



ENDING HIV-RELATED STIGMA FOR ALL





ABOUT ACON

ACON is NSW's leading health organisation specialising in community health, inclusion and HIV responses for people of diverse sexualities and genders. Established in 1985, ACON works to create opportunities for people in our communities to live their healthiest lives.

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We pay our respects to the Traditional Owners of all the lands on which we work, and acknowledge their Elders, past, present and emerging.

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CONTENTS

Executive Summary	5
Introduction	6
I. CONTEXT – POLICY AND LEGAL FRAMEWORKS	7
1. Greater & Meaningful Involvement of People Living with HIV	7
2. Stigma & Discrimination in HIV Strategies	8
3. HIV-related Stigma & Discrimination and the Law	9
II. PREVALENCE AND FORMS OF HIV-RELATED STIGMA & DISCRIMINATION	11
1. Stigma in Everyday Life	11
2. Stigma in Care Settings	14
3. Intersecting Stigma	15
III. THE IMPACTS OF HIV-RELATED STIGMA & DISCRIMINATION – WHY ADDRESSING STIGMA MATTERS	18
1. Impacts of Stigma on HIV Testing	18
2. Impacts of Stigma on Treatment Initiation, Access and Retention in Care	19
3. Impacts of Stigma on PLHIV's Related Quality of Life	20
IV. HOW TO REDUCE HIV-RELATED STIGMA & DISCRIMINATION	21
1. Changing Community Attitudes and Behaviours	21
2. Gaining Power over Stigma	23
3. Addressing Structures of Inequality and Exclusion	25
Conclusion: A Combination Approach to Eliminate HIV-related Stigma in NSW	27
Recommendations	28
References	29

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EXECUTIVE SUMMARY

- HIV-related stigma refers to the negative beliefs, attitudes, fears and judgements held against people living with HIV (PLHIV) and members of groups that are perceived to be associated with HIV, such as gay and bisexual men, people who inject drugs and sex workers.
- HIV-related discrimination is the unfair and unjust treatment of a person or group of people based on their real or perceived HIV status. It is illegal to discriminate against PLHIV in NSW.
- The *Eighth National HIV Strategy 2018-2022*¹ has set strong stigma reduction targets and has reaffirmed a commitment to the rights of PLHIV, including the right to participate fully in society and the Greater and Meaningful Involvement of PLHIV (GIPA/MIPA) principle.
- PLHIV in Australia continue to experience HIV-related stigma. Stigmatising behaviours take many forms, overt or subtle, online or in real life. Discrimination can occur in personal relationships and in relation to employment, insurance, accommodation and other services.
- A third of PLHIV in Australia report experiencing negative or different treatment by healthcare workers because of their HIV status. Poor HIV literacy contributes to unfounded fears and the perpetuation of stigmatising behaviours in healthcare and aged care settings.
- Discrimination can feed negative beliefs PLHIV may hold about themselves (e.g., self-stigma), thereby impacting their mental health and quality of life.
- HIV-related stigma is often compounded with prejudices based on sexuality, gender, race, drug use, sex work and other diseases (e.g., hepatitis C). More research is needed to understand the impacts of intersecting stigma – the association

of multiple stigmatised identities – on PLHIV who are Aboriginal and/or Torres Strait Islander, migrants, of colour, culturally and linguistically diverse and/or trans or gender diverse.

- HIV-related stigma has real consequences on the health-related quality of life of PLHIV. Stigma leads to poorer physical and mental health outcomes. It is a barrier to accessing healthcare and may contribute to incomplete disclosure about health status and medications by patients.
- HIV-related stigma hinders efforts to end HIV transmissions for all in NSW. It acts as a barrier for HIV testing, immediate treatment initiation and adherence. Undiagnosed HIV, or late diagnoses, are persistent, and present high risks for the individual and the community as onward transmissions may continue.
- A combination approach is required to eliminate stigma at an individual, community and structural level. This includes:
 - Empowering PLHIV to build resilience and mobilise as a community to challenge stigma. This can be done by addressing anticipated, perceived and internalised stigma.
 - Changing attitudes towards HIV and PLHIV. This includes programs to improve HIV literacy and dispel myths about HIV, connect HIV-positive and HIV-negative people, develop skills to recognise and address stigma, and promote positive representations.
 - Having a legal environment that is informed by public health evidence and conducive to community education is vital. This means keeping strong anti-discrimination protections, refuting proposed legislation that is not evidence-based and likely to strengthen stigma by promoting outdated and incorrect information about HIV, adequately funding care services, including aged care, and repealing laws that discriminate against key populations affected by HIV (drug laws and immigration laws).

INTRODUCTION

While leaps in antiretroviral treatments and biomedical prevention have radically changed the HIV landscape in Australia, living with a condition for which a cure is yet to be found still presents individual and collective challenges for the community of people living with HIV (PLHIV).

PLHIV contend with a world where societal attitudes towards HIV, and towards people, behaviours and identities associated with HIV, have not changed as rapidly as science. In the age of *Undetectable=Untransmissible* (i.e. the fact that PLHIV who have an undetectable viral load cannot pass on the virus to others) stigma remains unchanged.

Fear related to HIV was widespread and amplified by well-intentioned public health campaigns in the late 1980s and early 1990s. Since then, no commensurate mainstream educative efforts have taken place to update the population on the contemporary experience of HIV. It is not surprising, therefore, that outdated attitudes remain which feed the experience of stigma that is commonplace today.

HIV-related stigma refers to the negative beliefs, attitudes, fears and judgements held against PLHIV and members of groups that are perceived to be associated with HIV, such as gay and bisexual men, people who inject drugs and sex workers. HIV-related stigma may also become internalised by PLHIV and, through perceptions or anticipations of stigma, affect their social interactions with other people.

HIV-related discrimination is the enactment of HIV-related stigma – the unfair and unjust treatment of a person or group of people based on their real or perceived HIV status.

As the New South Wales Government prepares the next *HIV Strategy 2021-2025*, this paper investigates the state of HIV-related stigma today, its impacts and how it can be addressed to improve outcomes not only for those who are directly affected by it – PLHIV – but also to enhance efforts to end HIV transmissions for all. While primarily focused on what NSW can do,

the paper's findings bear on the broader national context as well.

Section one provides an overview of how HIV-related stigma is envisaged in policy responses. HIV-related stigma is a priority for national and NSW HIV responses, and, in many aspects of daily life, HIV-related discrimination is against the law in NSW.

Section two highlights the prevalence of HIV-related stigma in NSW today, both in day-to-day social interactions and in healthcare. It also points to renewed understandings of intersecting stigma – the convergence of multiple stigmatised identities. Rather than operating in a vacuum, HIV-related stigma is intimately linked to mechanisms of exclusion – homophobia, transphobia, biphobia, gender violence, racism & xenophobia, and moralising attitudes towards drug use and sex work.

HIV-positive women, Aboriginal and Torres Strait Islander people, trans and gender diverse people, migrants, people who use drugs, and sex workers face complex, compounded levels of stigma.

Section three focuses on the impacts of stigma on PLHIV and on public health more broadly. Stigma acts as a barrier to testing and service access for priority populations, including for migrant gay and bisexual men who now account for most new HIV notifications in NSW. As such, stigma hinders efforts to end HIV transmissions.

Finally, section four reviews effective interventions to eliminate stigma. No single stigma intervention can eliminate stigma on its own. Rather, a combination of approaches that are designed and implemented with the meaningful involvement of PLHIV and address stigma at multiple levels can durably reduce HIV-stigma and its effects. This means investing in initiatives to change attitudes towards HIV and PLHIV, strengthening the resilience of PLHIV, and addressing structural causes of inequality and exclusion. HIV-stigma is often a by-product of laws that criminalise HIV or people associated with HIV.



CONTEXT – POLICY AND LEGAL FRAMEWORKS

In Australia, the positive community has successfully advocated for effective, rights-based HIV responses. The Greater and Meaningful Involvement of PLHIV/AIDS (GIPA/MIPA), has contributed to making the fight against HIV-stigma a priority in global and national strategies (2) and in Australian and NSW anti-discrimination legislation (3).

1. Greater & Meaningful Involvement of People Living with HIV

The Greater and Meaningful Involvement of PLHIV/AIDS (GIPA/MIPA) is a fundamental guiding principle for the design and implementation of rights-based, effective strategies to eliminate stigma and discrimination against PLHIV.

Initially stemming from the 1983 Denver Principles and later the 1994 Paris Declaration², the GIPA and MIPA aim to realise PLHIV's rights to self-determination and participation in decision-making processes that affect their lives.

MIPA/GIPA are recognised, globally and nationally, as a key feature of effective HIV responses. As noted by UNAIDS, “experiences have shown that when

communities are proactively involved in ensuring their own well-being, success is more likely. GIPA seeks to ensure that PLHIV are equal partners and breaks down simplistic (and false) assumptions of “service providers” (as those living without HIV) and “service receivers” (as those living with HIV).”³

The importance of GIPA/MIPA in combatting HIV-stigma is two-fold. At program level, initiatives to combat HIV-stigma are more likely to be effective if they are informed, designed and implemented with the meaningful involvement of PLHIV. At a policy level, by being meaningfully involved in designing HIV responses, the positive community has been able to shape key Government policies, strategies and laws, and ensure the inclusion of anti-stigma as a key priority for action.

The diversity of the PLHIV community should be reflected in HIV responses. HIV-positive people who are Aboriginal and Torres Strait Islander people, migrant, of colour, culturally and linguistically diverse, trans and gender diverse, and/or who work in the sex industry and/or who inject drugs should be meaningfully included in the design and implementation of research, policies and programs.



2. Stigma & Discrimination in HIV Strategies

Action against HIV-related stigma is considered a priority under international and national HIV strategies, and an enabling factor to effective HIV prevention in NSW.

Globally, the UNAIDS 2016–2021 Strategy⁴, *On the Fast-Track to end AIDS*, aims to achieve zero discrimination. To do so, core actions include eliminating discrimination and stigma against people living with, at risk of and affected by HIV, including in health care, workplace and educational settings, as well as removing punitive laws, policies, and practices that violate human rights, increase people’s vulnerability to and risk of acquiring HIV and impede utilisation of services.

In Australia, policy makers have long recognised that action against discrimination, through the law and community education, is key to HIV prevention and to “ensure that people with HIV [...] retain the right to participate in the community and the same rights as other people”.⁵

The *Eighth National HIV Strategy 2018-2022* has reaffirmed the Australian Government’s commitment to ensuring PLHIV’s rights, including

the right to participate fully in society, and set the goal of eliminating the negative impact of stigma and discrimination.¹ These goals are backed up by a target to reduce by 75 per cent the reported experience of stigma among PLHIV, and expression of stigma, in relation to HIV status (compared with a 2018 baseline), and a target of 75 per cent of people with HIV reporting good quality of life. The Strategy does not, however, refer to specific programming or funding instruments for the realisation of these goals.

Relevant NSW policy documents currently envisage stigma primarily as an HIV prevention implementation issue. The *NSW HIV Strategy 2016 – 2020* does not contain specific targets in relation to HIV-stigma but describes “maintaining an enabling environment to reduce stigma and discrimination” as an enabler to reach the goal of eliminating HIV transmissions.⁶ The Strategy is completed with the *NSW BBV and STI joint work plan to address Stigma and Discrimination 2019/2020*, which proposes a range of initiatives that aim to 1) remove barriers to testing, treatment and prevention for BBVs and STIs in priority populationsⁱ; and 2) enable affected communities to provide direct and timely feedback about their health outcomes and experiences.

ⁱ Priority populations for BBVs and STIs include PLHIV, Hepatitis C and Hepatitis B, gay and homosexually active men, Aboriginal people, sex workers, people who inject drugs, and people from culturally and linguistically diverse backgrounds.

The development of the *NSW HIV Strategy 2021-2025*, currently underway, offers an opportunity to align State and National stigma reduction targets, priority areas of work, and community involvement standards (MIPA/GIPA). The Victorian HIV Strategy 2017-2020 also provides an interesting model for GIPA/MIPA standards, and ambitious stigma reduction targets.⁷

3. HIV-related Stigma & Discrimination and the Law

Anti-stigma and anti-discrimination laws to protect PLHIV and stigmatised communities associated with HIV have long been a key feature of Australia's world-leading HIV responses.

The 1989 *National HIV/AIDS Strategy* set out a suite of wide-ranging legislative reform to protect the rights of PLHIV – including healthcare, housing, employment and confidentiality rights; address discrimination; and ensure laws are evidence-based and enable HIV prevention. It is with these three pillars in mind that we will now examine recent developments in contemporary HIV law and the threats they are facing.



Protecting the rights of people living with HIV and people associated with HIV

As early as 1989, the *National HIV/AIDS Strategy* set out to ensure that people with HIV “have the same rights as other people to comprehensive and appropriate health care, income support and community services, [and] protection against unfair discrimination”.⁵ Subsequent legislative reforms at Commonwealth and State level substantially protect those rights.

NSW policy makers have also long understood that discrimination based on HIV disproportionately affects already stigmatised communities, including gay men, sex workers and people who inject drugs. Many of the laws that were criminalising or stigmatising PLHIV and/or priority populations at risk of HIV in NSW have now been removed or changed.ⁱⁱ This includes the decriminalisation of sex work in 1995, legislative instruments that allowed some drug harm reduction measures, and the gradual advancement of gay, bisexual and trans people's rights.

Protecting against discrimination, threats and violence

Treating someone unfairly based on their actual or perceived HIV status is unlawful in Australia. The *Commonwealth Disability Discrimination Act 1992* makes it against the law to discriminate against a person because of their HIV status, including in employment, education, services, renting or buying a house and accessing public places or facilities.⁸ Discrimination against people believed to have HIV, and those who associate with them, is also banned.

It is also against the law to vilify, threaten or incite violence against PLHIV in NSW. Banned in NSW under the *NSW Anti-Discrimination Act 1977*, vilification is a public act that incites hatred, serious contempt or severe ridicule towards people because they are or are perceived to be homosexual, HIV positive, transgender, or of a particular race. Under the *NSW Crimes Act 1900*, public threats of violence or incitement to violence against another person or a group of persons because of their HIV/AIDS status, sexual orientation,

ⁱⁱ Sex work remains criminalised, or partially criminalised, in other Australian states and territories. Visit www.scarletalliance.org.au for up-to-date information on the laws in each jurisdiction.

gender identity, intersex status, race, or religion are an offence.⁹

From time to time – as is currently the case in NSW¹⁰ – parliaments are asked to consider proposed legislation that would dismantle, unwind or otherwise weaken the protections and rights in antidiscrimination legislation. In these instances, while organisations with expertise in HIV make strong, evidence-based representations, other opinions and non-evidence-based views can be difficult to counter. Disadvantaged HIV positive populations do not carry sufficiently strong voices to carry the day and, at times, those who advocate with us are marginalised alongside us. A broader, contemporary understanding of HIV and its transmission is required to alter this situation.

Evidence-based public health legislation

Public health legislation in NSW has evolved over time to reflect progress in scientific understandings of the virus and effective prevention options, thereby creating a less stigmatising environment. This includes changes to the NSW *Public Health Act* in 2017, which mean that people with HIV are no longer legally required to disclose their status to sexual partners but must take reasonable precautions to prevent transmission of HIV.ⁱⁱⁱ These changes better reflect well-established evidence of the effectiveness of antiretroviral treatment, and other prevention methods, to stop onward transmission.¹¹

Because it is upon disclosure that PLHIV are most likely to experience stigma, ensuring strong privacy laws is essential.

In NSW, public health legislation offers some privacy and confidentiality protections. The NSW *Public Health Act*, and the *Health Records and Information Privacy Act 2002* set some limits on how people's health information, including HIV information, can be used and disclosed. HIV status may be disclosed to a person involved in someone's care (staff at any NSW public hospital or health

facility, GP, private health services) but penalties apply to staff who inappropriately access health information, including disciplinary action and potential criminal charges.¹²

Recent attempts to alter the basic principle that public health laws should be evidence-based and compatible with human rights pose a major threat to NSW's HIV responses. Since 2017, a police union has been lobbying for the introduction of new laws that would force people whose bodily fluids come into contact with police and emergency services personnel to take an HIV test.¹³⁻¹⁴ This means that someone spitting on a police officer could be forced, by law, to take an HIV test, despite well-established evidence that HIV cannot and has never been transmitted by spitting.¹⁵

Ever since the first National HIV/AIDS Strategy in 1989, HIV testing has been voluntary. Introducing mandatory testing for HIV would propagate fear and falsehoods about HIV transmissions and, as such, jeopardise NSW's world leading and science-based HIV responses.¹⁶

HIV simply does NOT get passed on through spitting, kissing, touching, shaking hands. HIV does NOT get passed on through saliva, sweat, tears, mucous, vomit, urine or faeces.



iii The means of minimising the risk of transmitting HIV to sexual partners and the precautions that should be taken to minimise the risk, may include the following: using a condom during sexual intercourse, the HIV positive partner seeking and receiving confirmation from a sexual partner that the sexual partner is on HIV pre-exposure prophylaxis medication, or the HIV positive partner knowing that he or she has an HIV viral load of less than 200 copies/mL. ACON recommends that people living with HIV consult their doctor about the best ways to protect their sexual partners in their specific circumstances.



PREVALENCE AND FORMS OF HIV-RELATED STIGMA & DISCRIMINATION

While HIV-related discrimination is illegal in NSW, subtle manifestations of stigma can be hard to challenge. In social situations and institutional settings (e.g. healthcare and aged care), HIV-stigma is often compounded with prejudices based on sexuality, gender, race, migration, or behaviours such as drug use and sex work.

1. Stigma in Everyday Life

PLHIV continue to report high levels of stigma. In 2018, more than half (56%) of PLHIV who participated in the HIV Futures 9 study reported experiencing some form of stigma in the past 12 months, including 9% reporting that they ‘often’ or ‘always’ experienced stigma.¹⁷ While these proportions are lower than in a survey conducted two years prior, methodological differences between the two surveys make it difficult to confirm whether stigma is indeed abating.¹⁸

What stigma looks like

Stigma is the product of views held by HIV-negative people towards HIV or PLHIV (i.e. interpersonal stigma¹⁹). Stigmatising behaviours can occur in many forms, online or in real life. This includes overt forms of stigmatising behaviour (e.g. rejecting someone online because of their positive HIV status), and more subtle forms, unconscious bias and micro-aggressions.

Examples of stigmatising behaviours include:

- Blaming or shaming someone, privately or publicly, because of their HIV diagnosis.
- Making assumptions about someone’s HIV status (i.e., assuming a person is HIV negative).
- Casting judgements about the actions or character of PLHIV (e.g., judging someone as too “promiscuous”).



- Using offensive or derogatory language to describe PLHIV (e.g., ACON Peer Testers report language such as “dodgy” or “dirty” being used by HIV-negative gay men to describe people or behaviours that they associate with HIV).
- Disclosing someone’s HIV status without their consent (e.g., a disgruntled ex-partner publicly sharing someone’s HIV status on Facebook; a newspaper publicly disclosing that someone has HIV).
- Ignoring scientific evidence on HIV and taking unnecessary precautions when interacting with someone living with HIV (e.g., refusing to shake the hand of someone living with HIV).
- Stating a preference against PLHIV or rejecting someone because of their HIV status (e.g., on dating apps). To make matters worse, these preferences are often expressed in offensive or derogatory language (e.g., someone indicating that they are looking for “clean guys” or “clean fun”).

The reality of PLHIV’s experience of interpersonal stigma is attested by surveys of the general population. In a recent study, only 48% of respondents declared that they would never behave negatively towards people because of their HIV.²⁰

HIV-related stigma and discrimination can also affect HIV-negative people who are perceived to be associated with HIV or someone living with HIV. One study estimated that one in five partners of PLHIV in high-income countries report experiencing stigma as their biggest challenge as a partner of someone living with HIV.²¹ Healthcare workers caring for people living with HIV may be subject to HIV-related discrimination by proxy as well.²²

Internalised stigma

Internalised, or self-stigma, refers to the negative views PLHIV may hold about themselves. *Positive Perspectives*, a survey of PLHIV in nine high-income countries, including Australia, found that self-stigma continues to have a big impact on the lives of PLHIV.²³ Over a quarter of respondents stated feelings of self-blame, guilt and a need for secrecy.

This survey echoes many of the insights shared by participants in ACON’s workshops, including the following comment:

“I felt as a gay man with HIV I am second rate, tainted, damaged”

Such feelings may be particularly exacerbated for those who held negative views about HIV, and/or behaviours or identities associated with HIV, before their diagnosis. Research among migrants to Australia suggests that perceptions of HIV formed in countries where the virus is stigmatised or, even criminalised, may contribute to internalised stigma later in life (see section III.1).

While self-stigma is a highly personal experience, the internalised beliefs that PLHIV may hold about themselves also speak to structures of exclusion. One study found that the most common evidence of HIV-related stigma arose when PLHIV described how they felt about themselves when disclosing their status, with a recurring use of metaphors about feeling dirty. Drawing on anthropological literature²⁴, the National Association of PLHIV Australia (NAPWHA) interprets this aspect of internalised stigma as the effect of social power structures that exclude and devalue people who don’t fit the norm.²⁵

U=U, Sex & Stigma

A large body of clinical evidence has validated the concept of HIV Undetectable = Untransmissible (U=U) and treatment as prevention²⁶⁻²⁷⁻²⁸⁻²⁹.

U = U means that people with HIV who receive antiretroviral therapy and maintain an undetectable viral load cannot sexually transmit the virus to others. Treatment as prevention is the use of antiretroviral medication to prevent the transmission of HIV to sexual partners.

Health promotion efforts, including ACON's *Ending HIV* campaign, have led to a greater understanding of the effectiveness of treatments in the gay community. In April 2019, 83% of respondents to our *Ending HIV* survey agreed that "HIV treatments

significantly reduce the risk of passing on HIV" compared with 33% in February 2013. 93% also agreed that "early HIV treatment is better for your health and can help protect your sex partners", compared with 74% six years prior.

While it is hard to estimate whether U=U knowledge has translated into behaviour change, the 2020 SSydney Gay Community Periodic Survey offers some indications about the use of treatment as prevention.³⁰ Having an undetectable viral load (UVL) is the prevention strategy most commonly used by HIV-positive participants who have condomless anal intercourse with casual partners. Among HIV-negative men who engage in condomless anal

intercourse with casual partners, just over 20% reported using UVL as a prevention strategy, on its own or combined with additional prevention strategies such as PrEP.

Anecdotally, ACON's HIV-negative clients report understanding the science behind UVL but prefer to use prevention methods such as PrEP that are within their control, rather than their partner's.

Sexual rejection because of HIV is often reported by PLHIV. The HIV Futures 9 study found that 18.4% of HIV positive people in Australia report that people often or always did not want to have sex or an intimate relationship because of their HIV status.¹⁷

Where discrimination occurs

HIV discrimination can occur in a range of settings, including in social interactions, at work or when accessing or attempting to access services.

HIV-positive and HIV-negative participants in ACON programs highlight that verbal abuse and rejection based on HIV status is commonplace on hook up apps, and particularly violent when perpetrated anonymously.

Participants in the HIV Futures 9 study reported experiencing HIV-based discrimination in relation to health services (25.7%), insurance (25%), employment (18.8%) and accommodation (8%) in the last year.¹⁷

These statistics align with reports by the HIV/AIDS Legal Centre (HALC), a Sydney-based legal centre specialising in assisting people in NSW with HIV or Hepatitis-related legal matters, that approximately half of their clients come to them to resolve matters related to employment, insurance (incl. total permanent disability cases), other forms of discrimination, and wills and estates. The

other half of HALC's clients come to them to resolve immigration issues (see section IV).

HIV-discrimination in employment often occurs as a result of pre-employment health-checks, according to HALC. While occupational health screenings are intended to ensure employees are fit for work and not using medication that may pose a risk to occupational health and safety (e.g. drowsiness for heavy machinery operators), they place PLHIV in a vulnerable position. By disclosing that they are using HIV medication, they are forced to disclose their HIV status and may face discrimination that is hard to prove, but not answering a health screening process truthfully may also expose them to being fired for breaching their disclosure obligations.

Discrimination is fundamentally incompatible with PLHIV's right and aspiration to participate fully in society. A participant in one of ACON's workshops explained:

"I want to live a normal life as everybody else, I want to be viewed and treated as normal, just like everybody else"

2. Stigma in Care Settings

While far from being stigma-free, there are indications that some of the most overt forms of discrimination have become rare in healthcare facilities, aged care services and other institutional settings. Older PLHIV are particularly vulnerable to the risk of encountering stigma due to greater need to access multiple services and a largely deficient aged care system.

Stigma & Discrimination in Healthcare Settings

PLHIV still report experiences of discriminatory treatment in Australian healthcare settings. In a recent study, one third (33%) of PLHIV reported being treated negatively or differently by healthcare workers because of their HIV status, including 5% who indicated that this was ‘often’ or ‘always’ the case.¹⁷ These proportions are lower than were found in an earlier study – 51% of participants reported negative treatment from health workers in 2016.³¹

Cisgender women and people who inject drugs appear particularly exposed to the risk of being treated differently by health workers on the basis of HIV status.^{17&32}

In NSW, instances of overt discrimination in healthcare settings have become less common. Nevertheless, examples of stigmatising behaviour or mistreatment recently reported to ACON include hospital personnel taking unnecessary precautions to care for someone living with HIV (e.g. double gloving), medical personnel using outdated or inappropriate terminology to describe HIV or behaviours associated with HIV, and dentists expressing concerns about the safety of treating PLHIV.

An international study found that there were three immediately actionable causes of HIV-related stigma in health facilities: 1) a lack of awareness of what stigma looks like and why it is damaging in the context of health care; 2) incomplete knowledge about HIV which creates unnecessary fear about casual contact; and 3) moral judgements about behaviours associated with HIV.³³ Inconsistent levels of HIV knowledge among health care workers have been observed in Australia.³⁴



Rather than being the sole responsibility of individual health workers, however, the persistence of HIV-related stigma in healthcare should interrogate institutional and policy shortcomings. These include a lack of policies to create stigma-free environments, gaps in medical staff training and qualification control and insufficient complaints mechanisms.

Aged Care

As PLHIV age, they are more likely to require a range of health services. A recent study highlighted the need for more evidence to address stigma in older people ageing with HIV, including those with comorbidities who are seeking services additional to their HIV-specific care.³⁵

Stigma and mistreatment of PLHIV in aged care settings persists. As highlighted by the Australian Federation of AIDS Organisations (AFAO) and the National Association of PLHIV/AIDS (NAPWHA), PLHIV are well aware of the shortcomings of the aged care system in relation to HIV care and often report significant apprehension about future placements into residential aged care facilities.³⁶

The tales of shocking neglect recently exposed by the Royal Commission into Aged Care, as well as the COVID-19 epidemic, have highlighted the magnitude of Australia's aged care system's failures.³⁷ In the midst of serious systemic deficiencies, including underfunding, a chronic lack of home care packages and poor staff training levels, the aged care system provides an environment that is conducive to poor-quality HIV care.

3. Intersecting Stigma

Better understanding intersecting stigma as a whole – the association of multiple stigmatised identities – is key to address its complex effects on health.³⁸

Australian HIV responses have long understood HIV-related stigma is a product of negative attitudes not only towards the virus, but also towards gay men, sex workers and people who inject drugs.

As the NSW epidemic evolves, it is becoming increasingly clear that HIV-related stigma is also compounded with prejudices based on gender, race and migration status.³⁹ HIV notifications among people born overseas, Aboriginal and Torres Strait Islander people, women and potentially trans and gender diverse people^{iv}, have not declined as rapidly as HIV notifications among Australian-born gay and bisexual men.

Sexuality

The complex and interrelated relationship between HIV-stigma and being gay or bisexual have been the focus of much of the HIV-related stigma literature. Despite progress towards equal rights, gay and bisexual men, regardless of HIV status, continue to report experiencing stigma and discrimination because of their sexual orientation.⁴⁰

HIV-related stigma is more commonly reported by cis-gender gay (31.4%) and bisexual men living with HIV (40.5%) compared with cis-gender heterosexual men living with HIV (28.9%).¹⁷ This includes experiences of HIV-stigma (e.g. sexual rejection) perpetrated within the gay community.⁴¹

Some have also argued that HIV-stigma can be felt by HIV-negative gay men who, as a group, are associated with HIV.⁴² In a recent study, most HIV-negative gay and bisexual men in Australia (72%) reported being treated differently by other people because they are perceived to be at risk of HIV. The study found that greater experience of HIV “stigma by association” was related to a greater likelihood of rejecting partners perceived to be HIV-positive.

There are gaps in the literature about interactions between HIV-related stigma and the broader spectrum of sexual identity (e.g. fluidity, pansexuality).

Sex Work

Legislation and intersecting stigma play a significant role in shaping sex workers’ experiences and health outcomes. A survey found that a majority of the Australian public would behave negatively towards sex workers because of their work.²⁰

Stigma is compounded for sex workers who work for survival, use illicit drugs, are trans or gender-diverse, Aboriginal or Torres Strait Islander, migrants or culturally and linguistically diverse, are parents, or work on the street.⁴³ Research on the experiences of migrant sex workers, who make up a substantial proportion of workers in the sex industry, has highlighted the intersection of social and structural barriers that marginalise migrant sex workers.⁴⁴ These include limited access to safe migration pathways, fear of deportation and language barriers.

Drug Use

PLHIV have higher levels of illicit substance use and injecting drug use compared with their HIV-negative peers⁴⁵⁻⁴⁶ and, as such, may experience intersecting stigma based on HIV and drug use.

The social acceptability of different drugs varies significantly. The Flux study on drug use among gay and bisexual men indicates low levels of acceptability for heroin and crystal methamphetamine use. About two-thirds of Flux participants believed that it is not at all acceptable among their gay friends to use crystal methamphetamine, the type of illicit drug most reported by gay men who inject drugs.⁴⁵

iv HIV notification data among trans people are often mis-reported. A landmark report noted that “since the dawn of the AIDS crisis, TGD people have been erased and excluded from HIV and sexual health surveillance systems in Australia. This has contributed to a lack of evidence about our sexual health, which has meant TGD people have been excluded from strategies, services, programs and campaigns.” See Callander D, Wiggins J, Rosenberg S, Cornelisse VJ, Duck-Chong E, Holt M, Pony M, Vlahakis E, MacGibbon J, Cook T. 2019. The 2018 Australian Trans and Gender Diverse Sexual Health Survey: Report of Findings.



Surveys of people who inject drugs (PWID) have consistently found high levels of reported stigma related to injecting drug use, particularly in healthcare settings.⁴⁷ Over a quarter of PLHIV who reported injecting drug use report experiencing stigma or discrimination as a result of their injecting drug use.¹⁷ 86% of the general public, and 56% of healthcare workers, also report negative attitudes towards PWID.²⁰

There are greater negative attitudes towards PWID compared with PLHIV, which highlights differences in public perceptions of stigmatised behaviours (i.e., injecting drug use) and stigmatised conditions (i.e., HIV, hepatitis C, sexually transmissible infections). Flowing on from this finding, Broady and colleagues highlight that any attempts to

reduce stigmatising attitudes within the general population must account for this intersection of stigma based on conditions and behaviours.⁴⁸

There are intersections between HIV stigma and Hepatitis C, both of which are transmissible through sharing injecting equipment. Participants in a study on LGBT people's experiences of injecting drug use and Hepatitis C seroconversion described feeling afraid to come out about their drug use to LGBT peers because of the associated stigma of Hepatitis C, and similar fears in relation to HIV-related stigma within the PWID community.⁴⁹ This study was conducted before the advent of Hepatitis C cure in Australia, which is likely to change stigma associated with this condition.



Gender

Women living with HIV are susceptible to experiencing intersecting stigma based on HIV status, gender, class and race. Cisgender women are the most likely to report being treated differently by healthcare workers due to their HIV status compared with cisgender men, non-binary/gender fluid people and transgender women.¹⁷ Women living with HIV also have high levels of financial stress, and greater housing instability and food insecurity compared with men.¹⁷

Trans and gender diverse people are also highly susceptible to experiencing intersecting stigma.⁵⁰ Identifying as transgender is a predictor of reporting delays in or being refused health care⁵¹ and experiencing inadequate or insensitive care.⁵² Despite the fact that transgender, non-binary and gender fluid people are often erased from health statistics in Australia, research has shown they are more likely than cisgender people to experience stigma on the basis of HIV.¹⁷

Race and Migration

A large body of evidence, primarily from the United States, has highlighted the role of racism in increasing the odds of delayed care or unmet need for PLHIV.⁵³ Young black and Hispanic/Latino gay men in America are disproportionately affected by HIV⁵⁴ and experience intersecting stigma on the basis of sexual minority status, race, and HIV status.⁵⁵ Racism, homophobia, and HIV-related stigma are barriers to regular HIV testing, treatment adherence among young American black gay men. Migrants from Sub-Saharan Africa in Ireland, the UK and New Zealand have also reported experiences of HIV-related stigma and racism from health service providers, where they were often associated with HIV risk because of their skin colour rather than behaviours.⁵⁷⁻⁵⁸⁻⁵⁹

In Australia, new migrants with HIV need to negotiate two major life disruptions simultaneously: migration and HIV.⁶⁰ As will be explored further in sections III and IV, HIV-related stigma is experienced by migrants at an individual, community and structural level.⁶¹ Immigration rules distort perceptions of HIV, contribute to increasing barriers to HIV testing and access to treatment, care and support and place migrants in a position of great uncertainty.

Aboriginal and Torres Strait Islander people

Aboriginal and Torres Strait Islander people remain under-represented in HIV-related stigma study samples despite being disproportionality affected by HIV.⁶²

Racism and other forms of discrimination combine to predict perceived barriers to health care in Australia⁶³ but more research is required to understand the role of racist power structures in producing intersecting stigma in the Australian context, marked by a legacy of racial segregation and violence against Aboriginal and Torres Strait Islander people.

There is a need for dedicated research to better understand the needs of Aboriginal and Torres Strait Islander people living with HIV and for more resources to be diverted toward HIV prevention, treatment and care for Aboriginal and Torres Strait Islander people in a way that is culturally appropriate and community led.¹⁷

III.

THE IMPACTS OF HIV-RELATED STIGMA & DISCRIMINATION – WHY ADDRESSING STIGMA MATTERS

HIV-related stigma, particularly where it intersects with other stigmatised identities, can have serious consequences on a person's health and quality of life, as well as on public health.

Stigma and discrimination have been recognised as persistent barriers to addressing the HIV epidemic, restricting access to prevention, testing and treatment services for those most at risk.⁶⁴⁻⁶⁵ Efforts to reduce stigma are an integral part of effective combination HIV prevention⁶⁶ and are key to ending HIV transmissions for all in NSW.

1. Impacts of Stigma on HIV Testing

Actual and perceived stigma is a significant barrier to getting tested for HIV. As such, it hinders efforts

to achieve and exceed the 95-95-95 targets set in the Eighth National HIV Strategy 2018-2022: 95% of PLHIV are diagnosed; 95% of people diagnosed with HIV are on treatment; and 95% of those on treatment have an undetectable viral load.

Fears of HIV lead to testing avoidance

An estimated 2899 (11%) PLHIV in Australia are unaware of their HIV status and, consequently, are not receiving the antiretroviral treatment they need. Without access to treatment, they may be unknowingly passing on the virus to others.⁶⁷ An HIV test is the only way to find out about one's HIV status and a crucial preliminary step before initiating treatment, reaching an undetectable viral load, and, in turn, prevent onward transmission^{26,29}

Stigma associated with HIV acts as a barrier for people who are unsure of their HIV status to get tested, resulting in HIV being left undiagnosed or diagnosed at a late stage of infection.⁶⁸

For fear of being judged, outed or discriminated against, some people may avoid requesting an HIV test, underplay their susceptibility to HIV and sexually transmissible infections and not disclose stigmatised behaviours such as anal sex or injecting drug use.^{69 70}

A participant in one of ACON's HIV workshops expressed these fears in the following terms:

“Stigma and the fear of being thought of as ‘diseased’ or ‘unclean’ stopped me being tested for so long”

Social, Community and Policy-level Stigma Affect Testing Rates in Migrant Populations

Migrant men are over-represented in HIV notification statistics and are at increased risk of obtaining a late HIV diagnosis with a lower CD4 count, compared with Australian-born gay men. According to NSW HIV notifications data, there was a 33% increase in overseas-born men who have sex with men being diagnosed late, compared to the five-year average. Over half of these overseas-born men diagnosed late had lived in Australia for four years or less and most had likely acquired their HIV infection overseas.⁷¹

HIV-related stigma experienced by migrants in Australia is a major barrier to HIV testing and linkage to care. A qualitative study on attitudes to HIV testing among Australian migrants born in Sub-Saharan Africa, Southeast Asia and Northeast Asia found that they experienced HIV-related stigma at an individual, community and policy level.⁶¹ Many feared judgements if they were to test, particularly from health service providers, and had concerns about confidentiality, and taboos around sexual behaviour limited sexual health help-seeking in this group.

At a policy level, Australia's current immigration policies create additional barriers to accessing care and support, including additional cost barriers for migrants who are not eligible for Medicare. Interviews with clients of the Multicultural HIV/AIDS and Hepatitis C Service and a sexual health clinic in Sydney highlighted difficulties for new migrants

with HIV to manage uncertainties about their migration status and HIV care.⁷²

For migrants undergoing an HIV test as part of the health requirement for their permanent residency application, a positive diagnosis jeopardised their prospect of staying in Australia and was at the same time a barrier to returning to the country of birth. Compulsory HIV testing for immigration purposes has also been found to contribute to the perception that “Australia has no HIV”.⁶¹

2. Impacts of Stigma on Treatment Initiation, Access and Retention in Care

Delayed HIV diagnosis and treatment initiation can have very serious health implications. Early initiation of and adherence to antiretroviral treatment are essential to achieve viral suppression and reduce morbidity and mortality among PLHIV.⁷³

Medical guidelines recommend initiating anti-retroviral treatment (ART) immediately (or as soon as possible) after HIV diagnosis in order to increase the uptake of ART and linkage to care, decrease the time to viral suppression for individual patients, and improve the rate of virologic suppression among persons with HIV.⁷⁴

Treatment Initiation

Initiating ART after a positive diagnosis can be a difficult process, in part because of HIV-related stigma, including one's own. PLHIV who participate in ACON's peer support programs or counselling often report that taking a pill every day often feels like a daily reminder of HIV and the absence of a cure for the virus.

A strong, stigma-free relationship between a patient and healthcare provider is an essential factor in ensuring rapid treatment initiation and adherence. Negative experiences with primary-care providers, including providers exhibiting judgmental behaviour, stereotyping, homophobia, and cultural inappropriateness when administering care can lead some PLHIV to avoid the health care system.⁷⁵ Working with patients as partners in care, and healthcare providers' displaying communication quality and clarity and compassion have been identified as factors that strengthen patient-healthcare provider relationships.⁷⁵



Stigma is a barrier to retention in care

Experiencing stigma and discrimination at the time of disclosure can be traumatic and have long term consequences.⁷⁶ Such experiences can create an anticipation that stigma may occur again and result in avoidance of situations where disclosure may be required (e.g. healthcare). Negative responses to HIV disclosure have been associated with HIV-related stigma, psychological distress, and reduced social support and health satisfaction.⁷⁷

Experiencing stigma and discrimination makes people less likely to seek health care or return to health care for follow up and monitoring.⁷⁸ A systematic review of 64 studies found significant associations between HIV-related stigma, higher rates of depression, lower social support and lower levels of adherence to antiretroviral medications and access to and usage of health and social services.⁷⁹

As noted previously, the intersection of HIV-related stigma with other stigmatised identities and behaviours, is a predictor of poorer access to healthcare. People who experience additional layers of stigma because of prejudice against certain (actual or perceived) attributes – gender, race, ethnicity, class, drug use or because they work in the sex industry – face additional structural impediments in accessing health services.⁸⁰

3. Impacts of Stigma on PLHIV's Health-Related Quality of Life

HIV-related stigma is strongly associated with poorer physical and mental health.⁸¹ A systematic review of the literature on the mental health and wellbeing of people with HIV found a high prevalence of depression and anxiety in PLHIV across high-income countries.⁸² The reported experience of stigma associated with HIV diagnosis, including internalised stigma, ranged between 42% and 83% of people across the studies reviewed.

Stigma still exerts negative social and psychological effects, which in turn have a major influence on the quality of life and resilience of PLHIV.⁸³⁻²⁴ An Australian study found that total health-related quality of life was notably reduced by perceived stigma, with a third of surveyed patients reporting persistent fears of both disclosing their HIV status and infecting others.⁸⁴ People recently diagnosed with HIV report lower health-related quality of life.⁸⁴⁻⁸⁵ As will be explored in section IV, empowering PLHIV to build resilience and confidence in challenging stigma reduce its impacts and social acceptability.

IV.

HOW TO REDUCE HIV-RELATED STIGMA & DISCRIMINATION

This section considers a range of approaches to reduce HIV-related stigma and its impacts, which can be grouped in three broad categories: 1. interventions to change individual attitudes towards HIV; 2. programs designed to mitigate the impacts of stigma by strengthening resilience; and 3. strategies to address underlying structures of inequality.

It must be noted that while there are many examples of HIV-stigma reduction interventions across the world, measuring their impacts can be difficult. Reviews of HIV-stigma interventions conducted by the National AIDS Trust in the UK⁸⁶, the Centre for Social Research in Health in Sydney⁸⁷ and others⁸⁸⁻⁸⁹ have highlighted the scarcity of well-designed evaluations and gaps in the literature. These include a lack of intervention studies in non-HIV-specific healthcare settings, including aged care, and regarding key populations such as migrants and trans and gender diverse people.³⁵

1. Changing Community Attitudes and Behaviours

Several stigma reduction interventions have attempted to change perceptions of HIV among members of the public or specific populations (e.g. the gay community, health workers) and generate more positive attitudes towards PLHIV.

Improving HIV literacy

Most HIV-related stigma reduction initiatives linked to HIV prevention objectives rely on sharing scientific facts about HIV to improve the health literacy of the general public or targeted groups (e.g. health professionals or people in the gay community). This may include, for instance, providing information and resources (e.g. factsheets or information delivered during medical consultations) to bust myths about HIV transmission.

In recent years, several HIV prevention and stigma reduction initiatives have focused on increasing knowledge of *Undetectable=Untransmissible (U=U)* in the gay community – the fact that positive people with undetectable viral load do not pass on the virus to others. This includes campaigns such as the *Can't Pass it On* campaign^v in the UK or the Institute of Many's *In bed with U=U* in Australia.^{vi}

Surveys conducted since the launch of ACON's *Ending HIV* show that sustained, extensive peer education in targeted community settings, including at ACON's a[TEST] centres, contributed to significantly higher HIV literacy levels among gay and bisexual men. In April 2019, 83% of respondents agreed that "HIV treatments significantly reduce the risk of passing on HIV" compared with 33% in February 2013. 93% also agreed that "early HIV treatment is better for your health and can help protect your sex partners", compared with 74% six years ago.

Considering the evolving epidemic in NSW, there is a need for campaigns designed with and for migrant and culturally and linguistically diverse people and address the intersecting nature of the stigma and discriminations.

A national HIV education campaign

While community organisations have developed strong targeted initiatives, there has not been a large, national publicly funded HIV information campaign in Australia since the 1987 fear-based 'grim reaper' ad. As a result, much of the general population is unaware of basic facts about HIV transmission, effective prevention options and what it means to live with HIV in the 21st century.

There is a need for a large, national campaign to inform the public about how much has changed in the HIV landscape in the past decades. Understanding the socio-demographic characteristics that are associated with stigmatising attitudes towards PLHIV can inform the development of such a campaign and who it should target. A recent study found there were less

negative attitudes towards PLHIV among people who know someone living with HIV, are younger, were born in Australia, have higher income levels and based on progressive political beliefs.⁴⁸

Developing skills to recognise and challenge stigma

Raising HIV awareness, calling HIV-related stigma out and shining a light on its impacts on the lives of PLHIV can contribute to reducing its prevalence. This includes Thorne Harbour Health's *HIV Still Matters* campaign posters, which centres on the message that 'stigma is real for people with HIV'.^{vii}

In addition to educating people about the impacts of HIV-related stigma, several initiatives provide tools for people to act in their spheres of influence. For instance, the US Centre for Disease Control and Prevention's *Let's Stop HIV Together* campaign provides tips on appropriate language and how to respond to situations where HIV-related stigma surfaces.^{viii}



v Visit the Terrence Higgins Trust website at <https://www.tht.org.uk/our-work/our-campaigns/cant-pass-it-on>

vi Visit the Institute of Many's website at <https://theinstituteofmany.org/in-bed-with-uu/>

vii Visit Thorne Harbour Health's *HIV Still Matters* website at <https://hivstillmatters.org/topics/stigma>

viii More on the CDC website at <https://www.cdc.gov/stophivtogether/hiv-stigma/ways-to-stop.html>

Workforce education

Developing skills on how to identify stigma, become aware of one's own prejudices and better engage with people with HIV has also been the focus of training programs for targeted audiences such as health care, aged care and or/disability care professionals. ASHM's online learning for all health care professionals and those working in health-settings focuses on equipping those working in health settings to 1. Understand stigma and discrimination barriers; 2. Recognise barriers in their practise; and 3. Take action to make a difference, including breaking old habits.^{ix}

The persistence of HIV stigma in healthcare (section II. 2) highlights the need to scale up workforce education in public health settings, general practice, private clinics, specialists and allied health services. Mandating the provision of training as part of relevant accreditation standards may be appropriate to ensure the provision of quality care.

Social contact: connecting HIV positive and HIV negative people

People are more likely to hold stigmatising attitudes against HIV when they don't know anyone living with HIV. A recent study found that knowing a person with HIV/STIs and putting a human face to these infections may contribute to a shift in stigmatising attitudes, even among those groups within the general population who are most likely to hold these discriminatory views.^{ix}

Social contact interventions focused on creating opportunities for HIV negative people to hear about, connect and empathise with HIV positive people's experiences can have a positive impact.

This includes opportunities to interact in real-life such as the Positive Speaker program run by Positive Life NSW, which offers agencies, schools, organisations or groups the opportunity to hear the experiences of PLHIV who are trained to share their stories.^x

Several public campaigns around the world have also used positive messaging and imagery designed to create emotional connections, respect and empathy. This includes the *Revelations* campaign in France, which showcased the contributions of HIV-positive people to the arts, such as a dance teacher and a classical musician. In the US, the Stigma project produced the Live HIV Neutral campaign, which showed positive imagery and language highlighting that HIV is only one part of a person's identity.

Challenging prejudice and promoting positive representations

Identifying community popular opinion leaders – highly regarded health professionals and media personalities to model positive attitudes, disseminate supportive messages, or challenge prejudice has shown effectiveness both in real life forms and through media campaigns.⁹⁰ For example, a campaign run by Aides, a French HIV community organisation, featured well-known celebrities who challenged audiences to reflect on their own biases, with variations on the slogan 'Would you still..., if I was HIV positive?'.⁹¹

Sustained campaign efforts can also succeed in changing representations of PLHIV in mass media. In the UK, the National AIDS Trust and Press Gang have successfully challenged negative and/or inaccurate news articles about HIV in the media, securing redactions to articles online and in print.⁹¹

2. Gaining Power over Stigma

While changing societal attitudes towards PLHIV is critically important, it is a process that takes time and may not always work for everyone in the community.

While not everyone's minds can be changed at once, a range of strategies can be deployed to enable PLHIV to gain power over stigma, including their own self-stigma. This includes promoting environments where PLHIV are free to make choices about who they disclose their status to, where they are supported to build resilience skills and where they can join together to promote their rights.

ix ASHM's *Removing barriers, easy as 1,2,3* resources are available at <https://removingbarriers.ashm.org.au/>

x To book a Positive Speaker event, contact the Positive Speakers Bureau <http://psb.positivelife.org.au/>

HIV Disclosure

The careful control of the process of HIV disclosure is exercised by all PLHIV, from the early days of diagnosis and throughout their lives. Research shows that, in Australia, PLHIV are often very selective about who they disclose their status to. Close to one in three (31.8%) HIV Futures 9 study participants reported disclosing their status to almost nobody, while one in four (25.2%) reported that most of the time, people around them were not aware of their HIV.¹⁷

Gay men living with HIV often choose not to disclose their status because of fears of rejection, self-blame or a desire to avoid upsetting family or friends.⁹² Recently diagnosed men who have sex with men often only tell partners perceived to be at risk about their status but not, or only few, close friends.⁹³ Regardless of how well they accept their diagnosis, most recently diagnosed gay men in Australia do not disclose their status to family members for fear of rejection or causing distress.⁹³

For women, not disclosing one's HIV status to sexual partners is often a strategy to avoid not only risks of rejection, but also violence. A qualitative study highlighted that, for many Canadian cis and trans women living with HIV, HIV status disclosure to sexual partners shifted the power dynamics in sexual relationships and many feared rejection, violence, and being outed as HIV-positive.⁹⁴

Resilience & Flourishing

From an individual perspective, resilience might mean being better able to cope with stigma. Social support and psychological resilience are associated with a higher quality of life, higher self-esteem and greater community engagement.²⁵ Building resilience enables people to develop mechanisms for protection against negative experiences, maintain balance during stressful moments and increase one's capacity to manage depression, stress and anxiety.³⁴

PLHIV can draw on individual, interpersonal, family and community resilience resources to combat stigma⁹⁵ and flourish. Flourishing means not only

experiencing frequent positive emotions, but also a sense of self-acceptance, meaning and of living in accordance with one's values. A study among 357 Australian HIV-positive gay men found higher levels of flourishing among those who had low internalised HIV-stigma, were employed, received greater level of practical support in their lives, who had a sense of belonging or companionship, and who felt supported by family".⁹⁶

Effective resilience programs consider the holistic needs and resources of PLHIV. This includes understanding the intersections of different forms of stigma and discriminations PLHIV may face (e.g. HIV-related stigma and racism experienced by migrants) and the unique aspects of person's identities and strengths (e.g. culture, language).

Genesis, a peer support program run jointly by ACON and Positive Life NSW, precisely seeks to build resilience and flourishing among gay men who have recently been diagnosed with HIV. *Genesis* aims to provide participants with practical help and knowledge to manage their HIV diagnosis, gain confidence, build resilience and make informed decisions around the various issues that may confront them after a HIV diagnosis.^{xi}

Connecting with peers, and overcoming stigma can have a truly transformative effect, as is reflected in feedback provided by one participant:

"The Genesis workshop has changed my life in such a powerful way. What was something that initially brought nothing but negativity and isolation into my life, is now something I see as a positive part of me. Something that will help me to change for the better."

At a structural level, creating enabling environments that promote resilience from diagnosis and onwards has identified as a priority under the National Association of People with HIV Australia's *National Strategic Framework to Address HIV-related Stigma and Build Resilience Capacity for PLHIV*.³⁴ NAPWHA and others have also highlighted the value of the concept of flourishing – the sense of self-acceptance, purpose and living in accordance with one's values – and thriving.

xi For more information about the *Genesis* program, visit endinghiv.org.au/astart or contact 02 9206 2000

Community Mobilisation

The history of grassroots community mobilisation since the beginning of the HIV epidemic, and the literature on community mobilisation and social change, can also inform HIV-related stigma responses. The most effective and powerful responses to the HIV epidemic have arisen when affected communities have mobilised to care for each other, fight back and resist against stigmatisation linked to HIV, and identities or behaviours associated with HIV.

In addition to mitigating the effects of stigma – PLHIV who are active participants in their community experience greater quality of life – developing the collective capacity of the positive community to call out, resist and challenge stigma also reduces its social acceptability and, ultimately, its prevalence. As concluded by Parker and Aggleton⁹⁷:

“Ultimately, together with a new emphasis on community mobilization aimed at unleashing resistance to stigmatization and discrimination, structural interventions aimed at developing a rights-based approach to reducing HIV and AIDS-related stigmatization and discrimination should be a high priority in order to create a transformed social climate in which stigmatization and discrimination themselves will no longer be tolerated. Within such a framework, discrimination becomes a clear breach of a basic human rights obligation.”



“Dealing with being poz and stigma has made me a stronger person”

Participant in ACON Workshop

In recent years, there has been renewed community mobilisation, including the creation of the Institute of Many (TIM), a peer-run movement for PLHIV, which acts as a social umbrella and advocacy platform. One campaign from TIM includes “Say it loud and say it proud: ZERO RISK = ZERO EXCUSES”, which sought to get organisations to speak up and let people know that PLHIV on effective treatment can’t pass on the virus.

3. Addressing Structures of Inequality and Exclusion

Rather than operating in a vacuum, HIV-stigma intersects with multiple forms of exclusion and disadvantage. Eliminating stigma requires looking beyond HIV responses and examining all aspects of the care system and structures that produce inequalities.

Addressing Institutionalised Stigma and Lifting Standards of Care

Significant and sustained investments into evidence-based, world-leading HIV prevention and care have been made by the NSW Government, in partnership with community, researchers and other stakeholders. The success of HIV responses, however, also depends on how well other parts of the care system, including healthcare and aged care, are performing to address complex and intersecting needs.

With a rapidly ageing HIV positive population which has complex health needs, lifting the standards in aged care and ensuring nursing homes are free of stigma is of tremendous importance.

The systemic failures dramatically exposed by the Royal Commission into Aged Care Quality and Safety hinder progress towards reducing stigma and improving standards of care for PLHIV.

Since its privatisation in the late 1990s, there has been a dramatic lowering of care standards. This degradation is well-illustrated by the drop in the average number of registered nurse hours typical nursing homes are funded for, from 308 hours before privatisation, to only 168 today.⁹⁸

In a recent submission to the Royal Commission, ACON has put forward a series of recommendations to lift the standards of care for PLHIV, including through improving workforce capability (HIV training), better standards enforcement, accreditation and complaints processes.⁹⁹

Addressing the intersecting needs of positive trans and gender diverse people is also a pre-requisite to effective stigma reduction interventions. The small number of healthcare providers and nongovernment organisations that provide services and programs for the trans and gender diverse community do so with very limited resources, making it impossible to meet the increasing demand from the community. ACON's *Blueprint for Improving the Health & Wellbeing of the Trans & Gender Diverse Community in NSW*¹⁰⁰ has outlined priority areas for change, including access to gender affirming care and an inclusive health sector.^{xii}

Changing stigmatising and discriminatory laws

Tackling intersecting stigma therefore requires maintaining an environment that protects people against discrimination based not only on HIV, but also on other stigmatised attributes. While much has changed since the beginning of the HIV epidemic – sex work is decriminalised and strong anti-discrimination and anti-vilification rules are in place (see I.3) – our laws still criminalise and discriminate against some populations at risk of HIV.

Drug Use

In a recent position paper on drug harm reduction, ACON highlighted the impacts of the stigma based on drug use, coupled with HIV-related stigma.¹⁰¹

The paper outlined a series of recommendations to address the impacts of drug use in our communities, including among people living with HIV.

Central among those recommendations was the need for the NSW Government to develop a NSW Drug and Alcohol (AOD) Policy/Strategy. The Strategy should acknowledge ACON's communities, including PLHIV, as a priority population, and ensure they are meaningfully involved in the design and delivery of adequately resourced AOD services.

Fixing Discriminatory Migration Rules

The HIV/AIDS Legal Centre report that half of their clients come to them to resolve immigration issues.

Australia's two-tier health system discriminates individuals based on where people come from. Australian citizens and permanent residents, as well as citizens from nine European countries, the UK and New Zealand, have access to Medicare and the Pharmaceutical Benefit Scheme, while most temporary visa holders do not.

Discriminatory by design, this system has detrimental impacts on overseas-born people, who now account for most new HIV notifications in NSW. For migrant PLHIV, this often means securing HIV medication through compassionate access schemes. Applications to access such schemes are considered on a case-by-case basis by the pharmaceutical companies who offer them.¹⁰²

When applying for a permanent visa (which often occurs years after first arriving in Australia) applicants must undergo an HIV test to determine whether they are free of any disease or condition requiring health services that may result in significant costs to the Australian Government.¹⁰³ Due to the costs of HIV treatment and care, which is calculated over a lifetime, PLHIV are unlikely to meet this immigration health criteria. Waivers to the health requirement may be obtained under certain conditions but this process is complex and uncertain.

xii The priorities outlined in ACON's *Blueprint for Improving the Health & Wellbeing of the Trans & Gender Diverse Community in NSW* are: A. Clear and easy pathways for accessing gender-affirming care; B. Affordable and available gender-affirming healthcare; C. An inclusive and knowledgeable health sector; D. Official government I.D.s and records that reflect trans and gender diverse people's gender through simple administrative procedures; E. Workplaces, educational settings and custodial settings that are inclusive and respectful of the needs of trans and gender diverse people; F. A vibrant, resourced trans and gender diverse community advocating for its own needs and priorities.



CONCLUSION: A COMBINATION APPROACH TO ELIMINATE HIV-RELATED STIGMA IN NSW

HIV-related stigma is highly complex and rooted in multiple individual, institutional and structural causes, which cannot be meaningfully addressed in isolation. Instead, much in the same way that HIV prevention has shifted to a combination approach, a combination stigma reduction approach is required as well, in order to tackle it at multiple levels.⁸⁶

Interventions led by PLHIV that target priority populations and settings (e.g. healthcare and aged care), combined with population-wide education campaigns, resilience-building initiatives and

changes to laws that nourish intersecting stigma, are more likely to result in long-lasting impacts.

In addition to improving health outcomes for PLHIV, a combination stigma reduction approach in NSW would align with the State's goal of ending HIV transmissions for all, and the National HIV Strategy, by reinforcing prevention messages, reducing barriers to testing and increasing the number of PLHIV with an undetectable viral load.

RECOMMENDATIONS

The development of NSW's new HIV Strategy for 2021-2025 offers a unique opportunity to adopt ambitious stigma reduction targets and make commensurate investments in effective stigma reduction interventions to improve the quality of life of PLHIV and end HIV transmission for all.

Lessons learnt from NSW's world-leading HIV responses also highlight the importance of aligning State and Commonwealth policies and legislation in a range of domains (e.g. immigration, aged care) with health policy objectives.

To continue protecting PLHIV's rights and create an environment that is conducive to changing attitudes in the community, ACON recommends the following priority actions for NSW:

Meaningfully involve PLHIV

1. Incorporate GIPA/MIPA principles in the new *NSW HIV Strategy 2021-2025* and in all aspects of the NSW HIV response, including in research, policy design and service delivery.

PLHIV who are Aboriginal and Torres Strait Islander people, migrant, of colour, culturally and linguistically diverse, TGD, and/or who work in the sex industry and/or who inject drugs should be meaningfully included.

2. Fund research to better understand the intersection of HIV-related stigma with stigma based on gender, race and other characteristics.

Stigma reduction targets

3. Adequately monitor and report progress on achieving the national targets of reducing by 75 per cent the reported experience of stigma among PLHIV and 75 per cent of PLHIV reporting good quality of life.
4. Adopt a specific target of ZERO persons living with HIV reporting experiences of stigma or discrimination when seeking or using health and community services in NSW.

Strengthen resilience

5. Continue to fund targeted interventions to increase resilience and reduce the impact of HIV-related stigma, including internalised stigma.

Funding should also encourage interventions to focus on the intersection of HIV-related stigma and other forms of discrimination, including racism and transphobia.

Invest in interventions to change attitudes towards PLHIV

6. Fund a comprehensive campaign to improve community-wide knowledge of HIV, to challenge stereotypes and combat stigma.
7. Mandate the provision of HIV education programs for health care workers, general practitioners, allied health and aged care professionals as part of relevant quality assurance standards.

Address structural causes of stigma

8. Ensure HIV prevention responses are conducive to community education on HIV-related stigma, including by maintaining a stigma-free, voluntary-based HIV testing regime.
9. Maintain robust anti-discrimination and anti-vilification laws to protect PLHIV, people associated with HIV and other stigmatised populations.
10. Ensure that all PLHIV in NSW, regardless of Medicare status, have access to affordable, high-quality care, including through the provision of free anti-retroviral medication.
11. Advocate for the Commonwealth Government to make Medicare available to all people who live in Australia to ensure access and retention in care.
12. Create a health-centred environment that is conducive to community education on drug use and intersecting stigma, including by recognising the needs and issue PLHIV face and by designing, delivering and supporting services for PLHIV.

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