the existing health dollars will be better spent. There is a growing feeling amongst grassroots PLHIV that HIV Services are being neglected with the shortage of S100 Providers causing increasing wait times to access HIV medical care. PLHIV really do need a One Stop Shop, with a Whole of Sector Capacity Building model in order to implement a new S100 delivery model that removes the stress from the current under resourced system that does not work and it is time to invest in a model that future proofs HIV Services & Advocacy and puts Western Australia on track to achieving it's target of eliminating HIV transmission by 2022.



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## **Easy Access**

Easy Access has a two fold quality, a dichotomy or duality, in which two ideas are both relevant at the same time. In this section our discussion of our proposed Perth Sexual Health Clinic and Community Hub includes the necessity of an easy access geographical location as well as the requirements, laid in the Western Australian HIV Strategy, for PLHIV to have easy access to HIV Treatment and information about their Health Care so as to become Literate Health Consumers, achieving improvements in resilience, mental health and social connectedness.

Ensure that PLWH receive the necessary support for developing health literacy on understanding life with HIV and sustained ART adherence, with support options that include community-based and peer-led approaches.

Facilitate options for PLWH that aim to improve mental health, resilience and social connectedness. From: Western Australian HIV Strategy, 2019–2023

For the Ageing PLHIV population and the known complications that HIV brings, Easy Access to Treatments plays a critical role in helping people with higher health needs stay in their own homes longer, with support from home care services, which results in savings in health care funding costs. Easy to understand information materials designed to help frail HIV people stay in their homes Access Care Services could be produced by a specialist Health Promotion Team at our proposed Perth Sexual Health Clinic & Community Hub.

The Melbourne Sexual Health Clinic is an excellent example of Easy Accessibility with a large building, a tram stop outside, located in the inner city and free consultations for consumers. Easy Access is also about the range of services included in a non-judgmental environment to meet the needs of People of all Sexual Orientations, Gender Identities, including those with Disabilities, Chronic Illness & Complex Medical Needs. Easy Access also means being able to schedule medical appointments, laboratory testing with 3 day result availability, pharmacy, psychology, and social support etc at one location.

A familiar Community Hub environment would provide Easy Access to Crisis Care and the ability for qualified caring health professionals to carry out Early Interventions for People in Need to reduce self harm and suicide. A Hub that co-locates a range of health-care professionals under one roof will facilitate easy access to Referrals and reduce the time needed to access treatment, especially for vulnerable people.

Australia is one of the wealthiest counties in the world yet in a State capital city that is positioning itself as the Gateway to the emerging Indian/Asia Economic Zone yet WA lags behind the Eastern States as a destination, in not having this vital Sexual Health infrastructure. The following quote is a reminder of how WA could have a world class Sexual Health Hub and make HIV treatments Easy to Access for PLHIV in WA.

‘If we can bring a bottle of Coke to every corner of Africa, we should be able to also deliver antiretroviral drugs.’ From: <https://medium.com/@DrRimmer/michael-kirbys-challenge-intellectual-property-hiv-aids-and-human-rights-2284d092397b>

BBV testing as part of Routine Sexual Health Care will educate the public to understand real risks. For example, the health risks of travel overseas can be discussed more readily as preparations for travel are undertaken. A easily accessible Perth Sexual Hub with an increased availability of HIV educated Doctors in a One Stop Shop setting will encourage “universal testing”, ensuring earlier diagnosis's in people diagnosed with BBV who underestimate their risk factors.

A “High Viz” Perth Sexual Health Clinic and Community Hub will enable “Easy Access” Memory of the Service Location for Local Residents as well as for Visitors from Regional Areas & Overseas. A location in an area where tourists and locals spend time will enable the Architecture Signage to advertise itself. People knowing where to go for help in



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advance is a way to minimise the stress of dealing with illness, enabling quicker diagnosis's and earlier treatment.

A Perth Sexual Health Clinic that enables overseas Visitors to easily access testing and treatment for STIs, without the Stigma they may face in their own countries, would be able to proactively prevent infections from overseas being transmitted in WA.

Guildford et al suggest that “access measured in terms of utilisation is dependent on the affordability, physical accessibility and acceptability of services and not merely adequacy of supply” and these considerations are important components of what makes up easy access. A financially affordable for All, One Stop Shop, Perth Sexual Health Clinic with a Community Hub, offering a comprehensive range of services, in a high viz location would provide Easy Access to hard to reach services.

“The Delivery Location dimension of service delivery, which is easily taken for granted, is often defined by the provider's needs rather than the client's... Health care gets delivered in clinics for outpatients and in hospitals for inpatients, even though an individual with a chronic disease may have to go to a host of locations for appointments, lab tests, physical therapy, medical accessories, and social support. Even if each of those services is competently provided, the overall delivery of the patchwork quilt of care may be inconvenient, expensive, and less effective than it could be. When access is difficult, patients are less likely to adhere to physicians' counsel. Both efficiency and outcomes may be compromised.

From: <https://hbr.org/2012/12/four-ways-to-reinvent-service-delivery>

Kate Emery's article in the West Australian Newspaper confirms that “WA has a relatively high proportion of straight people getting HIV” and asks the question “So why are so many straight men and women in WA contracting HIV?” Not understanding one's risk factors are the reason why so many Heterosexuals experience a late diagnosis of HIV with negative health outcomes. This and the following quote reinforces the importance of easy access to pharmacy services for treatment.

“Access to HIV medications is more important than ever. Access must be convenient, affordable with a minimum of prescription barriers. Treating HIV immediately reduces the amount of HIV in body reservoirs, reduces the amount of chronic inflammation that HIV causes, and also prevents the onset of other serious chronic diseases. From: <https://www.positivelife.org.au/your-voice/hiv-meds-in-community-pharmacies.html>

The following quote highlights how Consumer satisfaction & Easy Access to a HIV friendly health care service increases medication and appointment adherence in adults with HIV.

“Research suggests that health care workers often hold negative views of people with HIV and that their views tend to mirror those of the general public (Ahsan Ullah, 2011). Furthermore, when compared to other illnesses, biases towards HIV are far more negative (Li et al., 2007). Prejudicial attitudes of health care workers towards other stigmatised groups, such as PWID, have been shown to have a negative impact on treatment adherence (Brener, Von Hippel, Von Hippel, Resnick, & Treloar, 2010), while satisfaction with a healthcare provider has been shown to increase medication and appointment adherence in adults with HIV (Bodenlos et al., 2007)”. From: <https://www.aasw.asn.au/document/item/6780>

The Melbourne Sexual Health Clinic Model demonstrates the value of having a Connection between Doctors and a Hospital Pharmacy to enable distribution of treatment. Thus increasing efficacy of STI medication, especially if Clients with chaotic, homeless or nomadic travelling lifestyles take their medication on site, but most of all allowing consumers with chronic illness to reduce the long waiting times & visits to multiple locations.

In our study, patients not retained in care faced more barriers, particularly social



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and structural barriers, than those retained in care. Developing care models where social and financial barriers are addressed, mental health and substance abuse treatment is integrated, and patient-friendly services are offered is important to keeping HIV-infected individuals engaged in care. From: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4485864/>

Long Term Survivors, diagnosed when HIV was treated differently in WA, who have experienced being judged for being HIV+, been denied care or given second rate abusive care, and being discriminated against in the Health Care system carry the trauma of psychological abuse and the increasing difficulties and time delays in accessing HIV care are very upsetting reminders of times past and is the reasons why WA should not drop the ball on HIV Care. This is time is described below:

Research illustrates some of the ways in which stigmatising attitudes of healthcare workers are transformed into discriminatory practices and behaviours. Rintamaki, Scott, Kosenko and Jensen (2007) found that lack of eye contact; clipped or brusque speech and differential precautions were all attributed to HIV-related stigma, when describing the experiences of HIV-positive patients in the US. They also found more overt forms of discrimination, such as blaming patients for their status, physical abuse and the denial of care, and that many of the patients reported being very upset and even emotionally scarred (Rintamaki et al., 2007). Patients also reported experiencing substandard care, ranging from an inadequate time spent on their needs, to being left in extreme pain for an extended period of time. From: <https://www.aasw.asn.au/document/item/6780>

Australia's response to HIV has always been one that has included Human Rights and HIV Care and Support Services have long been regarded as essential to preventing HIV Transmission rates. A Perth Sexual Health Clinic that provides Easy Access to HIV Treatment for everyone is a basic Human Right. The following quote describes further why respecting human rights in Health Care is imperative.

Strategies to address the epidemic are hampered in an environment where human rights are not respected. For example, discrimination against and stigmatisation of vulnerable groups such as injecting drug users, sex workers, and men who have sex with men drives these communities underground. This inhibits the ability to reach these populations with prevention efforts, and thus increases their vulnerability to HIV. Likewise, the failure to provide access to education and information about HIV, or treatment, and care and support services further fuels the AIDS epidemic. These elements are essential components of an effective response to AIDS, which is hampered if these rights are not respected. From: <https://www.ohchr.org/EN/Issues/HIV/Pages/HIVIndex.aspx>

The websites of the HIV Industry in Australia all seem to contain the same similar superficial messages about how early treatment is beneficial for the individual, and the role treatments have in helping to prevent HIV transmission. These messages also highlight their commitments to global compacts, for example the 2015 UN targets of ending AIDS by 2030 with a target that includes 95% of all people living with HIV knowing their HIV status, 95% of people who know their HIV-positive status having access to treatment, and 95% of people on treatment having suppressed viral loads.

For PLHIV easy access to treatment guidance, during the process of commencing medication & during the times when changing treatment, is Essential. How can someone make an informed choice if there is no-one to get correct unbiased advice from? Complex Meds are a barrier to access & not having HIV Treatment Advice, undermines the goals of Early treatment. Exposing private information & asking for help from Strangers in Facebook Groups is dangerous in small towns like Perth and can lead to discrimination.

There is a lack of any in depth source of Treatments Information & Education Services to help Consumers interpret and de code complex medical information before commencing

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HIV Treatment. The main source of education for PLHIV stems from limited timed visits with their Doctor when decisions on treatment are made. A limited timed consultation lacks the ability to de code complex medical information into the clear and simple language all Consumers need to ensure they make informed choices.

A concern of many PLHIV in WA relates to the conflict of interests that stems from the HIV Service & Advocacy Organisation's sponsorship from the Pharmaceutical Industry and the level of bias attached to information given to clients. Further many PLHIV refuse to discuss their personal medical situation with non-medically qualified Peer Based Support Officers in unregulated HIV Service Organisations due to the fact that allegations about Breaches of Confidentiality are known to have occurred. From the Perspective of the WA State HIV Strategy, does One "Talk & Chalk" Treatments Seminar, with limited time for approved questions, which not everyone is invited to, timed approx every 18 months to 2 years, qualify as "the necessary support for developing health literacy on understanding life with HIV"? From: Western Australian HIV Strategy, 2019–2023

A Community Hub in a Perth Sexual Health Clinic could provide Easy Access to a Medically Qualified Treatments Officer as one of its core policies. The position could also be utilised to provide information on Treatments for all STI and BBVs. This would serve to increase the uptake of the HepC Cure. A Medically Registered & Properly Supervised Practitioner would eliminate the fear of breaches of Confidentiality and links could be made between GPs & HIV Specialist to ensure a holistic approach to maximising health outcomes is achieved.

The Community Hub would also be able to provide Consumers with a Health & Wellness Treatments Newsletter that supports the development of Consumer's Health Literacy and the goals of understanding life with HIV and sustained ART adherence to improve mental health, resilience and social connectedness in the Western Australian HIV Strategy. The Hub would be able to develop a data base that Consumers could opt in to receive information about events/services and a link to a pdf copy of the Newsletter.

HIV needs to be treated as a medical issue & not criminalised. Having a Treatments Officer as core to the Perth Sexual Health Clinic will ensure that people with mental illness remain on their medications, with the right support without the big stick approach. A Visible Community Hub will also allow people who do not identify as GLBTI or MSM to come forward to be tested. Decriminalisation has been proven to work as a better way to manage the spread of HIV and reduce the stigma that HIV face, as the only STI that is criminalised. Health Management would have better outcomes for Consumers and better protection of the wider community health than the last century fear, discrimination & imprisonment based approach.

The law needs to reflect the fact that self care should be a mutual, shared responsibility. Funded advocates need to develop a broad culture in which HIV negative people do not rely solely on Positive People to look after their health in regards to all STI and Blood Borne Virus transmission. One of the features of the HIV Epidemic that is often overlooked is the way in which Positive People have managed their health and effectively limited the spread of the epidemic in Western Australia. HIV Institute of WA Decriminalisation Discussion Paper. From: <https://www.facebook.com/HIV-Institute-of-WA-656846218021808/>

Easy Access to a Medically qualified, confidential, Treatments Officer is most certainly a Meaningful Involvement of People with HIV/AIDS Issue which all National, State and International HIV strategies have committed to implementing. Not being able to be meaningfully involved in decisions made about one's health care and being forced to do what a Doctor says, due to confusion = an inability to make an informed choice that is a horrific abuse of PLWHA Human Rights. This is reinforced by the quote below from the UNAIDS NGO Code of Practice, which AFAO & NAPWHA have signed up to endorse.

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“This includes the process of building literacy on ARV treatment and HIV health in preparing communities for access to ARV treatment, to ensure that treatment service providers understand community beliefs, knowledge and needs

When providing treatment, care and support services for PLHA, we need to:

involve PLHA, their families, partners, dependants and carers in programme design, implementation and evaluation. This includes the process of building literacy on ARV treatment and HIV health in preparing communities for access to ARV treatment, to ensure that treatment service providers understand community beliefs, knowledge and needs

provide individual assessment of the treatment, care and support needs of PLHA, taking into consideration the needs of their partners, children, other family members and carers

provide tailored support programmes that enable people to deal with the consequences of HIV and make informed decisions about their treatment, care and support needs, and

ensure that the social, economic and psychosocial affects of HIV/AIDS on PLHA, their family and carers are addressed”. From: <https://www.unhcr.org/405ac7542.pdf>

Australia's National HIV strategy mandates the Meaningful Involvement of People with HIV/AIDS (MIPA) in funding agreements. One of the biggest complaints relating to HIV Service & Advocacy Organisations in WA is that they all fail to engage meaningfully with Consumers on policy development and have tokenistic representation. A One Stop Shop, Community Hub can be mandatorily required to consult Consumers & Perth's ubiquitous toxic “Sandbox” culture of #FakeMIPA, Tokenism & Diversity without Inclusion can finally be seen to end. The Sandbox is described in the quote below.

“Texas-based HIV advocate Venita Ray gets frustrated by what she calls “the sandbox” – when people living with HIV are relegated to hospitality, greeting, or non-voting roles in HIV planning rooms. HIV Consumer Alliance of WA “MIPA Discussion Paper” From: <http://www.Facebook.com/ConsumerAllianceWA>

The current WA HIV Strategy's evaluation needs to ensure that Organisations funded to implement Core Action areas, such as the one below, deliver as they promise. Program Evaluations & Community Consultations in the LGBTI & HIV Sector seem to be designed in advance around an “Everything is Lovely” paradigm but they should be built on Rigorous Needs Analysis & Scientific Health Promotion Programming Evaluations measuring real success or failure in regards to Process, Impact and Outcome, Aims & Objectives, in order to avoid the tyranny of low expectations.

Real measures of program effectiveness are important to ensure that stated Core Actions to benefit PLHIV are delivered. One of the ways Action Area 5 could be improved is to Promote Treatment as Prevention (TasP) through the Anti-Stigma U=U Campaign, which has not been broadly implemented in WA. These Campaigns need to be more than small PR Campaigns distributed in the social networks of HIV Organisations. To maximise the changes in attitudes, knowledge & beliefs needed to to remove Stigma, the U=U Campaign needs to be tailored to reach all demographics, which is something a “Whole of Sector Capacity Building” Perth Sexual Health Clinic and Community Hub could create & distribute to Consumers across all of WA.

“Action areas 5.

Seek to improve the health outcomes for PLWH by increasing awareness on:  
the benefits of rapid ART initiation achieving and  
sustaining an undetectable VL

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Treatment as Prevention (TasP)

supporting mental health

diet and nutrition

comorbidity risk factors

engaging with primary health care providers for non-HIV related conditions”.

Western Australian HIV Strategy 2019–2023 From:

<https://ww2.health.wa.gov.au/~media/Files/Corporate/general%20documents/Sexual%20Health/PDF/Strategy/2019-2023/HIV-strategy.pdf>

It is of concern to the PLHIV Community that Core HIV services identified in the WA HIV strategy have actually been cut and are no longer provided by HIV Service Organisations in WA. These include, Group Programs for Peers to Support Mental Health, Nutrition and Meal Support Programs & Retreats that provide respite and education about treatments for PLHIV. Services that used to be provided by the SIDA Drop in Centre include Housing Managed by SIDA & fast tracked applications to HomesWest & in House Home Care Support for frail PLWHA.

The anecdotal evidence amongst grassroots PLHIV is that HIV Service Organisations do more for privileged LGBT HIV Negative People than HIV+ People and

“It is interesting that Margaret Court & her Victory Life Church's Community Outreach Program seems to do more to help PLHIV, including LGBT PLWH, living in poverty, with emergency food relief, than the anti-religionists at WA AIDS Organisations”. Sister Mary-Jane Singleton of the Divine Green Weed, Media Annuncio & Senior Sister at the Order of Perpetual Indulgence Abbey of the Black Swan, Perth. From: <https://www.facebook.com/AbbeyoftheBlackSwan/>

Peer Support programs are failing in Western Australia both from an Advocacy and Service Delivery approach. At a recent meeting between HIV Peers and the Health Department, held at the Health Consumer's Council, the POWA Leadership Group raised the concern that it is always only the same 6 people, including themselves, all of whom are Long Term Survivors with the average age of 55 y/o, making decisions on behalf of all the PLHIV Community at Community Meetings & Peer Led Support Groups. It is clear that old models of Board Managed Peer Leadership & Bureaucratic Heavy Service Delivery no longer engages the broader grassroots PLHIV Community.

One of the major problems in Western Australia is that many times Discrimination comes from within the PLHIV community and the fear of public Stigma prevents People who are discriminated from taking action to stop bullying or other forms of harassment. One factor linked to this is that PLHIV employed or volunteering within Service & Advocacy Organisations are not impartial observers. Employment Environments function as Peer Support and there are times in which Career Specialist PLHIV appear to focus on their own needs and/or set up Services/Activities that push their own Personal or Employer's Agendas.

NAPWHA's Last Century, Anti-MIPA, Peer Group Model requires Regular Bureaucratic Heavy Board Meetings that leave no time for Time Poor Leaders to engage with or provide Services to Members & the PLHIV Community. HIV Career Specialists who experience a very privileged “Living with HIV” with daily on demand support given to them in their workplace environments often seem unable to empathise with the needs of the isolated . Grassroots PLHIV, they represent.

The ability to engage in above the grassroots level policy development is empowering. The sources of information HIV Career Specialists have access to about HIV Treatments are not available to the grassroots PLHIV, they seek to represent. This contributes to the feeling amongst many grassroots PLHIV that the dominating HIV Career Specialist



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Leadership, in Unsupervised Peer Support Groups, does not empathise or have compassion for grassroots PLHIV.

The current Advocacy Models demonstrate a lack of respect for Long Term Survivors whose health status has caused them to experience being on long term low incomes in poverty or other PLHIV who work in environments that are not HIV Safe & Friendly. A Community Hub could employ Professional people with a greater understanding and empathy with PLHIV with complex health needs. In small Communities like WA, The Eastern States imported idea that HIV status is qualification enough for employment in HIV Organisations has proven to have not worked and in some cases the nepotism it has generated has been very destructive to our community.

An Easy to Access, New High Profile Perth Sexual Health Clinic with a Community Hub for Advocacy & Support is the much needed 21st Century Approach to reorganise BBV & STI Prevention, Treatment & Support into one central location that places Consumer Health First. Modernising the way WA treats STI & BBV and making the New Treatments Environment Easy to Access, will lead to old stereotypes including Fear, Ignorance and Stigma, disappearing along with the costs of duplicating Boutique Clinics, spread out all over Perth.





# **A New HIV Deal For WA = Perth Sexual Health Clinic & Community Hub!**

## **Conclusion**

Consumer Health should always be placed First and should not have to compete for Resources with Organisational Needs. A properly Regulated & Managed Sexual Health Clinic with a Community Hub will implement best practice standards of health care that everyone can access equally.

Consolidating all the BBV & STI revenue streams & the Boutique Services is a great opportunity for the WA State Government to lead Australia to redefine a last century Service Delivery & Support Culture. This will reinvigorate the Western Australian HIV Strategy so that the target of ending HIV transmission can become realistic and achievable.

Efforts to end the HIV epidemic must not ignore People already living with HIV. There is no current HIV Service Delivery Organisation in Western Australia that places the needs of Grassroots HIV Consumers First. Evidence for this can be seen in the following quote from the 2018 – 2019 WAAC Annual Report where in the CEO's Overview the first line is a celebration of Pride in WAAC's work for the LGBTQI+ Communities. The use of the word, "Client" that seems to occur only once and "PLHIV Community" not at all, sends a clear message that PLHIV Consumers don't come First.

"It is with pride that we reflect on the last 12 months, knowing that we have accomplished a great deal this year on behalf of Western Australia's LGBTQI+ communities" From:

[https://waaid.com/media/k2/attachments/WAZAidsZCouncilZ2019ZfinalZwebZversionZ2\\_compressedZ1\\_reduceZ2Z3.pdf](https://waaid.com/media/k2/attachments/WAZAidsZCouncilZ2019ZfinalZwebZversionZ2_compressedZ1_reduceZ2Z3.pdf)

WAAC has stated that it's focus is on work in Health and Prevention equally, however, in the Grassroots PLHIV Community it is suggested that in practice HIV+ People rank 3rd in priority and the only time PLHIV are Number One is in applications for funding! Grassroots HIV Consumers deserve a Service provider that is consistent and places the need to improve PLHIV Health Outcomes First. For example:

"It really is time we got back to treating the HIV Consumer First, especially long term survivors, who need more than a simple acknowledgment at the beginning of meetings to meet our health needs. We are over the era of AIDS Organisations and Peer Groups, We just want good health care, as We enter old age & become the path finders, again, for Positive People". Mother Gretta Amyletta of the Holy Vapours, HIV Spokesperson for the OPI Abbey of the Black Swan. From:

<https://www.facebook.com/SistersPerth/>

One of the concerns in WA is that there is an attempt being made to redefine the Principles of the Meaningful Involvement of People with HIV/AIDS to benefit Organisational Aims in such a way that the Human Rights of Grassroots PLHIV Consumers to be included & participate in the life of the Community are being reduced & not being respected. Without the inclusion of grass roots MIPA in the development of HIV policies & programs then Funders and the PLHIV Community cannot be confident that strategies implemented genuinely represent the needs of positive people.

An Aged Care Advocate needs to be a core position in a new Perth Sexual Health Clinic & Community Hub. Aged care is not a sexy issue and has been under the radar & with the increase in the HIV Ageing population, no frail positive person should be left behind. The Majority of Ageing HIV people come from low income and will need assistance in home care and in Aged Care facilities.

It is time Aged Care was made a core issue and stopped being passed around like a football as someone else's problem. Ageing HIV+ Western Australians deserve respect and dignity with out having to beg for help. The needs of PLHIV should not be lost sight of

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in the context of bureaucratic arguments about State versus Commonwealth responsibilities. This does not put Consumers First and risks doing more harm than good, as expressed in the quote below.

PLHIV already struggle with trauma & stigma so Forcing the PLHIV Community to protest for inclusion and non-discriminatory access does do harm to the mental health and wellbeing of Individual PLHIV & the overall community suffers so isn't this a breach of duty of care, a breach of MIPA & of "First, Do no Harm"? WA needs a NEW HIV Deal that places MIPA front & centre and gets rid of these tired old dictatorships that do more harm than good. From: HIV Consumer Alliance of WA MIPA Discussion Paper <http://www.Facebook.com/ConsumerAllianceWA>

A One central point of contact will enable current groups, which lack the capacity to provide effective services & authentic representation to their members to more easily connect with other Consumers. This will enable increased critical mass, reinvigoration of struggling groups with new ideas and where possible mergers of interest groups will lead to greater political capital & a more meaningful involvement as advocates in the development of public policy. As the quote below illustrates, PLHIV are sick of toxic leadership emanating from peak bodies who Fight with everyone and who can't or won't engage with the community.

"All too often, we feel like we don't have a voice, must remain silent, don't cause trouble. Too many times offenders of abuse, assaults, harassment, racism, discrimination lead a double life, sweet, charming all the time hiding their true nature. **All too often offenders are supported, promoted, defended by leaders of the community, their "cliques", their friends.** Never wanting to hear a bad word about the people they call friends. Too often abusers, rapists, assaulters get away with their crimes in the gay community. Here we are in a New Year, a new decade...Time to start calling out those who don't deserve your love, your support or your friendship. Time to start cleaning up our community and supporting/protecting those who must deal with the consequences of the darker side of our society".  
From: Gary Page, Adelaide, 2020.

The implementation of far reaching Anti-Stigma Campaigns through the Sexual Health Hub that educates everyone in WA about Prep & the need to continually maintain safe sex practices to prevent STIs, is a demonstration of how valuable every human life is. The WA HIV Strategy Aims of empowering PLHIV to achieve their best health outcomes, outlined in the quote below, will be achieved by providing easy access to non-political, open to everyone, HIV Support Services with Unbiased Medically Qualified Treatments Officers to help PLHIV make informed choices about the right Medication for them.

Beyond medical and healthcare support, PLWH may need psychosocial, physical, socio-economic, nutritional and legal support from the point of diagnosis and throughout the course of their life, as social and structural factors can affect a person's ability to link into and remain in connection with disease management and clinical care services. From:

[https://ww2.health.wa.gov.au/~/\\_media/Files/Corporate/general%20documents/Sexual%20Health/PDF/Strategy/2019-2023/HIV-strategy.pdf](https://ww2.health.wa.gov.au/~/_media/Files/Corporate/general%20documents/Sexual%20Health/PDF/Strategy/2019-2023/HIV-strategy.pdf)

Elevating the self esteem of PLHIV, helps individuals make educated, smart choices when making lifestyle and Health decisions or engaging in sex. Empowering PLHIV to make them feel good about themselves and valued in the Community leads to a high level of respect for their own bodies. A truly strong, empowered HIV Industry would practice these things, before they practice "their right to a paycheck".

The WA State Government needs to modernise the BBV & STI sector with a new Perth Sexual Health Clinic & Community Hub, for everyone, to avert the unfolding crisis' in HIV

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Aged Care & HIV Service Delivery Systems. Peer Led Organisations and funded HIV Service Organisations need to be audited and required to refocus on their Constitutional Obligations to put the needs of PLHIV First & start to actively deliver on the Goals they are funded to implement, that are laid out in the UNAIDS Code of Conduct for NGOs & the WA State and Australian National HIV Strategies etc.

The paper is written by grassroots PLHIV and we hope that this document will lead to serious & considered discussions in Western Australia about how to achieve a Consumer First reform of the BBV & STI Sector that includes the meaningful involvement of grassroots PLHIV in the Conversation.



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### **Submission to the Parliament of Australia, House of Representatives Inquiry into the use of 'fly-in, fly-out' (FIFO) Workforce Practices in regional Australia. (2012)**

It is time for a new and collaborative community response to BBV and STI prevention and this includes the need for discussion about the methods used to disseminate information not only generally to the public but also for travellers and FIFO/DIDO workers to reduce the rate of STI's and guard against other BBV infections.

The epidemiology of BBV's and STI's in Western Australia is marked by continuing rises of the rate of new infections to the point that this state has the highest rate of infection in all of Australia. In spite of the 10s of thousands of dollars spent on advertising in the Gay Press, in 2011 the rate of HIV infection amongst Gay Men also rose. These factors combined with the alarming increases in the rate of STI's is evidence that Present Strategies for safe sex messages are not resulting in reductions of measurable outcomes, the rate of infections. In the grand scheme of things, luck not good management is the reason why HIV infections have not risen further than they have in WA.

The fact is there is a clear epidemiological link between HIV and high rates of STI infections. Anyone who has the capacity to do a basic google search will find evidence put forward by many sources that where there are High rates of STI's then HIV infection rates also increase as a flow on effect.

Avoidable STI and BBV infections add to already over burdened health care systems, especially in rural and remote areas. There are also issues relating to the nature of FIFO/DIDO employment and the need to access specialised treatments for BBV's in major capital cities which make management of complex health conditions difficult while maintaining employment.

The "HIV Tattoo in Bali" story raises more questions about the politics underpinning the prevention of Blood Borne Viruses & STI Prevention here at home and the quality and availability of health messages provided to Australians, especially those who are Fly in Fly out Workers who travel to Asian Countries on the way to and from work, prior to their overseas travel, than it does about Indonesian Tattoo Parlours.

**This issue also highlights structural deficiencies within the way Health Departments & BBV/STI NGO's are managing the prevention of Blood Borne Virus infections. Not having one single "one stop shop" agency responsible for providing information means that people who are concerned about their health are forced to wade through multiple agency websites with competing mission statements and priorities. This political landscape associated with Blood Borne Virus Prevention fosters inter agency competition and "turf wars" which actually serves to prevent members of the public from accessing basic information written in clear and simple language that they can use to protect their health.**

It should be a concern to everyone in Australia that people are being infected with serious infections simply because educational material is not easily accessible by members of the public to prevent infections.

From: [https://www.apf.gov.au/Parliamentary\\_Business/Committees/House\\_of\\_Representatives\\_Committees?url=ra/fifodido/subs/sub157.pdf](https://www.apf.gov.au/Parliamentary_Business/Committees/House_of_Representatives_Committees?url=ra/fifodido/subs/sub157.pdf)



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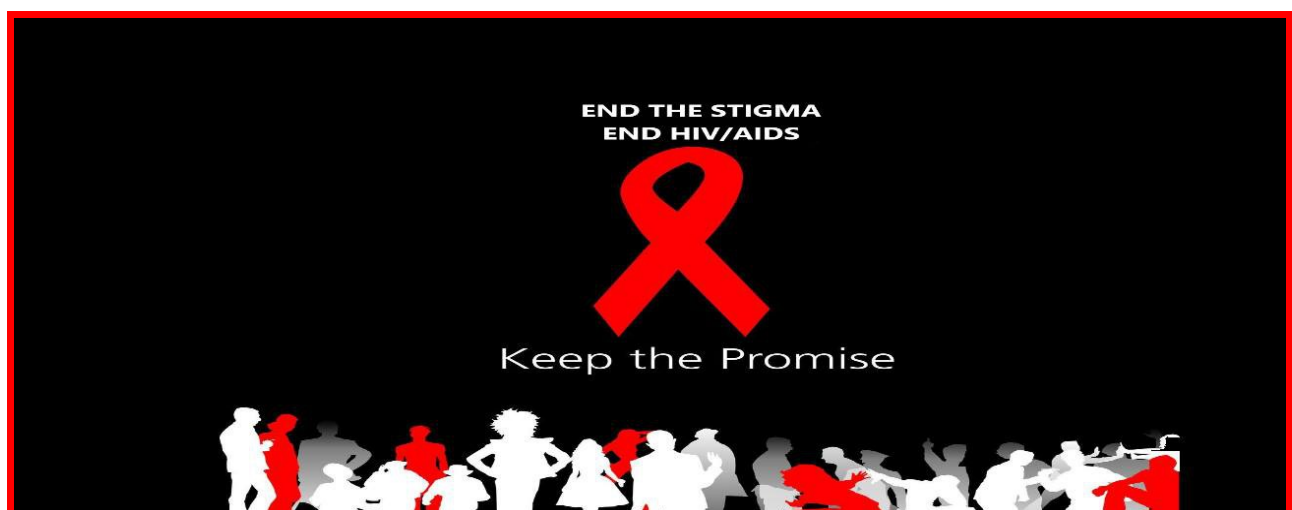
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## A New HIV Deal For WA = Perth Sexual Health Clinic & Community Hub!



### Our Vision.

**A New HIV Deal for WA = A New One Stop Shop,  
Perth Sexual Health Clinic & Community Hub For Advocacy & Support Groups**

A New Regulated, Free, One Stop Shop Model, **Perth Sexual Health Clinic**, that Merges ALL BBV & STI in a high Viz location for Regional & Overseas Visitors to Perth, to Streamline Service Delivery, End the Costly Duplication of Services, Increase Treatment Uptake & Enable More Effective Prevention Strategies.

A Community Hub, Staffed by Qualified Advocacy & Support Professionals to Empower Health Consumers to undertake Peer Led Community Development through Engagement & Advocacy Groups.

A New Century Approach will deliver Better & Broader Outcomes in the area of Health and Mental Health through a better spend of Existing Funding.

