HIV STIGMA, RESILIENCE and FLOURISHING

Discussion Paper - September 2017

INTRODUCTION

HIV-related stigma and discrimination remain a persistent challenge to the stated aims of the current Australian HIV strategy. Developing understandings of resilience is a significant opportunity to response to the seemingly intractable nature of stigma and as such has caused NAPWHA to focus upon this intersection of stigma and resilience as a topic for a discussion paper.

While the predominate focus of this paper is on HIV-related stigma and its negative impact on the psychological resilience of people living with HIV (PLHIV) it will also articulate other compounding factors affecting HIV stigma and resilience as well as introduce the concept of *positive mental health* and how an individual can thrive or *flourish* even in the presence of HIV stigma.

ABOUT NAPWHA

The National Association of People with HIV Australia (NAPWHA) was founded in 1989 and is the peak organisation representing people with HIV at the national level. Our members comprise State and Territory organisations of people with HIV. Our focus is on policy and program reform to help ensure that Australia attains the highest standards in HIV prevention, treatment, care and research. NAPWHA's vision is that people with HIV will live our lives to our full potential, in good health and free from stigma, discrimination and criminalisation, fully exercising our central role in ending the HIV epidemic, our mission is to provide national HIV Positive leadership and representation to improve our health and quality of life and combat stigma, discrimination and the criminalisation of people with HIV. NAPWHA builds and draws upon knowledge about the experiences of living with HIV to inform the work of the organisation as it attempts to achieve its vision and fulfil its mission.

LINKS BETWEEN STIGMA AND RESILIENCE

This discussion paper on resilience is preceded by early work of NAPWHA particularly *The HIV Stigma Audit: Community Report*[i] published in 2012.

This report proposed that initiatives to build resilience among people with HIV should be developed. The first three recommendations of this report proposed that anti-stigma and resilience building interventions occur at three different levels with proposed formats which have been and will continue to be referenced as the current work continues and future work is proposed.

- **INDIVIDUAL LEVEL**

  Personal skills development including cultivating specific skills for combating HIV stigma and a broader set of life-enhancing skills that improve wellbeing.

- **COMMUNITY LEVEL**

  Development of resilience building activities including finding opportunities for promoting resilience across the health promotion efforts and education work occurring in the community-based response to HIV.

- **SOCIETAL LEVEL**

  Broad general public social marketing and targeted community awareness initiatives, which may include campaigns and events that broadcast PLHIV are not passive receptors of stigma. Rather, PLHIV are overwhelmingly resilient in the face of what remains a significant life challenge.

These three levels are worth considering as we examine what are the potential for future resilience interventions at an individual, community/group and societal levels, including current evidence about what works, resourcing and production capacity.

WHAT IS RESILIENCE?

Resilience embodies the personal qualities that enable one to thrive in the face of adversity and describes a process whereby people bounce back from adversity and go on with their lives.[ii]

Building resilience is not unique to the issue of combating HIV stigma. In fact, it is a proven strategy used to articulate effective responses from schoolyard bullying through to military training to addressing post-traumatic stress disorders. Skills which are seen as outcomes from building resilience would include:

- **Ability to create and sustain networks** which includes understanding how and who to access for support when needed, including from the HIV community, to build a protective barrier around yourself.

- **Practicing reflective practice** also called mindfulness, where a person is able to see through the stigmatising behaviour they may be subject to, to identify the causes and drivers and appreciate that the stigma often has far less to do with the person being affected than with the perpetrator.

- **Building adaptive capacity** and cultivating the capacity to bounce back from, or not take to heart perceived slights, to be resilient.

In an article on resilience and vulnerability in relation to post-traumatic stress disorder in *Advances in Psychiatric Treatment* (August 2007),[iii] the authors identify a number of *internal characteristics* which enable a resilience capacity and can be applied to our understanding of resilience generally (and specifically to those living with HIV) such as:

- Self-esteem
- Trust
- Resourcefulness
- Self-efficacy
- Internal locus of control
- Secure attachments
- Sense of humour
- Self-sufficiency
- Sense of mastery
- Optimism

- Interpersonal abilities such as social skills, problem-solving skills and impulse control

In addition to these internal characteristics, they identify four *external factors* which play an important role in further promoting resilience such as:

- Safety
- Religious affiliation (for our purposes otherwise described as spiritual connection or the like)
- Strong role models
- Emotional sustenance (being the extent to which others provide the individual with understanding, companionship, sense of belonging and positive regard)

These internal characteristics and external factors are important to consider in relation to building resilience among PLHIV and how interventions targeting the three different levels (individual, community and societal) can be conceived and the outcomes they may be seeking to achieve.

WHY IS RESILIENCE IMPORTANT?

The NAPWHA report on HIV stigma identified that social support and psychological resilience are two variables known to reduce the negative effects associated with a stigmatised illness. They are also variables that are correlated and work together to buffer the individual from the negative effects of stigma. When looking at the factors associated with social support and resilience the report found that both social support and resilience were positively correlated with a higher quality of life, greater levels of self-efficacy, higher self-esteem and greater engagement with an HIV community. On the other hand, lower levels of both were associated with a greater experience of HIV-related stigma as well as an increased risk of stress, depression and anxiety.[iv]

Building psychological resilience is important for a number of reasons;

- it enables us to develop mechanisms for protection against experiences which could be overwhelming,
- it helps us to maintain balance in our lives during difficult or stressful periods of time, and
- it can buffer us from developing mental illnesses such as depression, anxiety or post-traumatic stress disorder. It does so by helping offset certain risk factors that increase the likelihood of experiencing psychological distress.[v,vi]

BEYOND HIV STIGMA - DRIVERS NEGATIVELY AFFECTING RESILIENCE

Multiple studies have consistently highlighted a vast range of factors underlying vulnerability and negatively affecting resilience[vii]. These are grouped into four general headings and explored further on in this paper specifically in relation to PLHIV.

1. Psychosocial factors (such as stress, depression, social isolation, hopelessness, and job control, etc.)
2. Marginalised identity (such as a minority sexual or gender identity, cultural background or chronic condition)
3. Social status (such as the level of privilege and access to resources that an individual has and general social disadvantage[viii])
4. Co-morbidities (including both mental health conditions as well as physical aliments)

These additional factors intersect with HIV stigma to further confound and exacerbate low levels of resilience and reinforce vulnerability. To build a sustained resilience capacity among PLHIV means that identifying and mitigating these additional factors should be seen as important as building the personal skills to challenge HIV stigma.

Interestingly and importantly, dispositional optimism, active coping, and spirituality show the most evidence for predicting slower disease progression among PLHIV.[ix]

By focusing upon building resilience in general amongst PLHIV may well provide a degree of personal agency for PLHIV to have the facility to consider and address these additional vulnerabilities on their own independently.

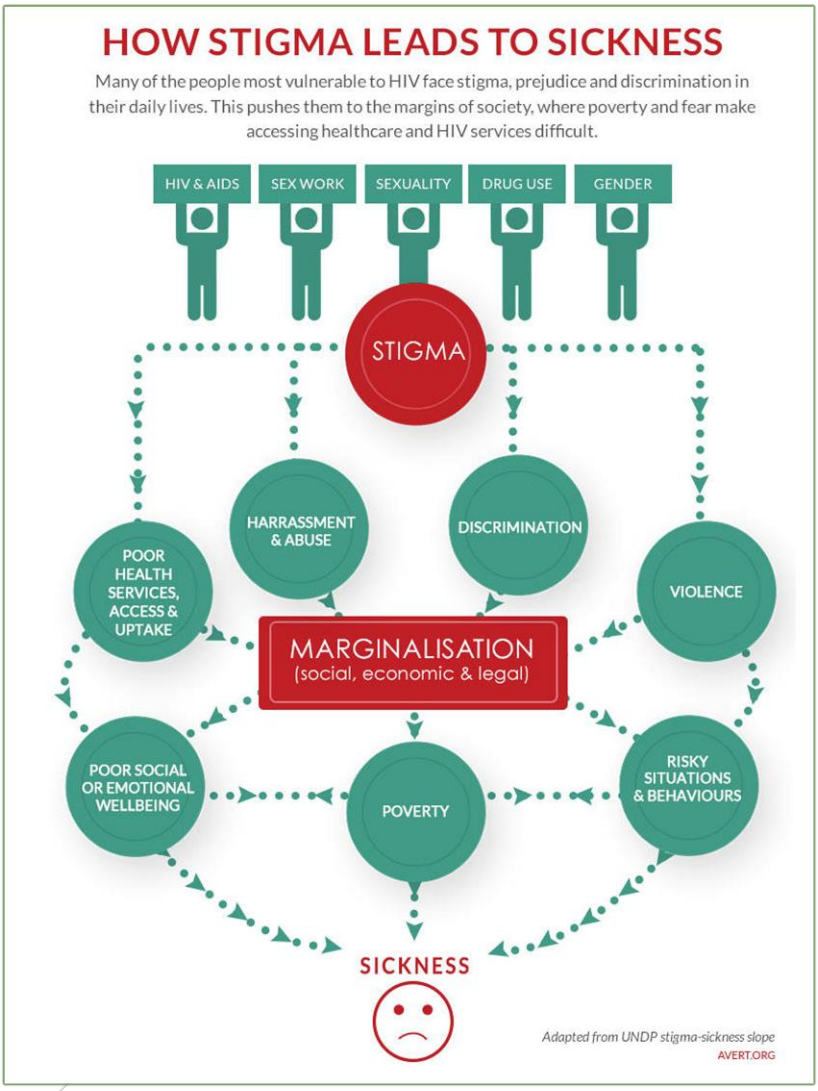
FROM RESILIENCE TO FLOURISHING

Flourishing is conceptualised as having two main components. The first is a *hedonic* component in which a person experiences frequent positive emotions, such as happiness and optimism. The second is a *eudemonic* component in which a person has a sense of self-acceptance, a sense of meaning or purpose, and feels that much of their life is lived in accordance with their values.[x]

In a national sample of Australian HIV-positive gay men[xi], internalised HIV-related stigma was found to be a major barrier to flourishing. Higher levels of flourishing, however, were found among those who perceived a greater level of practical support in their lives, who had a sense of belonging or companionship, and who felt supported by family.

These findings provide guidance for policymakers, health professionals, support workers, and anyone seeking to optimise support programs for PLHIV. In particular, this study and its findings offer new information to help facilitate programs that are not only aimed at treating or preventing mental illness among PLHIV, but also seek to foster higher levels of well-being or indeed flourishing.

MORE ABOUT HIV STIGMA



For the purposes of this paper, we are specifically focused upon HIV-related stigma and discrimination in reference to the prejudice, negative attitudes and abuse directed at people living with HIV and AIDS.

HIV related stigma and discrimination and its impact on the lived experience of people with HIV has been well described[xii] and the image below explores the intersectionality of HIV stigma, social vulnerability and marginalisation and the profound relationship it has to the health and well-being of PLHIV. What is less understood is the role of building a 'resilience capacity' being the capacity to recover quickly from difficulties; or to spring back into shape[xiii] and specifically the PLHIV's capacity in response to HIV stigma and discrimination and the protective factors traditionally related to resilience including the personal characteristics and social and affective support networks.[xiv]

This is of particular significance when we consider that HIV stigma and discrimination continues to persist in many areas of daily life for those living with HIV – either as overt manifestations such as unfair laws that criminalise PLHIV to the daily challenges of disclosure in interpersonal relationships. Ironically, despite the frequent identification of the disabling effect of HIV-related stigma and discrimination and reference to the NAPWHA HIV Stigma Audit Community Report in the recent 7th National HIV Strategy including a commitment to "inform further efforts to both address and monitor the impact of stigma and discrimination over the life of this strategy"[xv] little progress has been made to monitor and measure the progress of HIV stigma and discrimination efforts in Australia as it affects the quality of life of PLHIV.

Strategies to counter the stigma associated with HIV are necessary and welcome; initiatives such as social marketing and community campaigns are key to challenging the manifestations of stigma in both the social and institutional domains (e.g. workplaces, health and educational settings as well as more intimate settings) of the lives of PLHIV. However,

we contend that while this social change work occurs, concurrent investments in the development of individual psychological resilience programs across the HIV response in Australia are required. Initiatives that equip PLHIV with personal attributes to respond to the experience of stigma in ways which maintain if not bolster self-esteem and efficacy can also equip PLHIV to tackle other burdens of chronic illness. This ‘equipping’ may unfold in a way that increases the possibility of flourishing[xvi] not just surviving in an otherwise disabling environment.

MORE ABOUT PLHIV VULNERABILITIES

Psychosocial factors

Mental Health - more than half the participants in HIV Futures 8 (51.8%, n=454) indicated they had been diagnosed with a mental health condition at some point in their life, while 31.9% (n=277) had taken medication for a mental health condition within the past six months. [xvii]

Recreational substance use – for some subpopulations of PLHIV substance use is more prevalent compared with the general population. Prevalence of substance use is not necessarily an indicator for misuse nor harm. There are a range of reasons why some PLHIV choose to use substances, such as for pleasure in association with some sexual subcultures and practices. Harm reduction initiatives and education about safer substance consumption (including safer injecting practices) should therefore be priority for PLHIV.[xviii]

Coping - studies have investigated potentially positive aspects of coping responses (e.g., active coping, problem solving, and acceptance) and HIV disease progression.xix The logic sequence which describes the progression from coping to empowering PLHIV as described below.[xx]

Marginalised identity

There is now substantial evidence that supports what is called a Minority Stress Theory[xxi], which suggests that belonging to a stigmatised group can result in additional life stress and a greater risk for mental health and other health problems[xxii, xxiii].

Increasingly there has been a call to reframe the PLHIV identity not as a source of shame or risk but as a participant in an emerging HIV culture, with a unique history, language, artefacts and art.[xxiv] This provides two consequential outcomes of:

- creating opportunities for PLHIV to affect social change, and
- a protective social element that a culture creates.

Social status

Socioeconomic status (SES) encompasses not just income but also educational attainment, financial security (including housing security), and subjective perceptions of social status and social class. SES is a key factor in determining the quality of life for PLHIV.[xxv]

Additionally, structural factors including poverty, lack of employment opportunities, limited health care access and limited transportation infrastructure have been highlighted as both independent and interactive contributors to health care engagement and disease progression amongst PLHIV.xxvi

Co-morbidities

PLHIV were found to have significantly higher co-morbidity and higher incidence rates that HIV-negative people in a large scale study in the USA.[xxvii]

Some of the most common comorbidities amongst PLHIV are hepatitis, mental health disorders and cardiovascular disease with studies showing that male, caucasian and older patients are more likely to have a co-morbidity, with co-morbidities appear to be largely independent of HIV duration.[xxviii]

Ageing - PLHIV who were older were more likely to report poorer physical health, more likely to have co-morbidities and more likely to report limitations in their capacity to undertake daily tasks due to poor health.[xxix] During the natural progression of HIV infection, the immune system is chronically and progressively impaired. HIV infection and normal ageing exert many similar effects on the immune system. For example, the T-cell population, particularly in the gastrointestinal tract, is strongly affected by both HIV and ageing, as are nearly all aspects of immunity.[xxx]

Responding to Resilience – Options and Recommendation

Options for individual resilience capacity building

The American Psychological Association has identified 10 ways in which an individual can build their individual resilience [xxxi] and these are summarised below.

- **Make connections.** Good relationships with close family members, friends or others are important.
- **Avoid seeing crises as insurmountable problems.** Accepting that stressful events happen and looking beyond the present to how future circumstances may be better helps deal with difficult situations.
- **Accept that change is a part of living.** Accepting circumstances that cannot be changed can help you focus on circumstances that you can alter.
- **Move toward your goals.** Developing realistic goals and monitoring movements toward these goals is important.
- **Take decisive actions.** Act on adverse situations. Take decisive actions, rather than detaching completely from problems and stresses.
- **Look for opportunities for self-discovery.** Many people who have experienced tragedies and hardship have reported better relationships, greater sense of strength even while feeling vulnerable, increased sense of self-worth, a more developed spirituality and heightened appreciation for life.
- **Nurture a positive view of yourself.** Developing confidence in an ability to solve problems and trusting instincts helps build resilience.
- **Keep things in perspective.** Try to consider the stressful situation in a broader context and keep a long-term perspective.
- **Maintain a hopeful outlook**. An optimistic outlook enables an expectation of wellness into the future.
- **Take care of yourself.** Pay attention to needs and feelings and engage in activities that are pleasurable and relaxing. Exercise regularly.

Certainly there is scope to rearticulate these individual strategies in the context of an HIV identity through existing community-based activities such as workshops for those who are newly diagnosed or providing interventions or support programs via the web or smartphone apps.

Options for community resilience capacity building

Specifically, having access to practical or material support (measured as tangible support) and companionship or having someone to do things with (measured as belonging support) were linked to higher levels of flourishing among PLHIV.[xxxii]

This has a direct impact upon the need to maintain current activities in this regard and expand programs that provide materials/practical support such as the Bobby Goldsmith Foundation in NSW and South Australia or state-based programs like the David Williams Fund in Victoria. It also strongly suggests that activities and events which aim to reduce social isolation (i.e. workshops for newly diagnosed PLHIV and social support activities like Planet Positive) as well as programs which aim to build peer networks (i.e. Positive Leadership Development Institute and the Peer Navigation program run by QPP) are

essential aspects of building community resilience. Not only do these such programs foster social support networks they certainly help buffer stigma-related stress with peer-led navigation and counselling and support as one option that has been shown to improve well-being among PLHIV.[xxxiii]

Options for society resilience capacity building

Where stigma is a particular issue, public stigma-reduction programs that address community attitudes toward PLHIV are essential to affecting the long-term social change required to effect community attitudes.

Interestingly, it has been identified that a PLHIV's connection with their family has a direct bearing upon their self-perception of worth and broad public campaigns may also be beneficial for helping families cope and respond more positively toward family members who are either gay or living with HIV, especially if families fear being stigmatized themselves.[xxxiv]

Recommendation

That a framework of best practice be developed which identifies resilience building opportunities across the interpersonal, community and societal axis that meets the need for inclusion regardless of geographic, demographic or other diversities.

[i] http://napwha.org.au/files/napwa_stigma_audit_report.pdf

[ii] https://static1.squarespace.com/static/51abe64ee4b0a1344208e98a/t/51d3ce77e4b001d5c13a7e87/1372835447995/CD-RISC+%28Connor+%26+Davidson%2C+2003%29.pdf

[iii] http://apt.rcpsych.org/content/13/5/369

[iv] http://napwha.org.au/files/napwa_stigma_audit_report.pdf

[v] https://wayahead.org.au/mental-health-information/fact-sheets/building-resilience/

[vi] www.counselling-directory.org.uk/counsellor.../the-importance-of-building-resilience

[vii] http://apt.rcpsych.org/content/13/5/369

[viii] http://jech.bmj.com/content/57/8/565

[ix] https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2614870/

[x] http://www.jstor.org/stable/3090197?seq=1#page_scan_tab_contents

[xi] https://bmcpsychology.biomedcentral.com/articles/10.1186/s40359-016-0154-z

[xii] http://cdn.agilitycms.com/wacc-global/resources/multi-year-projects/ghana/d-HIV-Stigma-and-Discrimination-Annotated-Bibliogaphy.pdf

[xiii] https://en.oxforddictionaries.com/definition/resilience

[xiv] https://www.ncbi.nlm.nih.gov/pubmed/17700938

[xv] http://www.health.gov.au/internet/main/publishing.nsf/content/8E87E65EEF535B02CA257BF0001A4EB6/$File/HIV-Strategy2014-v3.pdf

[xvi] https://www.eiseverywhere.com/file_uploads/006d6dee4728cadc0f274bba4f82a09c_AnthonyLyons.pdf

[xvii] http://www.latrobe.edu.au/__data/assets/pdf_file/0006/766896/HIV-Futures-8-Broadsheet-1-on-Health-and-wellbeing.pdf

[xviii] ibid

[xix] https://www.ncbi.nlm.nih.gov/pubmed/8926605

[xx] https://www.researchgate.net/publication/319536610_Responding_to_HIV_resilience_-_first_step_HIV_stigma

[xxi] http://psycnet.apa.org/doiLanding?doi=10.1037%2F0033-2909.129.5.674

[xxii] http://ajph.aphapublications.org/doi/10.2105/AJPH.2009.168815

[xxiii] http://ajph.aphapublications.org/doi/10.2105/AJPH.2012.301069

[xxiv] https://www.researchgate.net/publication/315780914_Informed_Sophistication_Managing_an_HIV_Identity_and_Risk_in_a_Bio-Tech_World

[xxv] http://www.apa.org/pi/ses/resources/publications/hiv-aids.aspx

[xxvi] http://onlinelibrary.wiley.com/doi/10.1016/j.jmwh.2005.05.001/full

[xxvii] http://www.aidsmap.com/Co-morbidities-are-common-and-rising-among-people-with-HIV-in-the-US/page/3105593/

[xxviii] https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4238727/

[xxix] http://www.latrobe.edu.au/__data/assets/pdf_file/0006/766896/HIV-Futures-8-Broadsheet-1-on-Health-and-wellbeing.pdf

[xxx] https://www.ncbi.nlm.nih.gov/pubmed/19265479

[xxxi] http://www.apa.org/helpcenter/road-resilience.aspx

[xxxii] https://bmcpsychology.biomedcentral.com/articles/10.1186/s40359-016-0154-z

[xxxiii] http://www.catie.ca/en/pc/program/peer-navigators

[xxxiv] https://bmcpsychology.biomedcentral.com/articles/10.1186/s40359-016-0154-z