

**#RESISTSTIGMA**

# How Do We Get There?

**A Scoping Review**

Maggie MacAulay and Skyler Wang

## Acknowledgements

The authors wish to thank the members of the Resist Stigma team who have supported this project by providing assistance with the development of this scoping review:

Oliver Ferlatte (UBC)

Rick Marchand (CBRC)

Terry Trussler (CBRC)

Daniel Grace (University of Toronto)

Travis Salway Hottes (University of Toronto)

Keith Reynolds (Project Manager)

Financial support for this project has been provided by the Public Health Agency of Canada. The opinions expressed in this report are those of the authors and do not necessarily reflect those of the Public Health Agency of Canada.

Editor: Craig Barron

Design/Layout: [pulpandpixel.ca](http://pulpandpixel.ca)

Translation: Elie Darling

2016

# Table of Contents

Executive Summary	1
<b>1</b> Introduction	3
<b>2</b> Locating Stigma Intervention in its Theoretical Framework	5
<b>3</b> Methodology	9
<b>4</b> How is Stigma Conceptualized?	13
<b>5</b> Level of Intervention	17
<b>6</b> Populations	23
<b>7</b> Web/Social Media	29
<b>8</b> Lessons Learned	30
<b>9</b> Recommendations	32
<b>10</b> Conclusion	35
Recommended Readings	37



# Executive Summary

**D**espite advances in treatment, educational efforts, and mobilizations by people living with HIV, HIV stigma remains a community and public health problem. The shame and silence that continues to surround HIV often discourages disclosure, acts as a barrier to testing, and can impede medication adherence, care-seeking, and overall wellness among people living with HIV. Efforts to tackle stigma depend on how it has been defined. Much scholarly literature and popular discourse takes a psychological approach to the issue, framing it as both a felt and enacted phenomenon—an individual condition, attribute, or mark that elicits negative attitudes and results in a person’s exclusion from mainstream society. Interventions in this arena typically target individual attitudes, values, and beliefs through workshop, counselling, and skills-building activities designed to cultivate empathy, empower individuals, and educate participants. Others have advocated more sociological approaches that treat stigma as a dynamic process shaped by power relations. Proponents of this perspective identify major social institutions such as schools, media, medicine, government, and law as sites in need of reform. Such approaches ask us to consider the ways in which stigma reproduces hierarchies and inequities among us, taking into account how social categories such as sexuality, gender, race/ethnicity, and nationality are not simply neutral descriptors of identity.

In this CBRC report, we take this into account as we investigate some of the most effective or promising ways to reduce HIV stigma. Conducting a scoping review of both the peer-reviewed and grey literature in regions such as Canada, the US, the UK, the EU, and Australia, our findings identify a range of campaigns, programs, policies, and interventions dealing with HIV stigma. Given the fact that HIV continues to disproportionately affect young gay men, we were particularly interested in efforts designed for them that made use of social media. Broadly speaking, most efforts target specific communities like gay, bisexual, queer, and trans men, ethno-cultural groups, and members of the general public. They frequently exist in the form of awareness campaigns or community education efforts. Given the wide reach and relative affordability of Internet communication, many contemporary efforts make extensive use of social media to both challenge stereotypes and inform publics about the medical realities of living with HIV in 2016. And yet, we found relatively few examples of efforts designed specifically for young gay men—suggesting a need to develop campaigns to reach this group and capitalize on the affordances of social media.

Although this review presents a number of promising examples, it remains unclear “what works” to resist stigma. This is due less to inherent problems of specific efforts than the persistent problem of having little to no resources to conduct long-term evaluation. This suggests that we should use the successes and challenges of past efforts to guide us in an area of many unknowns. We end this report by considering some of lessons learned as well as offering a list of recommendations borrowed from the field of mental health. We hope that this report will be a useful resource for other community-based organizations, HIV/AIDS service groups, researchers, practitioners, educators, and policymakers in the field, as well as informing the development of our Resist Stigma campaign. Our aim is to demonstrate that although resisting stigma is an ambitious practice, it is something we can work towards together.



# Introduction



Despite advances in treatment, educational efforts, and mobilizations by people living with HIV (PLWH), HIV stigma remains a community and public health problem. Historically, HIV/AIDS' status as a mysterious and fatal condition led to collective fear and panic that resulted in the exclusion, discrimination, and scapegoating of many who were already living on the margins of society. This led to individual and community-wide calls promoting acceptance of and sympathy for PLWH, while discouraging “blaming the victim”. This strategy of combating stigma was also born out of necessity, insofar as the legal protections for PLWH in areas such as access to medicine, housing, and employment were nascent or non-existent.

Today, the scientific realities of living with HIV are different but HIV stigma remains. Many people living with HIV are managing their condition effectively, able to work, attend school, have active sex lives, and be an active part of their communities. And yet media representations, laws, policies, and the experiences of a number of PLWH suggest that we as a society have not yet quite caught up. Sensationalistic media coverage of HIV non-disclosure court cases continues to present victim/perpetrator narratives grounded in outdated understandings of the risk of transmission. Blood bank policies continue to discriminate against men who have sex with men (MSM) regardless of their serostatus. And PLWH continue to regularly report experiences of discrimination and exclusion at the hands of health care providers, family members, and potential sexual partners.

It has become increasingly clear that although the effects of HIV stigma are felt most acutely by PLWH, they negatively affect outcomes for people regardless of status. HIV stigma can create a taboo that discourages conversations involving risk and disclosure; it facilitates a sense of fear or dread that can prevent people from accessing health care services (i.e. testing or treatment); and divides communities by creating an us/them mentality. Given the recognition of the important role that community plays in health, how can we mobilize to create meaningful strategies to resist stigma? What can we learn from others?

In this scoping review, we survey the landscape of campaigns, programs, policies, and interventions that individuals, communities, organizations, institutions, and governments use to resist HIV stigma and promote change. Consulting both the scholarly and grey literature, gathered from countries such as Canada, the US, the EU, the UK, and Australia, we can examine initiatives at the individual, community, and structural levels while taking into account different populations and their respective needs. We also consider how people have used social media in their efforts, paying close attention to some of the lessons learned to inform a set of best practices for future campaigns.

As with any other complex social problem, there exists no panacea: mitigating HIV stigma requires significant time, resources, time, allies, and champions at multiple levels. That said, we strongly believe in the value of learning from past efforts to inform future interventions that challenge existing structures.

We hope that this report will serve as a resource guide useful to individual readers, health providers, and community organizations that share our interest in resisting stigma.

*Although nobody technically forces stigmatized groups to accept and believe they are deserving of their circumstances, the structures of inequity are stronger. Individuals constantly subject to domination and control become exhausted, which weakens their belief in their ability to resist. And, the status quo reminds them of this. To resist hegemony means to call into question the very structures that hold up society.*

(See Parker and Aggleton)

# Locating Stigma Intervention in its Theoretical Framework



What is stigma? In scholarly literature, it depends. The most widely cited definition comes from the work of sociologist Erving Goffman (1963), who describes stigma as a “deeply discrediting” attribute that reduces its bearer from a “whole and usual person to a trained, discounted one” (p. 3). Stigma becomes a “spoiled identity” that reduces the stigmatized person to the negative attribute they possess. Society labels stigmatized people as “different” or “deviant,” creating rules and sanctions that reinforce this otherness. It is important to note that people can be stigmatized for a variety of reasons—physical appearance, disabilities, education level, citizenship, income etc. In this section, we will introduce both psychological (individual) and sociological (collective) ways of understanding stigma.

## 2.1 Psychological Frameworks

In the psychological tradition, stigma is constructed as an individual-level phenomenon in the form of attitudes, values, and beliefs. It can either be felt or enacted. Felt stigma refers to an individual’s lived experience with stigma, their awareness of its prevalence, and how it manifests (Brown et al., 2003). We can compare this to internalized stigma, which is a form of felt stigma that occurs when an individual not only accepts the negative attitudes or stereotypes directed at them, but begins to adopt these very ways of thinking themselves. Enacted stigma describes how others discriminate against stigmatized individuals or groups. This can take the form of value judgments, prejudice, and overt hostility in a variety of social settings (Herek et al., 2008).

This may lead to a variety of stigma management strategies (Goffman, 1963) that include self-isolation, partial disclosure of their condition, or concealing their condition from others. It is important to note that felt and enacted stigma can also work hand in hand. For example, someone may permanently choose to conceal their HIV status in order to prevent being ostracized by their existing social network. Although this may help individuals in the short run, such coping mechanisms can have negative long-term effects. At a psychological level, individuals who are forced to mask their conditions may report lower self-esteem, experience loneliness, and be more susceptible to depression and substance abuse. At the physical level, this may also result in delayed health care seeking, poor medication adherence, and neglecting one’s overall well-being (Herek et al., 2008).

In this tradition, people typically use cognitive and social psychological approaches to reduce stigma (see Brown et al., 2003). By focusing on attitudes, values and beliefs, practitioners design interventions to help individuals identify and confront the stereotypes and prejudices they hold towards affected groups. Brown et al. (2003) note that such categorizations are meaningful to our understandings of interventionist efforts, as they allow us to better understand how focused strategies targeting specific identities can deliver more precise and effective results.

Parker and Aggleton (2003) identify three common approaches. The first approach targets the emotional level, where efforts are invested in increasing “acceptance” of stigmatized groups, promoting empathy and altruism, and reducing people’s anxieties and fears. Typically, this is done through information-based interventions that expose participants to advertisements, presentations, and videos designed to raise awareness regarding HIV stigma and the day-to-day challenges faced by PLWH (Brown et al., 2003).

The second type of intervention involves psychological counselling and depends on whether one potentially enacts stigma or experiences it. In the case of the former, efforts often emphasize increasing contact with PLWH. Such efforts rely on contact theory, which posits that personal contact with marginalized populations can challenge the prejudiced views one might hold against stigmatized groups (Brown et al., 2003). Examples may include inviting a PLWH to speak to a group or sharing recorded testimonials. Counselling is a strategy deployed mainly with the objective to provide a safe, judgement-free zone for discussion where information about HIV can be shared while promoting social support for behavior change or maintenance. For those living with HIV, interventions are framed to enhance their capacity to manage their stigma productively and effectively. In counselling efforts designed for PLWH, heavy emphasis is placed on addressing internalized stigma.

Skills-building is the third form of psychological intervention, where stigma is framed as being constructed and sustained by misinformation and misunderstanding. Here, negative attitudes, values, and beliefs are challenged through the provision of information and education to targeted groups. This is done to equip people with the necessary skills used to navigate real-life situations. These sessions typically involve participatory, hands-on learning. In the context of HIV stigma, it often requires participants to confront their prejudicial views toward groups disproportionately affected, such as gay and bisexual men, transgender women, people who inject drugs, and sex workers.

## 2.2 Limitations of Psychological Frameworks

Although Goffman’s definition of stigma has been useful in helping researchers and practitioners understand how stigma operates at the individual level, there are several limitations. First, an overemphasis on individual psyches and experiences risks neglecting the social processes that drive stigma. As Link and Phelan (2001) note, “stigma comes to be seen as something in the person rather than a designation or tag that others affix to the person” (p. 366). Rather than solely focusing on the experiences of those who have been stigmatized, Link and Phelan suggest directing attention to enacted stigma, or discrimination performed by perpetrators of rejection and exclusion.

Another challenge with individual-level approaches is that they frame stigma as a relatively static phenomenon, ignoring the fact that it is a dynamic and often resisted social process (Parker & Aggleton, 2003). Although there is no question that stigmatized people encounter barriers and

roadblocks in life, the tendency to frame stigmatized people as helpless victims risks undermining their capacity to resist and be resilient; consequently, it prevents us from understanding all the productive ways that individuals and groups manage stigma or mobilize against it collectively.

Finally, critics have pointed out that psychological frameworks and approaches towards stigma underemphasize the role of structural and material power (Link & Phelan, 2001; Parker & Aggleton, 2003). In other words, stigma is not simply what individuals think or do to one another, but it is also upheld by institutions (i.e. media, law, medicine, government) that perpetuate inequity among people. Stigma must therefore be understood with broader notions of domination, power, and control that require us to dig deeper.

## 2.3 Sociological Frameworks

Sociological frameworks ask us to consider how individuals, communities and institutions are implicated in these processes. Parker and Aggleton (2003) turn to social theory and the work of Michel Foucault, who described expert systems such as science and medicine as “cultural systems” that produce their own ways of knowing. These institutional ways of knowing are legitimized and act to exert control over individuals and populations by producing difference—Foucault’s work on how psychiatry creates ‘the mad,’ prison creates ‘criminals,’ and sexology creates ‘sexual deviants’ are examples. In other words, power and knowledge create categorical differences to hold up current systems of power and social exclusion. We cannot have the ‘healthy’ without the ‘diseased’ nor the ‘dangerous’ without the ‘safe.’

But how does such a model account for people’s lived experiences of stigma? Parker and Aggleton (2003) turn to the work of theorists Pierre Bourdieu and Antonio Gramsci. For Bourdieu, all cultural meanings and practices embody interests and functions to preserve the status quo by enhancing social distinctions or hierarchies amongst people. Through cultural socialization, people learn to compete with each other for status and resources. Bourdieu suggests that when stigmatized or underprivileged groups are convinced to accept such processes as normal and natural—and their social positions as inevitable—this becomes “symbolic violence.” But how does this happen and why don’t people simply resist and fight back? Antonio Gramsci’s concept of hegemony explains why. Although nobody technically forces stigmatized groups to accept and believe they are deserving of their circumstances, the structures of inequity are stronger. Individuals constantly subject to domination and control become exhausted, which weakens their belief in their ability to resist. And, the status quo reminds them of this. To resist hegemony means to call into question the very structures that hold up society (Parker & Aggleton, 2003: p. 18).

## 2.4 Interventions

These perspectives consider the social consequences of stigma and how they perpetuate inequities. They require that we examine how broader social, cultural, political, and economic factors shape and sustain stigma at the micro- (individual), meso- (community), and macro- (societal) levels. As such, Link and Phelan recommend we design multi-faceted interventions that target multiple levels—challenging prejudice while pushing for social change (2001, p. 381).

Keeping in line with an emphasis on multi-level interventions, Heijnders and Van Der Meij (2006) describe five levels where stigma-reduction efforts should be directed: intrapersonal (counselling, empowerment); interpersonal (home care teams, community-based rehabilitation); organizational/institutional (training programs for staff, patient-centered approaches); community (social movements, education); and governmental/structural (policy changes, rights-based approaches). They suggest that while individual and community-level interventions have been commonly evaluated, more evaluation is necessary regarding structural measures.

Interventions should also develop ways to measure stigma and its effects. Link and Phelan (2001) recommend we do so by considering how stigma intersects with various elements of social life such as employment, income, social ties, housing, criminal involvement, health, and so on. By emphasizing social relations and developing stigma concepts and measures around social structures, we gain a more thorough understanding of what stigma looks like, how it affects people, and what we need to do about it.

Our overview of different approaches to stigma suggest that stigma-reduction efforts vary based on the populations targeted. Individual-level approaches to stigma focus on changing attitudes, values, and beliefs possessed by both dominant groups and those affected by stigma. Although they offer promising strategies through information and education, many of them do not take into account the social dynamics and institutions that also play a role.

By comparison, sociological approaches to stigma broaden our understanding of its origins and their effects. Such interventions, however, tend to require more long-term systematic change that may be difficult to achieve in a short period of time. We are not trying to suggest that one approach is better than the other—rather, our aim has been to explain the various ways people interpret and act to reduce stigma so as to broaden its concept and application. In the next section, we begin by explaining our report’s methodology—a scoping review—and how we collected our data.

*“Interventions should also develop ways to measure stigma and its effects ... how stigma intersects with various elements of social life such as employment, income, social ties, housing, criminal involvement, health, and so on.”*

# 3

## Methodology

### 3.1 Scoping Review

Our report used a scoping review methodology (Arksey & O'Malley, 2005) to help us determine the best practices in HIV stigma reduction. A scoping review is a type of literature review where researchers collect, evaluate, and present evidence from relevant materials gathered from a wide range of sources. Although scoping reviews share similarities with systematic reviews, they are different in two ways. First, systematic reviews tend to focus on a well-defined question aimed at identifying appropriate study designs, while scoping reviews tend to address broader topics where the particularities of study designs are less important. Second, systematic reviews tend to answer specific questions from a relatively narrow range of quality-assessed studies, whereas scoping studies are less concerned with these issues.

We can also think of the difference between the two in the following way: where a systematic review emphasizes depth of knowledge about a particular field or topic, a scoping review emphasizes breadth and diversity. In other words, scoping reviews cast a wider net.

### 3.2 Research Questions

Our primary question for this review is: What are the most effective or promising ways to reduce HIV stigma? We also asked: What works in terms of reducing HIV stigma affecting young gay men? and How can social media be used to reduce HIV stigma? Even before we began our review, we were well aware of the fact that there would not be a one-size-fits-all approach to stigma reduction. Instead, our goal was to find some of the best practices or lessons learned so that future generations of intervention planners would not have to start from scratch. We also recognized that the definition of “HIV stigma reduction” might vary across settings, and hence we chose to cast our net wide.

### 3.3 Identifying Relevant Studies

In order to be as comprehensive as possible, we consulted both the academic and grey literature. We consulted scholarly databases, grey literature databases and search engines. This produced an initial sample of peer-reviewed journal articles, reports, theses/dissertations, conference abstracts and proceedings, bibliographies, newsletters, and meeting minutes. We also included conference presentations and campaign websites, as they often offered a great deal of information. Further, we also included book chapters that did not come up in the peer-reviewed journal search as part of our grey literature pool.

Our search was limited to materials published between 1980 and 2015, published in either English or French, and in geographic areas politically similar to Canada: the United States, the United Kingdom, Northern and Western Europe, and Australia. Although this limits the applicability of our findings, narrowing our parameters in such a manner has helped us select a manageable number of items to review.

## 3.4 Study Selection

We included studies that focused specifically on HIV stigma, and the publications had to detail a specific effort or make recommendations that would help us understand how to reduce it. One author searched, read, and charted all of the scholarly, peer-reviewed sources while the other focused specifically on grey literature. The researchers discussed progress, challenges, and initial observations regularly, and consulted with others as the study progressed. For the scholarly peer-reviewed literature, the researcher read the entire article before deciding whether it should be included. For the grey literature, materials tended to be shorter and therefore it was easier to quickly scan them to see if they met the selection criteria.

For the peer-reviewed articles, we consulted the databases PubMed, PsychINFO, Sociological Abstracts and CINAHL using the search string (hiv AND stigma or discrimination or prejudice) AND (intervention OR program OR policy OR campaign OR social marketing OR reduction). We found a total of 6,082 articles, of which 3,470 did not meet our selection criteria and 2,400 were duplicates. This left us with an initial sample of 212 articles. In the process of sieving out relevant peer-reviewed articles, we found four existing scoping reviews that target HIV stigma intervention evaluations (Brown et al., 2003; Heijnders & Van Der Meij, 2006; Sengupta et al., 2011; Stangl et al., 2013). With a few exceptions, most of the articles we initially collected were already included in these reviews<sup>1</sup>. Our final sample included 26 peer-reviewed articles, which evaluated 28 studies<sup>2</sup>.

Our grey literature search produced 3158 items, of which 2914 items did not fit the criteria, and 169 were duplicates. This produced a final sample of 74 items. Of these 74 items, we were able to locate all but two of the documents, leaving us with a final total of 72 grey literature documents. To supplement this component of our data collection, we added a “consultation exercise” to the process (Arksey & O’Malley, 2005). This resulted in an additional 14 campaigns that we came across during our search. Some of the documents mentioned more than one intervention, and some discussed the same one. After sorting through the grey literature, we ended up with a total of 121 HIV stigma interventions, campaigns, and programs. We also included a few documents outlining best practices in the field, and counted media kits and events as examples. Notably and regrettably, there was very little formal evaluation of these efforts.<sup>3</sup>

**1** It is important to note that the focus of these reviews are global, and hence contain some material and data derived from interventions conducted in non-Western and developing nations. However, the lessons learnt still largely contain knowledge generated from studies conducted in regions that fall within our geographical range, and remain significant and immensely applicable  
**2** The article by Bean et al. (1989) evaluated three HIV stigma reduction interventions.

**3** We did not find an extensive amount of overlap in our samples. Notable exceptions include interventions described in Adam et al. (2011), Krauss et al. (2006), and Deutsch (2007).

## 3.5 Charting the Data

Using an Excel spreadsheet, we organized our data according to author name, publication year, study/report location, database, search terms, description of the intervention, definition/conceptualization of stigma, intervention level (individual/community/structural), population targeted, web/social media component, and lessons learned. Although we attempted to fill all of these categories, it was not always possible to find the necessary information (a common reality for scoping reviews). When too many gaps were observed in a particular piece of grey literature, we would always try to supplement the data by replacing it with a more comprehensive source (i.e. if an item only briefly mentioned an intervention, a Google search was conducted to see if there was a more comprehensive document available).

## 3.6 Collating, Summarizing and Reporting the Results

After charting the data from the materials, we present our findings in a few ways: 1) conceptualizations of stigma, 2) level of intervention, 3) populations targeted, and whether there was a social media component in the sections that followed. Some of the interventions, campaigns, and programs were multi-level, and some targeted multiple audiences. To address these issues, we coded those items more than once. This data gave us a good summary of the most common types of interventions used and the populations involved. We did not quantify how authors conceptualized/defined stigma, as much of it was interpretative knowledge and could lead to imprecise statistics. In general, we found that most efforts designed to reduce HIV stigma were individualistic and either focused on testing or risk-reduction.

One limitation of our study lies in the lack of available evaluation data in our grey literature search. This made it difficult to add information about the lessons learned. An alternative approach would have been to contact the authors or organizations of each item and ask them for additional information. Although this happened occasionally, time limitations made it difficult for researchers to do so comprehensively. In the following section, we present the results of our review in terms of how past and present efforts have conceptualized stigma and present five common categories.



**LET'S BRING  
HIV OUT OF  
THE CLOSET.**

**WATCH THE VIDEO. SHARE IT.**  
**SPEAKOUT**  
[greaterthan.org/speakout](http://greaterthan.org/speakout)

**WE**  
**AIDS**



# How is Stigma Conceptualized?

# 4

In our scoping review, we found that much of the literature used Goffman's (1963) definition of stigma. Others, however, offered different interpretations that were more in line with social ecological/structural efforts. We grouped definitions/conceptualizations of HIV stigma into the following categories, noting that some materials defined it in more than one way. It is important to stress that these definitions are not mutually-exclusive and often overlap.

## A Negative attitudes

The majority of the initiatives we surveyed framed stigma as holding negative attitudes, values, and beliefs about specific groups. Often, they focused on stereotypes and prejudices against people living with HIV (PLWH). There was a strong emphasis on HIV stigma as something primarily affecting PLWH. In the pool of scholarly articles, the goal of several HIV-stigma interventions was to revert negative attitudes by inducing more 'positive' feelings and concerns for people living with stigma—developing empathy was seen as an important step forward. In the grey literature, stigma as a negative attitude was often seen as something that could be ameliorated through education, public campaigns, and targeted interventions (see Crawley, 2009; CAMBA, 2012; Deutsch, 2007; Nichols, 2013).

## B Fear and Ignorance

Fear and ignorance was also a prominent theme (Bean et al., 1989). Although some might collapse negative attitudes with fear and ignorance, we felt it necessary to distinguish them. For instance, a person or group may genuinely believe that they do not hold prejudicial views against PLWH, while still fearing the risk of transmission through casual contact. In turn, they may reduce or restrict their social interactions with PLWH.

This can also occur among service providers. Stewart et al.'s (1999) study on HIV stigma among hospital nurses found that many still continued to associate infection with groups like gay men and people who inject drugs, with those possessing less accurate information about HIV more likely to fear and avoid PLWH (p. 688). In the scholarly literature, fear can be eliminated when those who hold negative attitudes gain a sense of compassion and altruism (Bean et al., 1998).

The grey literature stressed more informational and educational approaches. Social media campaigns like The Stigma Project (*thestigmaproject.org*) use memes to distribute information on the realities of living with HIV in the 21<sup>st</sup> century; while the Vancouver STOP Project's It's Different Now (*itsdifferentnowbc.org*) used video and social marketing to encourage members of the general public to test more frequently (CATIE, 2013). Similarly, the International Student Union of Norway (2010) organized an HIV= No Crime anti-criminalization campaign to both educate publics about advances in medicine and how the criminalization of non-disclosure perpetuates HIV stigma.

↳ **Crawley, H. (2009).** Understanding and changing public attitudes: A review of existing evidence from public information and communication campaigns. Retrieved from <http://bit.ly/2a8EWDR> (PDF)

↳ **CAMBA. (2012, July 3).** CAMBA launches 2012 anti-stigma campaign urging compassion for 27,000 Brooklynites living with HIV/AIDS. Retrieved from <http://bit.ly/1XT4h8o> (PDF)

↳ **Deutsch H. (2007).** Reducing HIV stigma: a common group identity perspective. Bloomington, IL: Illinois Wesleyan University. Available from: <http://bit.ly/1S31gcX>

↳ **Nichols, K.M. (2013).** Examining the effects of a motion comic intervention on HIV-stigma among a sample of adolescent men who have sex with men. Retrieved from <http://bit.ly/1UMt0af>

↳ **Bean, J., et al. (1989).** Methods for the reduction of AIDS social anxiety and social stigma. *AIDS Education and Prevention*, 1(3), 194-221.

↳ **Stewart, K. E., et al. (1999).** Adolescents and HIV: Theory-based approaches to education of nurses. *Journal of advanced nursing*, 30(3), 687-696.

↳ **CATIE. (2013).** Its Different Now and Change HIVstory: A social marketing campaign. Retrieved from <http://bit.ly/1tt3TRU>

↳ **International Students Union of Norway. (2010).** Minutes of the national assembly at NTNU at Trondheim, October 15-17. Retrieved from <http://bit.ly/1WLZ4P2> (PDF)

## C Silence & Taboo

Themes of silence and taboo came up frequently. In these contexts, HIV stigma was either framed as something pressing PLWH to conceal their condition from others or something that prevented people from discussing HIV in an open, honest way. We found that such themes often came up in relation to social institutions like the family, the school, and the local community. Krauss et al. (2006)'s study on parental training in reducing HIV stigma amongst children found that silence could be attributed to a fear of interactional awkwardness for those who feel unequipped to engage in dialogues about HIV. In these scenarios, stigma made discussions of safe sex and risk-reduction challenging. We also found one book designed for secondary school teachers and administrators that documented some of the challenges of living with HIV from the perspectives of schoolchildren (Jones, 2006).

**Jones, R. (2006).** Living with HIV/AIDS: Students tell their stories of stigma, courage, and resilience. Washington, D.C.: National School Boards Association.

We could also see how the silence surrounding HIV may lead people to make incorrect assumptions about a sexual partner's status or discourage disclosure. In Canada, ACCHO's (2013) work on HIV stigma among African, Caribbean and Black communities in Ontario suggested that feelings of shame often made it difficult for PLWH to be open about their status, while the Kaiser Family Foundation's Speak Out campaign (<http://greaterthan.org/campaigns/speak-out>) was specifically designed to encourage gay and bisexual men to address stigma by talking with each other about HIV.

We found a few examples of community theatre efforts that centred around this theme. In Australia, productions like *The Haunting* featured older gay men living with HIV discussing their experiences while *Fathers & Feathers* was a solo performance documenting the playwright's personal experiences disclosing his status to his father and finding his acceptance as a "wayward son" (Woodward, 2014). Efforts that defined HIV stigma in this way often overlapped with other definitions, but that they also tended to emphasize group and institutional processes beyond individual-level behaviour change.

Keep It Alive campaign. Courtesy of ACCHO.

## D Barrier to care

Some of our findings suggested that HIV stigma negatively affected people's health. For PLWH, HIV stigma was frequently cited as a barrier to support, counselling, treatment access, medication adherence, and disclosure of status. For example, Rounds et al. (1995) found that HIV stigma often deterred PLWH from attending support groups (p. 442). As for seronegative people, it was most commonly listed as a barrier to testing (Regional HIV/AIDS Connection, 2011; Little, 2010). Efforts in this area tended to focus on the behaviours, attitudes, and values of care providers rather than populations themselves.

In the peer-reviewed literature, Gerbert et al. (1988) found that dentists who did not receive HIV education were less willing to attend to PLWH's dental concerns than those who did. In his study of physical therapy students, Held (1993) found that those who received an AIDS education unit reported a greater willingness to treat and provide quality care to PLWH. In the grey literature, we found that efforts were often located at the regional, provincial, or national level, with Australia's Queensland Association for Healthy Communities (2012), Nova Scotia's Advisory Commission on HIV/AIDS (2004), and the Public Health Agency of Canada (2012) working to address stigma through regulations, guidelines, and policies.

▣ **Rounds, K. A. et al. (1995).** Evaluation of telephone support groups for persons with HIV disease. *Research on Social Work Practice*, 5 (4), 442-459.

▣ **Regional HIV/AIDS Connection. (2011).** Are you doin' it? Testing week 2010 final evaluation and report. Retrieved from <http://bit.ly/28A4mky> (PDF)

▣ **Gerbert, B. et al. (1988).** Changing dentists' knowledge, attitudes, and behaviors relating to AIDS: A controlled educational intervention. *Journal of the American Dentists Association*, 116, 851-854.

▣ **Held, S. L. (1993).** The effects of an AIDS education program on the knowledge and attitudes of a physical therapy class. *Physical Therapy*, 73, 156-164.

▣ **Queensland Association for Healthy Communities. (2012).** Annual Report, 2011-12. Retrieved from <http://bit.ly/21iZxXm> (PDF)

▣ **Nova Scotia Advisory Commission on AIDS & Collective Wisdom Solution. (2004).** Review of Nova Scotia's strategy on HIV/AIDS: Looking back & moving forward. Retrieved from <http://bit.ly/1U9NNaK> (PDF)

▣ **Public Health Agency of Canada. (2012).** HIV screening and testing guide. Retrieved from <http://bit.ly/1sD2p6r> (PDF)

## E Exacerbates stigma on those already stigmatized

A number of efforts emphasized the ways in which HIV stigma intensifies discrimination for people already marginalized on the basis of race/ethnicity, sexuality, gender, socio-economic status, and nationality. In the US, we found that such efforts often took place in churches serving the needs of African-Americans (Berkley-Patton et al., 2013; Pitkin Derosé et al., 2012), or in health settings where African-American and Latino groups often experienced marginalization at the hands of service providers (NASTAD, 2014).

In Canada, we found efforts focused on the compounding effects of HIV stigma on groups like gay, bisexual, and other men who have sex with men in addition to African, Black, and Caribbean communities (BC PHO, 2014; ACCHO, 2013; Lawson et al., 2006). This theme also was expressed by African communities living in the UK and Australia (Stackpool-Moore, 2007; AFAO, 2014), suggesting that HIV stigma reduction efforts must take into account how other factors such as racism, homophobia, poverty, and immigration status shape people's perceptions, fears, values, and actions vis-à-vis HIV stigma.

In this section, we have presented five common ways that stigma reduction efforts define HIV stigma. Although the emphasis on stigma as a negative attitude primarily affecting PLWH continues, we see that there are also a range of definitions and strategies that attempt to mitigate stigma at the level of fear/ignorance, silence/taboo, healthcare, and in terms of social change. In the next section, we will present findings from the perspective of individual, community, and structural-level interventions.

I am a friend, a student, and an activist.  
And I am living with HIV.

*Let's stop HIV together.™*

*-Damaris*



Damaris (right) has lived with HIV since 1991.

**Get the facts. Get tested. Get involved.**

[www.cdc.gov/ActAgainstAIDS](http://www.cdc.gov/ActAgainstAIDS)



Let's Stop HIV Together campaign poster (CDC, 2016).

# Level of Intervention

## 5.1 Individual

Individual-level interventions are designed to challenge HIV stigma by focusing on attitudes, values, and beliefs. Often, they include an educational component designed to either disseminate knowledge or skills to help reduce HIV stigma. We included interventions which not only targeted groups most likely to be affected by HIV, but their care providers as well (Held, 1993).

In the peer-reviewed literature, we found a number of studies designed to reduce HIV stigma among students by exposing to them to education materials, films, local events, testimonials, recorded interviews, guest lectures, interactions with people living with HIV and skills-building activities (see Batson et al., 1997; Bean et al., 1989; Deutsch, 2007; Held, 1993; Maierson et al., 1996; Markham et al., 2000; Merakou & Kourea-Kremastinou 2006; Paxton 2002). Another popular target for individual-level intervention were mothers and pregnant women. In two studies, researchers found that direct educational and interactional efforts helped increase individual mothers' HIV knowledge, increase their willingness to test, and decreased stigma (Ashworth et al., 1994; Simpson et al., 1998).

We found that individual-level approaches often worked to enhance information regarding HIV or promote testing. In the grey literature, we found targeted interventions for at-risk communities in the US, with AltaMed Health Services Corporation's Sin Verguenza telenovela for Latinos (Sanchez et al., 2013) and a 5-session risk-reduction curriculum designed for at-risk Latino youth (Blanco et al., 2008) as examples. In Canada, this often appeared in the form of campaigns. COCQ-SIDA's Signets (2008) campaign distributed information about HIV stigma to French-speaking ethno-cultural communities in Québec while and Ontario's Are You Doin' It? (2011) campaign emphasized testing.



Le VIH ne discrimine pas, seuls les gens le font. Notre attitude fait toute la différence.

Signets (COCQ-SIDA, 2008).

We also found a number of campaigns designed to address negative attitudes, fear, and ignorance among members of the general public. Canadian HIV/AIDS Awareness Week's 'Anytime. Anywhere. Anyone. HIV/AIDS does not discriminate' campaign coincided with World AIDS Day (Health Canada, 2003), as did the Tumblr campaign #CHANGETHEFACE World AIDS Day ([changetheface.tumblr.com](http://changetheface.tumblr.com)). A number of national and regional health bodies also designed such

# 5

▣ **Batson, C.D. et al. (1997).** Empathy and attitudes: Can feeling for a member of a stigmatized group improve feelings toward the group? *Journal of Personality and Social Psychology*, 72, 105-118.

▣ **Maierson, M.J. et al. (1996).** Children's perception of peers with AIDS: Assessing the impact of contagion information, perceived similarity, and illness conceptualization. *Pediatric Psychology*, 21(3), 321-333.

▣ **Markham, C. et al. (2000).** Impact of HIV-positive speakers in a multi-component, school-based HIV/STD prevention program for inner-city adolescents. *AIDS Education and Prevention*, 12(5), 442-454.

▣ **Merakou, K., & Kourea-Kremastinou, J. (2006).** Peer education in HIV prevention: an evaluation in schools. *The European Journal of Public Health*, 16(2), 128-132.

▣ **Paxton, S. (2002).** The impact of utilizing HIV-positive speakers in AIDS education. *AIDS Education and Prevention*, 14(4), 282.

▣ **Sanchez, N. et al. (2013).** Telenovelas' impact on the public health arena and implications for public health messaging and sustainability. Retrieved from <http://bit.ly/1UPneii>

▣ **Blanco, E. et al. (2008).** Evaluation of an HIV prevention and HIV-stigma reduction behavioral intervention in a population of high risk Latino youth. Retrieved from <http://bit.ly/1Yoj7Te>

▣ **COCQ-SIDA. (2008).** Signets. <http://bit.ly/1PYVuyR>

▣ **Health Canada. (2003).** Looking forward, focusing the response: Canada's report on HIV/AIDS 2003. Retrieved from <http://bit.ly/25TURHW>

↳ **Trenwith, L. (2012).** Positive Directions pilot program. Retrieved from <http://bit.ly/21j0ka7>

↳ **Ware, K.B. (2014).** Promotion of stigma reduction and linkage to care in persons living with HIV/AIDS (PLWHA). Retrieved from <http://bit.ly/1WNxYqR> (PDF)

↳ **Sadowsky, D., & Kunzel, D. (1992).** Measuring dentists' willingness to treat HIV-positive patients. *Journal of the American Dental Association*, 125, 705-710.

↳ **Sowell, R., Seals, G., Wilson, B., & Robinson, C. (1998).** Evaluation of an HIV/AIDS continuing education program. *Journal of Continuing Education in Nursing*, 29(2), 85-93.

↳ **Zachariah, Gary S.** "AIDS Fear in Health Care Workers: The Development of an Educational Program to Decrease the Fear." Order No. 9926078 Spalding University, 1999. Ann Arbor: ProQuest. Web. 11 June 2016.

↳ **House of Lords. (2011).** Select committee on HIV and AIDS in the United Kingdom- Written evidence. Retrieved from <http://bit.ly/1Yn3IHV> (PDF)

efforts. Notable examples include Ireland's Stamp Out Stigma (Crawley, 2009) national campaign, the US CDC's Let's Stop HIV Together (<http://cdc.gov/features/LetsStopHIV>), and the Florida Department of Public Health's We Make the Change: Faces of HIV (<http://stopthespread.com>).

Given the ways in which HIV stigma in healthcare disproportionately affects people living with HIV (PLWH), we were surprised to find few individual-level interventions for them or their health providers. Notable exceptions for PLWH included Australia's Positive Directions volunteer buddy program (2012), UK's *www.T-Cell.Org.UK* (2011) website, and support for Black women living with HIV in the US (Rao et al., 2011).

We found fourteen interventions involving providers: seven in the US (Alabama Department of Public Health, 2013; NASTAD, 2014; Ware, 2014; Sadowsky & Kunzel 1992; Gerbert et al., 1998; Sowell et al., 1998; Zachariah 1998), three in Canada (deBruyn, 2004; Nova Scotia Advisory Council, 2004; PHAC, 2012), three in the UK (House of Lords, 2011; Stewart, 1999), and one in Australia (AFAO, 2013).

Although these examples suggest that there is acknowledgement that provider stigma is an important issue, the comparatively low number of interventions in this area suggests that more exploration could be done.

## 5.2 Community

Community-level interventions are designed to promote change by appealing to one's sense of collective identity as well as their norms and values. We found a number of interventions designed for racial and ethnic minority communities. In Australia, a range of interventions have been developed for African-Australians and subpopulations such as women and youth (AFAO, 2013). In the US, we also found a few community-level interventions designed for Latino and Asian-American populations (Little, 2010; Rios-Ellis et al., 2015). Typically, these interventions were not exclusively focused on reducing HIV stigma so much as integrating anti-stigma messaging into broader community services and programs.

Given that a number of ethno-cultural communities have a religious focus, we also found a number of community-level interventions aimed at mobilizing religious leaders or people of faith attending events in both Australia and the US (AFAO, 2013; Prince George's Healthcare Action Coalition, 2014; Berkley-Patton et al., 2013; Martinez, 2013).

Our Canadian sample listed three examples of community-level efforts designed for African, Caribbean, and Black populations in Ontario: The Ontario HIV/AIDS Strategy for African, Caribbean and Black communities (ACCHO, 2013), the Keep It Alive campaign (Shimeles et al., 2012) and a study of experiences of HIV stigma and discrimination among members of these communities (Lawson et al., 2006).

In the UK, there was a strong emphasis on specific neighbourhoods. Terrence Higgins' Trust's Changing Perspectives campaign (Elam, 2003) and its' Awaredressers initiative (Prost et al., 2006) relied on both images of change and mobilizing community champions (in this case, local hairdressers and barbers) to promote their campaign. One initiative for minority gay men was Barnet PCT's "Club Afreaka" intervention, which created a nightclub-like atmosphere aimed for young African men who have sex with men (ibid.).

↳ **Little, S. (2010).** Considering the impact of stigma on HIV prevention in relationship to the National HIV/AIDS strategy. Retrieved from <http://1.usa.gov/1tqt05p> (PDF)

↳ **Prince George's Healthcare Action Coalition. (2014).** HIV & STI work group 2013 outcomes report. Retrieved from <http://bit.ly/29Vc4k3> (PDF)

↳ **Elam, G. (2003).** Perspectives on Terrence Higgins Trust's HIV prejudice and discrimination poster campaign: Views of Barnet residents, African business owners and their customers. Retrieved from <http://bit.ly/1tw1MME> (PDF)

↳ **Prost, A. et al. (2006).** A review of research among Black African communities affected by HIV in the UK and Europe. Retrieved from <http://bit.ly/1tw0XUe> (PDF)

Two particularly notable community interventions were CAMBA's HIV stigma project, a combination of a theatre troupe and social marketing campaign designed for African-American, Afro-Caribbean, and Latino men and women between ages 25-45 living in high HIV prevalence Brooklyn neighbourhoods (Musgrave, 2012). The second was Live Consortium's Stigma Stops with You campaign and anti-stigma day designed for college students attending a historically Black university in the Southern United States (Locke et al., 2014). We found these interesting because they paired both campaigns with events to encourage greater community participation. Notably, we found one HIV stigma reduction intervention for MSM of colour, those living with HIV, and transgender women from New York's Gay Men's Health Crisis (Little, 2010). We also found a few interventions designed specifically for Aboriginal/Indigenous populations, such as Oregon's Project Red Talon's Native. LGBTQ. Proud campaign (2013) and CAAN's efforts to develop policies among communities, organizations, and businesses to better support the needs of Aboriginal and Indigenous peoples living with HIV (2005).

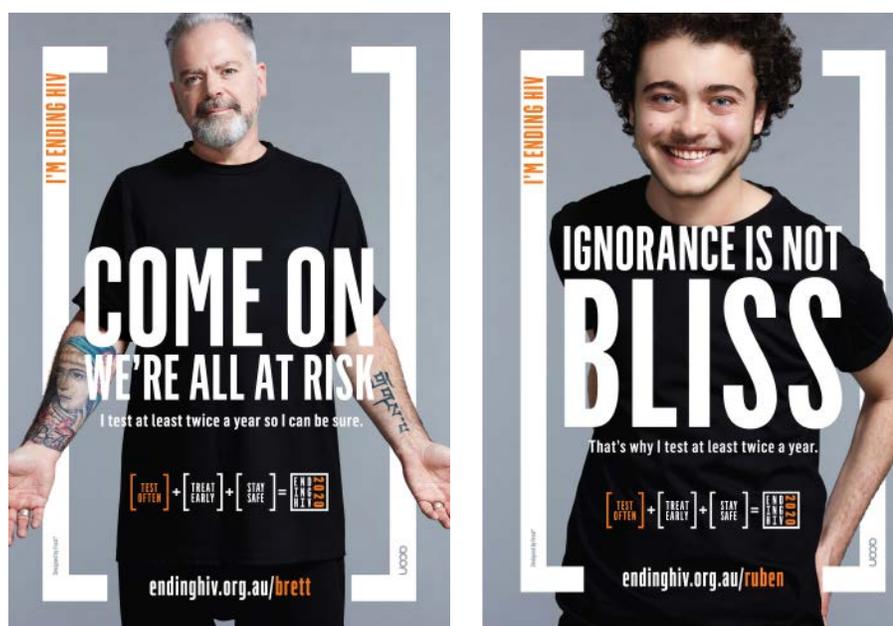
Comparatively, in our sample we found few community-level interventions designed for women. Notable exceptions were programs designed to support women living with HIV and culturally and linguistically diverse women in Australia (AFAO, 2013), a photovoice intervention and a workshop for US women of colour living with HIV (Brown & Davytan, 2013; Alabama Department of Public Health, 2013), and Gay Men's Health Crisis' program for transgender women (Little, 2010).

We also found few community-level interventions designed specifically for youth. In Australia, we found efforts to develop an HIV conference for African communities as well as the Centre for Culture Ethnicity and Health's (CEH) Hip Hop & Health intervention, a community-level educational effort attempting to educate young people about HIV prevention and destigmatize it for them (AFAO, 2013). In the US, we found two interventions that targeted youth centres and adolescents respectively (Bellingham & Gilles, 1993; Krauss et al., 2006). By utilizing community programs and parental support, these efforts fortify a sense of empathy among younger generations, in attempts to creating stronger and more accepting school and familial communities.

We did, however, find a number of community-level campaigns online. ACON's Ending HIV (<http://endinghiv.org.au>), Better World Advertising's HIV Stops with Me (<http://hivstopswithme.org>), and Rise Up to HIV/No Shame About being HIV+ (<http://riseuptohiv.org>) are examples. We also found that many of these campaigns worked alongside efforts to challenge HIV stigma among gay men regardless of serostatus. In Australia, some notable campaigns by ASOs included Living Positive Victoria's ENUF (<http://enuf.org.au>), AFAO's Fear Less Live More (<http://fearlesslivemore.org.au>), Western Australia AIDS Council's One Campaign (<http://1community.org.au>) and HIV Foundation Queensland's E.N.D. HIV (<http://endhiv.org.au>).

Musgrave, G. (2012). Incorporating peer-led theater & social marketing into HIV services. 7th Annual Iris House Summit. Retrieved from <http://bit.ly/1Q4kh4A> (PDF)

Locke, E. et al. (2014). Reductions in HIV stigma as measured by social distance: Impact of a stigma reduction campaign in a historically black university. *International Journal of Social Science Studies*, (2(3): 117-122.



Ending HIV campaign poster. Courtesy of ACON.



Housing Works' Shower Selfie campaign (Jack Mackenroth, 2014).

📌 **Housing works. (2014).** HIV shower selfie challenge. Retrieved from <http://bit.ly/1WM3UvG>

perpetuate stigma. Housing Works' #weareallclean selfie campaign (2014) is one example, as is the Vancouver-based Health Initiative for Men's Think Before You Type (<http://thinkbeforeyoutype.ca>) awareness campaign to encourage app users to reconsider how voicing one's 'preferences' online can unintentionally stigmatize groups.

Regional and national campaigns included AIDS Bureau of Ontario's Be REAL campaign (Ross & Rynard, 2007), COCQ-SIDA's Stop Serophobia/Stop Serophobia (<http://stopserophobia.org>), CDC's Start Talking. Stop HIV (<http://cdc.gov/actagainstaids/campaigns/starttalking>) and Greater than AIDS' Speak Out campaign (<http://greaterthan.org/campaigns/speak-out/>). The Internet was a particularly well-used medium in this regard. Ontario's Gay Men's Sexual Health Alliance's HIVStigma.com was a community-level video intervention designed to address stigma among gay men (Adam et al., 2011), while a number of other campaigns encouraged audiences to reconsider how everyday language can

## 5.3 Structural

Structural interventions are designed to promote change at the level of code, policy and laws (Wohlfeiler, 2000). We found comparatively fewer interventions in this area, likely because structural interventions are ones that require time and often cannot be implemented by ASOs and CBOs alone. Nevertheless, they are important, and we found many interesting examples, namely at the level of media, public policy, education, and work.

Media is an important agent of socialization. Although negative and sensationalistic coverage about HIV can exacerbate stigma, it is also important to acknowledge the tireless efforts of individuals who have worked to educate media personnel on the social and scientific realities of living with HIV in the 21st century. British Columbia's Provincial Health Officer Review of Provincial Strategy encourages us to present media representations of the uphill challenges people living with HIV can sometimes face (2014), while Ireland's Stamp Out Stigma campaign (Crawley, 2009) worked specifically with media personnel. In the UK, groups like the National African HIV Prevention programme (NAHIP) created media kits to coincide with their World AIDS Day soccer-themed "Kick Out Stigma" campaign (House of Lords, 2011).

Some helpful resources in this area from the US include Positive Women's Network-USA's Five Things Media Makers Can Do NOW to Stand Up to HIV Stigma (2015) and the Kaiser Family Foundation's HIV/AIDS Reporting Manual (2012). Just as we can use media to promote campaign messages, so too can we use campaigns to challenge the HIV stigma we see in the news, on television, and online.

📌 **Positive Women's Network USA. (2015).** Five Things Media Makers Can Do NOW to Stand up to HIV Stigma. Retrieved from <http://bit.ly/1tnmVrP>

Public policy is another important avenue for structural interventions. Given the current legal landscape surrounding the criminalization of HIV non-disclosure, we found a number of efforts dedicated to challenging stigma in this manner. In the US, the Sero Project's (<http://seroproject.com>) HIV is not a crime is one example and so is the HRC's It's Time to End Bad HIV Laws (<http://hrc.org/pages/endpointlaws>).

In Canada, the activist group AIDS Action Now's Think Twice campaign (<http://thinktwice.hiv.com>) was a video social marketing initiative designed to discourage gay, bisexual, queer, and transgender men from reporting their partners to the police in the event of non-disclosure. There are also a number of resources, such as AFAO's HIV, Crime and the Law in Australia: Options for Policy Reform advocacy kit (Cameron, 2011) and AFAO's Australia, migration and HIV – an evolving policy landscape (Forbes & Frommer, 2013) which sought to reform criminalization and mandatory HIV testing for migrants.

We also found a few interventions designed to challenge HIV stigma at the educational level. In Scotland, both the government and HIV organizations have developed initiatives to educate students on the social and scientific realities of living with HIV, with the HIV charity Waverly Care's HIV Always Hear campaign as an example (<http://hivalwayshear.org>). These efforts attempt to intervene at the level of curricula and programming. In the US, we found more episodic efforts: Live Consortium's Stigma Stops with You campaign + anti-stigma day (Locke et al., 2013) was designed for a historically Black college campus in Texas, while a video-based intervention at Illinois Wesleyan University was designed to challenge HIV stigma using the trope of 'school spirit' (Deutsch, 2007).

We found only two examples of interventions designed for the workplace. The UN's Be Stigma Free campaign (<http://bestigmfree.org>) was part of a larger initiative by the UN to create workplace anti-discrimination policies, while the UK's Unite the Union Negotiator's pack on tackling HIV discrimination at work (2012) provides guidance for union negotiators to consider the effects of HIV stigma on workplace environments. Given that media, law, policy, school, and work are important environments where stigma can both manifest and be resisted, we think it is important that future efforts at least consider these venues as sites for intervention.



Think Twice Campaign (AIDS Action Now).

↳ Cameron, S. (2011). HIV, crime and the law in Australia: Options for policy reform. Retrieved from <http://bit.ly/239RGNr> (PDF)

↳ Forbes, L. & Frommer, M. (2013). Australia, migration and HIV—an evolving policy landscape. Retrieved from <http://bit.ly/1S5kiiQ> (PDF)

↳ United Nations. (2012). Stigma fuels HIV: A campaign for the UN workplace to address HIV-related stigma and discrimination. Retrieved from <http://bit.ly/21j79c9>

↳ Unite the union. (2012). Negotiator's pack on tackling HIV discrimination at work. Retrieved from <http://bit.ly/1Yn99kG> (PDF)

## 5.4 Multi-Level Interventions

Despite recommendations in the literature that stigma efforts be multi-level, we found relatively fewer examples. Six addressed stigma at all three levels and came from provincial or national bodies (de Bryun, 2004; BC PHO, 2014; Nova Scotia Advisory Commission on AIDS, 2004; ACCHO, 2013; Stutterheim, Bos & Schaalma, 2008; House of Lords, 2011). Seventeen addressed stigma at two levels: twelve targeted individuals and social structures, focusing primarily on testing and enhancing care for people living with HIV (CATIE, 2013; Crawley, 2009; AFAO, 2013; NASTAD, 2014; Ware, 2014; Alabama Department of Public Health, 2013; Bellingham & Gilles 1993; Gerbert et al., 1988; Sadowsky & Kunzel 1992; Stewart 1999; Sowell et al., 1998; Zachariah 1998). Four emphasized communities and structures, focusing on the ways in which HIV laws disproportionately affect marginalized communities (Chinouya et al., 2014; Stackpool-Moore, 2007; Prentice & CAAN, 2005; AIDS Action Now, 2014). Three focused on individuals and communities, often emphasizing testing and culturally-specific educational efforts (House of Lords, 2011; US DHHS, 2012; Krauss et al., 2006).

In this section, we described HIV stigma reduction efforts that take place at the individual, community, and structural level. We found that most efforts targeted individuals in terms of education, awareness, and testing. Community-level interventions often focused on changing the values and norms of groups disproportionately affected by HIV as well as finding ways to empower them. We found a number of campaigns at this level. Despite the importance, we found comparatively fewer structural and multi-level interventions. In the next section, we will describe the common populations whom HIV stigma reduction interventions are designed for.

Alabama Department of Public Health. (2013). Addressing stigma related to HIV and other sexually transmitted infections. Retrieved from <http://bit.ly/1Uz7uTM> (PDF)

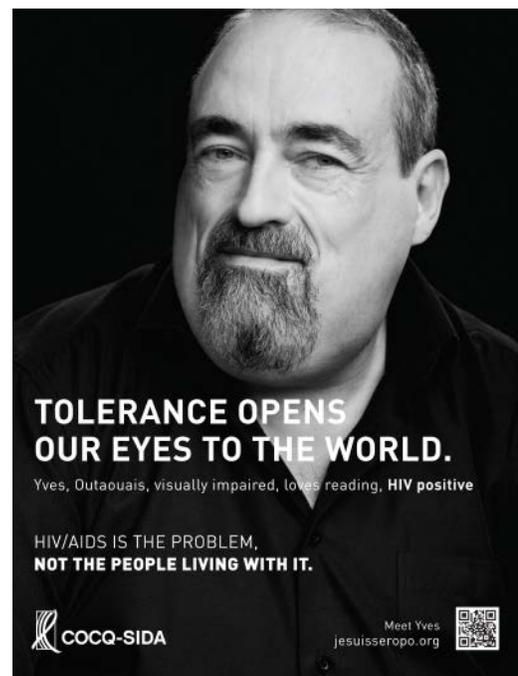
Bellingham, K., & Gilles, P. (1993). Evaluation of an AIDS education programme for young adults. *Journal of Epidemiology and Community Health*, 47, 134-138.

Chinouya, M.J. et al. (2014). Migrants and HIV stigma: Findings from the stigma index study. Retrieved from <http://bit.ly/1VZ81n5> (PDF)

US Department of Health and Human Services. (2013). National HIV/AIDS strategy: Implementation progress report. Retrieved from <http://1.usa.gov/1VW5ZUG> (PDF)



J'pense positif (COCQ-SIDA/Exosphère, 2015)..



Je suis séropo (COCQ-SIDA/Mobidic, 2011)..

# Populations

## 6.1 General

Campaigns aimed at the general population tended to focus on stigma at many levels and often used social media/Internet communication. We often found these in the form of national campaigns and policy documents. Campaigns targeted at members of the general population often focused on the theme that while “HIV/AIDS does not discriminate, people do” (Canberra Department of Health and Housing, 1993; COCQ-SIDA, 2007).

We also found campaigns designed to promote the notion of HIV as a manageable, chronic condition, with COCQ-SIDA’s *Elle/Il Vit avec le HIV/SIDA* (2006), *Je Suis Seropo* (<http://jesuisseropo.org>), *j’pense positif* (<http://pensepositif.org>) and STOP HIV’s *It’s Different Now* campaign (<http://itsdifferentnowbc.org>) as examples. And we also found efforts to normalize HIV and encourage members of the general public to resist stigma together, with campaigns such as: *Faces of HIV* (<http://stopthespread.com>), *The Stigma Project* (<http://thestigmaproject.org>), CDC’s *Let’s Stop HIV Together* (Deluca, 2012), *HIV Equal* (<http://hivequal.org>), and Ireland’s *Stamp Out Stigma* (Crawley, 2009).



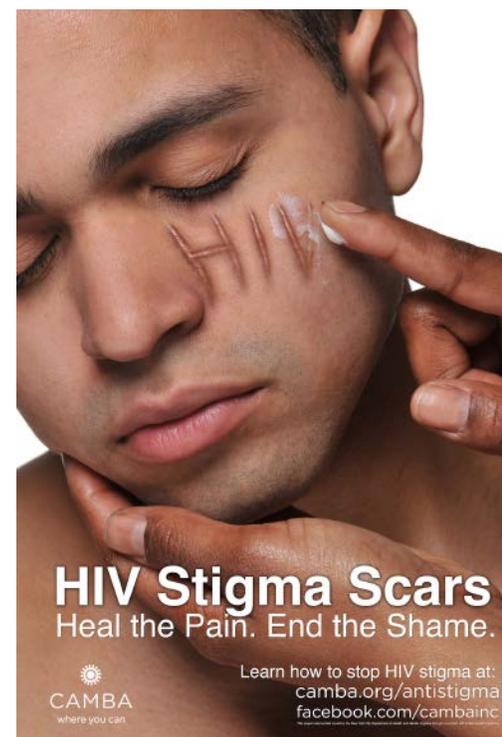
Department of Health, Housing, Local Government and Community Services, Australia. (1993). 1993 HIV/AIDS related discrimination education campaign: Evaluation report. Canberra: Commonwealth Dept. of Health, Housing, Local Government and Community Services.

COCQ-SIDA (2007). *Le discrimination est partout*. Retrieved from <http://bit.ly/1Ynbe01>

## 6.2 Ethno-Cultural Communities

Campaigns designed for ethno-cultural communities often addressed the cultural dimensions of HIV stigma and used the theme of community as a way to challenge it. ACCHO’s *Keep It Alive!* (2009) focused on Ontario’s African, Black, and Caribbean communities, while CAMBA’s *HIV Stigma Scars. Heal the Pain. End the Shame.* campaign (2012) used both community theatre and a social marketing campaign to mobilize neighbourhoods to fight stigma. We also found the theme of communities and neighbourhoods in Barnet PCT’s *Trusts’ Prejudice and Discrimination Awaressers* campaign, as well as Terrence Higgins Trust’s *Changing Perspectives* campaign (Stackpool-Moore, 2007) in the UK.

We also found a number of skills-building/educational interventions designed for ethno-cultural groups. Ten came from Australia, with all of them focusing on African-Australian or other culturally-and-linguistically-diverse (CALD) communities (AFAO, 2013). The majority of these interventions operated at the community-level, focusing on community/religious leaders, women, families, and youth. The interventions emphasized educating people about HIV transmission and promoting safer sex, while also supporting members of these communities living with HIV. Individual and structural level interventions in these areas emphasized providing special training for care providers serving these communities, or mobilizing peer educators.



HIV Stigma Scars bus shelter ad (CAMBA, 2012).

Thirteen skills-based/educational interventions came from the US. These mainly took place at the community level and focused on minority populations such as African-Americans and Latinos (Rucker & Gipson, 2007; Pitkin Derose, et al., 2012; Blanco et al., 2008; Little, 2012; Ware, 2014; Alabama Department of Public Health, 2013; Martinez, 2013; Krauss et al., 2006; Berkley-Patton et al., 2013; Rios-Ellis et al., 2015), with one intervention focusing specifically on Black and Latino gay men/MSM and their service providers (NASTAD, 2014).

↳ **NASTAD. (2014).** Addressing stigma: A blueprint for improving HIV/STD prevention and care outcomes for Black & Latino gay men. Retrieved from <http://bit.ly/1EkEnef>

↳ **Rao, D. et al. (2011).** Stigma reduction: Experiences and attitudes among Black women living with HIV. 139th APHA Conference. Retrieved from <http://bit.ly/1UjuJuv>

We also found some formative research that provided useful insights, particularly those focusing on the experience of living with HIV for people of colour (Rao et al., 2011; Lawson et al., 2006; Brown & Davtyan, 2013). Such efforts often used focus groups and were in the service of either developing a campaign or designing strategies to support the needs of people living with HIV.

Although we found that many contemporary interventions have an online presence, we did not find many that used media as a way to deliver an intervention. Some exceptions were the use of CD-ROMs to deliver HIV information to culturally and linguistically-diverse women in Australia as well as an Ethiopian community radio program organized by Perth Ethiopian Radio and the Western Australian AIDS Council (AFAO, 2013).

In the grey literature, we also found that events were used as a way to resist HIV stigma. Events can help organizers celebrate campaign successes, provide opportunities for people to meet like-minded people, and establish a venue where interventions can be implemented. We found 10 examples. In Australia, we found examples of engaging African-Australian groups in forums, conferences, festivals and even sporting events (AFAO, 2013). In the US, we found an anti-HIV stigma day at a historically Black college (Locke, 2013) as well as a forum and prayer breakfast in a predominantly African-American community in Maryland (Prince George Action Coalition, 2014). For young men of colour who have sex with men, the only example in our sample was a nightclub intervention called Club Afreaka—designed specifically for young African men who have sex with men in the UK (Prost et al., 2006).

## 6.3 MSM

Campaigns designed for gay men focused on challenging stigma within the community. Often, they did so by emphasizing HIV stigma as promoting silence and shame that makes disclosure difficult. HIV stigma.com tells about the experience of stigma from the perspective of seropositive men (Adam et al., 2011). AFAO's Fear Less Live More campaign addressed the ways in which HIV stigma reinforces homophobia and presented positive images of serodiscordant couples (Donohoe & Tart, 2012). We found similar themes in COCQ-SIDA's Stop Serophobia (2009), which represents the experience of rejection after disclosure. The theme of the closet was also present in Greater than AIDS' Speak Out: Let's Bring HIV Out of the Closet (2013). Such efforts remind us that HIV stigma is not only a felt or enacted experience at the hands of dominant groups but can also divide communities internally.

We also found a few examples of aesthetic interventions designed either by or for gay men. One historic example is the AIDS Memorial quilt, where in the late 1980s families and loved ones began memorializing the deceased with custom quilt patches (Singhal & Rogers, 1993). We also found that events like AIDS conferences were sites where HIV stigma was examined through art.

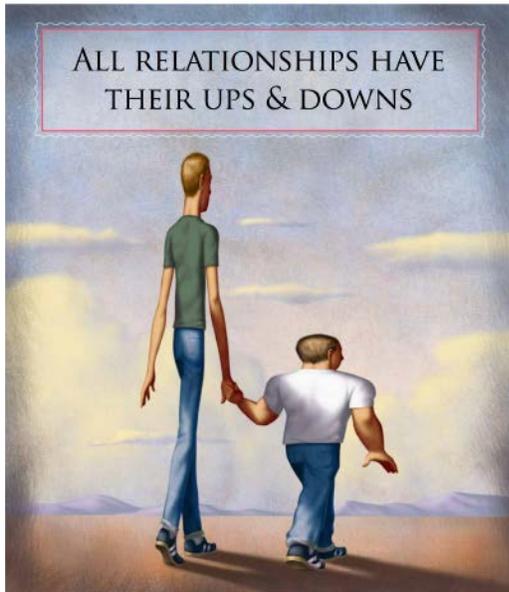
↳ **Singhal, A., & Rogers, E. M. (2003).** Combating AIDS: Communication strategies in action. Thousand Oaks, Calif.: Sage Pub.

Installations like GL RY used the metaphor of the glory hole to encourage people to talk about living with HIV; Bedding explored the experience of a new diagnosis with pieces of bed small enough to fit through glory hole (Symons, 2014).

↳ Symons, G. (2014). GL RY: Adventures in public art, HIV discourse and queer aesthetics. *HIV Australia*, 12(3): 27-30. Retrieved from <http://bit.ly/10mrkFa> (PDF)



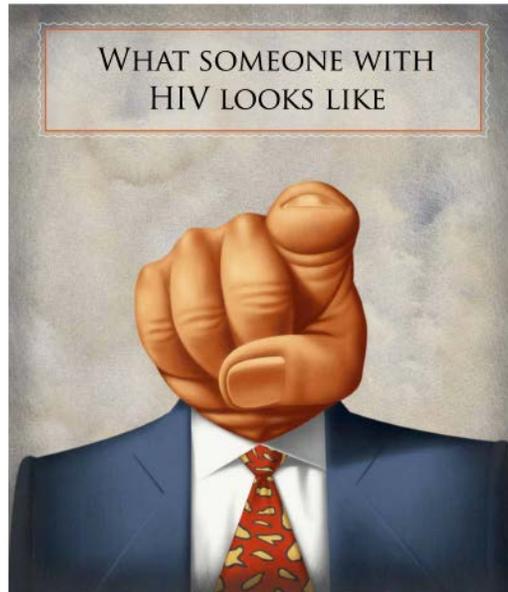
GL RY3 - A kiss through the GL RY-box helmet. (Left), GL RY1 - Bedding installation: half-way there. (Right)  
Reprinted from *HIV Australia*, published by the Australian Federation of AIDS Organisations.



Lots of positive and negative men are in relationships together - over half of positive men are in relationships with negative guys. They argue and they make up but their status usually isn't the issue - unlike the toothpaste or the snoring!

[www.FEARLESSLIVEMORE.org.au](http://www.FEARLESSLIVEMORE.org.au)

Produced by the Australian Federation of AIDS Organisations and the National Association of People Living with HIV/AIDS



You can't tell by looking - men of all types get HIV and most remain very healthy. Don't worry, lots of positive and negative men have great sex together without passing on any viruses - they simply use condoms or act safely.

[www.FEARLESSLIVEMORE.org.au](http://www.FEARLESSLIVEMORE.org.au)

Produced by the Australian Federation of AIDS Organisations and the National Association of People Living with HIV/AIDS



Fear Less, Live More campaign posters (Australian Federation of AIDS Organisations, 2011). Copyright Jim Tsinganos..

We also included recommendations or suggestions for campaigns. This included recommendations on designing campaigns for gay men that take into account the different campaign needs of people according to serostatus (Reeders, 2007), best practices for campaigns targeting gay men (Stutterheim et al., Bos & Schaalma, 2008), and formative research that provided useful insights with specific attention to the experiences of gay men (Parr et al., 2009).

## 6.4 LGBTQ2S

Although we found a number of efforts designed for gay men, we also identified efforts that spoke to LGBTQ2S communities more broadly. Oregon’s Project Red Talon’s Native. LGBTQ. Proud. was a campaign designed specifically to empower Native American youth to take pride in their identities (<http://ihs.gov/hiv/AIDS/mediacampaigns>). HRC’s Its Time to End Bad HIV Laws (2016) spoke directly to LGBT communities about the stigmatizing effects of punitive HIV laws in the US. In Australia, the One Campaign—a revival of a previous HIV stigma campaign—focused on the theme of unity to encourage publics to challenge stigma and adopt safe sex practices (<http://1community.org.au>). Given the variety of ways in which gender and sexual minorities define themselves, thinking about how to appeal to diverse sets of audiences may be instructive.

## 6.5 People Living with HIV

Many of the campaigns we examined for people living with HIV tended to focus on their experiences of discrimination and how to empower them to take control of their health. Better World Agency’s HIV Stops with Me (Ontario AIDS Bureau, 2006) was a campaign designed to encourage seropositive gay men to reduce their risk of transmission. Although this was an attempt to promote positive representations of people living with HIV, there was also some resistance to the notion that HIV prevention is solely the responsibility of people living with HIV.

By comparison, the support services we found were designed mainly for communities of colour living with HIV. We found that formative research was important here, and reflects the premise that the needs and experiences of people living with HIV should be placed at the centre. We found focus groups designed for African-American women living with HIV (Rao et al. 2011), Black, Caribbean, and African populations in Ontario dealing with HIV stigma (Lawson et al., 2006), and a Photovoice intervention where seropositive women of colour in the US were given cameras to document their experiences living with stigma (Brown & Davytan, 2013).

✦ Brown, B. & Davytan, M. (2013). Implications of HIV-stigma on health: From local to global. Southern California Sexual Health Collaborative. Retrieved from <http://bit.ly/1rpJxqr> (PDF)

## 6.6 Youth

We found a small number of interventions aimed at youth, although many of them incorporated stigma messaging as part of a larger program. In Australia, PEACE Multicultural Services' African Communities HIV Conference and the Centre for Culture Ethnicity and Health's (CEH) Hip Hop & Health intervention aimed to engage African-Australian youth in broader community initiatives (AFAO, 2013). In the US, we found a 5-session risk-reduction curriculum for at-risk Latino youth in San Diego (Blanco et al., 2008), a parent-child educational intervention for residents of a high-prevalence New York City neighbourhood (Krauss et al., 2006), and a motion-comic intervention for adolescent men who have sex with men in the state of Georgia (Nichols, 2013).

In the UK, Bellingham & Gilles' (1993) intervention featured an AIDS education program designed for youth aged between 16-19. The only other intervention designed specifically for young gay men was the Club Afreaka intervention, which was also in the UK (Prost et al., 2006).

## 6.7 Women

As mentioned previously, we found comparatively fewer interventions designed specifically for women. We found two examples in the scholarly literature, both of which targeted mothers and pregnant women. Ashworth et al.'s (1994) intervention targeted mothers as part of a Women, Infants, and Children (WIC) program, and sought to reduce stigma by comparing the effectiveness of written material, nurse-educated, and videotape-educated interventions. They found that nurse-educated and videotape-educated mothers demonstrated enhanced HIV knowledge and that the intervention had positive influences on their attitudes and behavioral intent. In a study of pregnant Scottish women, Simpson et al. (1998) examined whether or not certain methods of delivery affected their attitudes towards HIV testing.

In the grey literature, we found that most efforts designed for women involved skills-building or educational efforts and were gender-sensitive in design. For example, one African HIV-Positive Women's Group in Australia held separate meetings for women and then invited their children and families to attend workshops on the weekend (AFAO, 2013). We see this as a way to not only reduce the barriers for seropositive women to attend, but also to involve their families as part of the process. Women's empowerment was also a common theme. In Australia, the PEACE Multicultural Services & African Communities Leaders Advisory Forum (ACLAF) held a World AIDS Day Celebration in 2011 for women living with HIV (AFAO, 2013).

Notably, we found only one example of an HIV stigma intervention for transgender women. New York's Gay Men's Health Crisis has conducted an Anti-Stigma Awareness Program (ASAP), a social marketing campaign designed to meet their needs in addition to those of MSM of colour and MSM living with HIV. .

 Ashworth, C.S. et al. (1994). An experimental evaluation of an AIDS education intervention for WIC mothers. *AIDS Education Prevention*, 6(2), 154-162.

 Simpson, W. M. et al. (1998). Uptake and acceptability of HIV testing: A randomized controlled trial of different methods of offering the test. *BMJ*, 316: 262-267.

## 6.8 Aboriginal/Indigenous

We also found a few efforts designed for Aboriginal/Indigenous communities. In Australia, HIV Foundation Queensland's E.N.D. HIV (<http://endhiv.org.au>) was developed to engage Aboriginals and Torres Islanders, as well as health providers. Project Red Talon's Native. LGBTQ. Proud. was one campaign along a host of other efforts to conduct outreach with Native Americans/American Indians (<http://ihs.gov/hiv/aids/mediacampaigns>).

We also found three specific initiatives in Canada: Canadian Aboriginal AIDS Awareness Day Poster coinciding with 2002 World AIDS Day (Health Canada, 2003); its development of a manual to support the development of non-discrimination policies for Indigenous communities, businesses and community-based organizations (Prentice & CAAN, 2005); and formative research among 2-spirit First Nations men in Canada (Thoms, 2007). Although only one of these examples specifically targeted HIV stigma (Prentice & CAAN, 2005), the small number we found often emphasized changing attitudes and values at multiple levels.

In this section, we have surveyed a range of populations commonly served by HIV stigma reduction efforts. Efforts developed for ethnocultural communities often work toward mobilizing community leaders to deal with the multiple forms of discrimination members of these communities experience. Those developed for gay, bisexual, queer, and transgender men often emphasize campaigns that tie HIV stigma to homophobia and signal the ways both can work together to promote silence and shame. Efforts designed for people living with HIV tend to emphasize service and support, helping individuals dealing with stigma to find community. We found comparatively fewer examples of efforts developed for LGBTQ populations more broadly, women, youth, and Aboriginal/Indigenous groups. In the next section, we will describe some of the ways stigma reduction efforts have used the web or social media.



Native. LGBTQ. Proud. campaign poster (Project Red Talon, 2013).

# Web/Social Media

In the grey literature, we found 49 examples of stigma reduction efforts that used the web or social media. Often, the Internet was used as a site to host a campaign (through a website), share resources, or use social media to prompt a call to action. Many of the campaigns we looked at also used hashtags as a way to brand their efforts (Vanguardist Magazine, 2015) and encourage audiences to share their message with their networks.

The goal of many of these interventions appeared to be to use online communication to promote discussion among users and audiences regarding HIV stigma: Greater Than AIDS' Speak Out; Globally Aware's Positively Fabulous mannequin intervention (O'Keefe, 2012); AFAO's Fear Less Live More; the CDC's Start Talking, Stop HIV campaign; and Quebec's COCQ-SIDA's Je Suis Seropo (<http://jesuisseropo.org>).

We also found that a number of efforts made use of photo and video-sharing platforms, either to distribute content or encourage audiences to contribute as a mode of interactivity—with Australia's One Campaign (Toussaint, 2014), UK's Waverly Care's Always Hear (<http://alwayshear.org>), Housing Works' #weareallclean selfie campaign, and the HRC's It's Time to End Bad HIV Laws as examples.

Some more recent interventions made extensive use of social media memes to both share information and create buzz. The US-based campaigns HIV Equal (<http://hivequal.org>) and The Stigma Project (<http://thestigma-project.org>) are examples: they often share and create images used to raise awareness about the realities of living with HIV today and use eye-catching visuals that resonate with a younger web audience. We also saw that some campaigns made use of other social media platforms—Facebook, Twitter, and Tumblr not only share campaign messages but also collect media coverage about campaigns and keep audiences informed of developments.

Although there are no hard and fast rules for using the Internet and social media to resist stigma, there are some lessons people have learned along the way. AFAO staff who administered the Fear Less Live More campaign site reported that although they monitored comments, they took a 'handsoff approach' as much as possible. This allowed users the space to debate issues themselves and operate as a 'self-correcting' community (Queensland Association for Healthy Communities, 2012). They found that social media was effective at both encouraging and supporting gay men living with HIV, as well as supporting the existing resilience of HIV-positive gay men around issues of stigma and discrimination (ibid.).



↳ Vanguardist Magazine. (2015). HIV Heroes Edition, 52. Retrieved from <http://bit.ly/1XUtr6R>

↳ O'Keefe, F. (2012). Positively fabulous: the art of raising awareness and A1:AZ152 women's lives. HIV Australia, 12(3). 23-26. Retrieved from <http://bit.ly/10mrkFa> (PDF)

↳ Toussaint, N. (2012, March 20). One community campaign. Retrieved from <http://bit.ly/25UXkYW>

↳ Queensland Association for Healthy Communities. (2012). Annual Report, 2011-12. Retrieved from <http://bit.ly/21iZxXm> (PDF)

# 8

## Lessons Learned

In this section, we share some of the lessons planners have learned through HIV stigma reduction interventions—mainly in terms of representation, audience, and resource demands.

Representation is a delicate balance. On one hand, we want to use powerful images that resonate with publics and encourage conversation. And yet, it is important to ensure that such images and representations are respectful (Thoms, 2007). Based on focus groups of HIV prevention posters conducted with Two-spirit men in Canada, Thoms found that participants rejected images of “clean-cut” people who did not seem sincere. Images of elders often resonated with them, as did family images and themes of rejection.

Although earlier we had mentioned that places of worship can be useful in promoting anti-stigma messages in certain ethno-cultural communities, this report suggests that religion may not be appropriate for every audience. Further, Thoms also found that overtly sexualized images alienated some of his focus group participants. Although we think that campaigns geared at sexual minorities should affirm their identities in creative and sex-positive ways, we interpret this to mean that campaigns should emphasize a variety of ways people express and explore their sexuality.

A number of campaigns stressed the need to consider the intended audience. Although it is important to ensure messages resonate with target groups, we may wish to consider the ‘second audience’ and how they may respond to messaging (Symons, 2014). Symons found that although aesthetics-based interventions resonated well with gay men at AIDS 2014, non-gay men were only able to identify once they saw women’s stories represented. And even in the case of campaigns designed for men who have sex with men, practitioners may wish to consider groups traditionally underrepresented.

In the Gay Men’s Be REAL campaign, for example, Ross and Rynard (2007) found that messages were not sufficiently targeted and also excluded some groups like male sex workers. Given the complexity of identities, it may not be possible to develop a message that will speak to everyone equally. And yet, involving a diverse range of perspectives in the planning process may help identify omissions or gaps early on.

Much of the literature also stressed the importance of tailoring HIV stigma messages for contemporary audiences. Crips (2015) recommended a need to continue to include information about transmission along with anti-stigma messages. NAHIP suggests that measures to tackle stigma need to balance normalisation with accurate information about HIV—still recognizing the virus as lifelong, incurable, and focused on marginalised communities. Raising awareness of issues faced by people with HIV and increasing awareness of domestic violence faced by newly-diagnosed women and men who have sex with men may add a new dimension to stigma messaging (House of Lords, 2011).

Designers may also wish to prepare for audiences who interpret messages differently. Although ambiguous messaging can sometimes result in confusion, we also believe that people will read messages in various ways no matter how tailored and tested they are. In an evaluation of a 1993

↳ Crips. (2015). La prévention s’affiche: Lutter contra le sérophobie. Retrieved from: <http://bit.ly/1Z02P4A> (PDF)

anti-HIV/AIDS stigma campaign in Australia, evaluators found that audiences were split over the message: some read it as saying that anyone could be at risk of HIV; others read it as about discrimination (DHHLGCS, 1993). We found a similar trend today, as many publics continue to assume that all HIV messaging is about safe sex (Parr et al., 2009).

The issue of blame is also another important lesson. In their work with African, Caribbean, and Black communities in Ontario, ACCHO (2013) and Shimeles et al. (2012), found that stigma manifests in three ways: 1) through association (as a ‘gay disease’, as attached to promiscuity, as connoting death); 2) through resistance to having their communities associated with HIV, or HIV being viewed as a Black or African disease; and 3) through homophobia within the community (ACCHO, 2013; Shimeles et al., 2012; see also Elam, 2003).

Not surprisingly, a number of reports mentioned how much time and resources anti-stigma efforts require. This is particularly important to consider when it comes to testing promotion. In their church-based testing intervention, Pitkin Derose et al. (2012) found that factors like the size of membership, organizational structure, schedules, space availability, and culture/language often made it difficult to accommodate needs for confidentiality and proper test procedures when large numbers of people wanted to be tested at the same time.

National campaigns may also wish to consider the time it can take to ensure regional partners have received materials. When dealing with geographically remote communities, organizers may want to consider how shipping times may affect schedules (Health Canada, 2003). Those seeking to develop anti-stigma policies in their communities, workplaces, and businesses may wish to take into account how time-consuming the process of getting everyone to agree and approve such documents can be (Prentice & CAAN, 2005).

# 9

## Recommendations

Using the work of Stuart, Arboleda-Florez, and Sartorius (2009), we end with six recommendations for resisting stigma.

Stuart, H. Arboleda-Florez, J. & Sartorius, N. (2009). *Paradigms Lost: Fighting stigma and the lessons learned*. UK: Oxford University Press.

### 1

The first is to put people first—placing the experiences of people living with HIV at the centre of inquiry, design, and implementation of campaigns that create opportunities for community-based research. These collaborations provide the opportunity for advocates to identify specific areas to target and design more directed messages informed by real life experiences. Interventions that are identity-oriented also tend to resonate with their audience more and foster deeper levels of connection. They can also help promote leadership among people living with HIV to model resilient behaviours and act as role models in their communities (Fenoglio, 2014). Chinoya et al., (2014) recommend embedding anti-stigma messages in human rights approaches that may help strengthen the political urgency behind efforts to resist HIV stigma.

Fenoglio, P. (2014). Dimensions of HIV-related stigma: exploring stigma through artistic practice. *HIV Australia*, 12(3): 40-42. Retrieved from <http://bit.ly/10mrkFa> (PDF)

### 2

The second recommendation is to plan for sustainability by focusing on interventions that ensure a consistent renewal of advocates and resources. Although campaigns and programs designed to raise awareness, educate, and promote contact with people living with HIV show some promise, their episodic nature cannot guarantee long-term attitudinal and behavioral change. Many of the experimental studies examined in the peer-reviewed literature relied on pre- and post-test attitudinal measures, but few looked at longitudinal effects of these changes. This speaks to the difficulty in designing sustainable interventions.

From a campaign design perspective, it is recommended that groups borrow inspiration from others whenever possible (with permission of course) (USDHHS, 2012). The Ontario AIDS Bureau (2006) recommends creating reusable campaign messages with long-term durability, a tactic that was used in Australia's One Campaign updating itself for contemporary audiences (Toussaint, 2012). In their report on Ontario's gay men's Be REAL campaign, Ross and Rynard (2007) also recommend developing more long-term strategies that learn from marketing, reach out beyond traditional groups using new media, and enlist the expertise of media professionals.

To ensure sustainability, Ross and Rynard (2007) recommend that campaigns should coordinate with others, create events, and do multi-media promotion. Planners may also want to take into account that some participants in interventions may experience burn out, meaning that it is important to ensure there is adequate time and support in these cases (Musgrave, 2012).

# 3

The third recommendation is to focus on activities that change behaviours. In this case, we can emphasize traditional public health activities like HIV testing and risk-reduction, and we can also focus on changing attitudes, values, and beliefs about HIV and stigma. Making connections between factors leading to stigma and those that inhibit behaviours like condom use and testing is important, and messages should communicate that HIV stigma negatively affects the health of people regardless of serostatus (Reeders, 2007; O’Keefe, 2014). Finding ways to measure stigma and how it changes is helpful in this regard (O’Keefe, 2014).

At the level of culture, we can also think about changing attitudes through interventions that challenge stigma in online spaces (Reeders, 2007; Housing Works, 2014; Health Initiative for Men, 2015) and through representations that include positive images of people living with HIV and serodiscordant couples. Perhaps most important, however, is to find ways to address the challenge of disclosure—both in terms of developing ways to help people feel comfortable enough to ask about, and comfortable enough to disclose their status with prospective partners (Shimeles et al., 2012; McCullom, 2015).

↳ O’Keefe, F. (2014). ENUF Already: Stories of resilience told through artistic collaboration. *HIV Australia*, 12(3): 37-39. Retrieved from <http://bit.ly/10mrkFa> (PDF)

↳ McCullom, R. (2015). Stemming stigma. Getting to zero San Francisco. Retrieved from <http://bit.ly/1tu9JCa>

# 4

The fourth recommendation is to target activities to well-defined groups by ensuring that messages are tailored and culturally-appropriate. Planners may want to consider that audiences may have different health literacy skills, and represent a range of identities and languages (ACCHO, 2013; Shimeles et al., 2012; Regional HIV/AIDS Connection, 2011; AFAO, 2013).

In many of the efforts we examined, it became clear that campaigns need to acknowledge that the experience of HIV and stigma varies according to serostatus (Queensland Association for Healthy Communities, 2012; Parr et al., 2009). Those who worked on AFAO’s Fear Less Live More campaign observed that men living with HIV engaged with online content much more frequently than seronegative men (Queensland Association for Healthy Communities, 2012). Planners should also ensure that diverse groups are not only represented but actually get to participate in the process. And attention should be paid to intersectionality—HIV stigma may be one experience around which people can gather, but it is important to acknowledge the other structural factors people may be struggling with beyond serostatus (deBruyn, 2004; Lawson et al., 2006).

# 5

The fifth recommendation is to think big but start small—being realistic about short-term goals and celebrating small wins. Mobilizing allies can be helpful in this regard (Toussaint, 2012; Regional HIV/AIDS Connection, 2011; House of Lords, 2011). This can include members of the community, who can act as spokespeople (Lawson et al., 2006), community or religious leaders who are already active in supporting efforts (Little, 2010, Martinez, 2013; AFAO, 2013), and even celebrities who may resonate with target audiences (Crawley, 2009). Media can also be a useful ally when groups build relationships with journalists to give them an added interest in checking the accuracy and language of their stories (Stackpool-Moore, 2007). Healthcare providers, employers, and school administrators may also serve as campaign advocates at its early stages.

# 6

The sixth recommendation is to build better practices. Planners should be sure to document their progress and let mistakes, evaluations, and results find their way to decision-makers, to organizations, and into publications. Although a number of the campaigns we found in the grey literature were evaluated according to metrics like audience reach or outlets used, we found fewer examples of campaigns that were formally evaluated in terms of behavioural change. We also

think that learning from the past successes and challenges of prior campaigns is useful in this regard. When we consider online campaigns that have resonated with publics—the It Gets Better project (<http://itgetsbetter.org>), the Assumptions HIV prevention campaign for gay and bisexual men (<http://www.actoronto.org/assumptions>), or HIM’s It’s Hottest at the Start campaign regarding acute HIV infection (<http://checkhimout.ca/hottest>)—what are the lessons we can learn? What has worked in terms of social marketing (and now, social media), and where can we improve?

# Conclusion



In this report, we have examined some of the common and promising ways that researchers, practitioners, and community members have worked to resist HIV stigma. We began our report with an overview of the concept of HIV stigma, comparing the differences between individual, psychological definitions of stigma as a mark of difference (Goffman, 1963) to more sociological perspectives that situate it as a result of domination and structural inequities. Common strategies in this area ranged from educational, counselling, and contact theory to human rights approaches designed to disrupt the status quo.

Next, we presented a brief overview of our scoping review methodology (Arksey & O'Malley, 2005) and the results of our scholarly and grey literature search. We followed this with an overview of how various campaigns, policies, programs, and initiatives conceptualized stigma, ranging from traditional individual models to ones focused on how HIV stigma exacerbated other forms of discrimination and oppression. Next, we followed with an overview of interventions geared at the community, individual, and structural levels. We found that most interventions targeted communities and connected factors such as racism and homophobia to HIV stigma. Individual-level interventions often emphasized testing, risk-reduction, or general awareness. We found fewer examples of structural interventions, with the majority of them developed by regional and national health bodies.

Following this, we presented an overview of the most common communities whom interventions are designed for: ethno-cultural groups; gay, bisexual, trans, and queer men; people living with HIV; LGBTQ groups; Aboriginal/Indigenous communities; and women. Often such efforts came in the form of campaigns, although we also saw a number of more programmatic approaches developed for ethno-cultural groups. We also examined efforts to reduce HIV stigma using the web or social media, finding a number of interactive examples designed to reduce HIV stigma among gay men and members of the general public. We ended this report by outlining some of the lessons learned in terms of campaign representation, messaging, audience interpretation, and resources before borrowing from the work of Stuart, Arboleda-Florez, and Sartorius (2009) to make six recommendations.

So to answer our initial question: what are some of the most effective or promising ways to reduce HIV stigma? Our review suggests that effective interventions are multi-level, address the multiple social factors that underpin stigma, centre the experiences of affected communities, and mobilize champions.

To answer the question of what works in terms of reducing HIV stigma affecting young gay men?, we only found a handful of examples specifically designed for this group (Nichols, 2013; Prost et al., 2006). Although young gay men are ostensibly included in efforts designed for gay, bisexual, trans, and queer men, we think there is a need to acknowledge the way generational differences shape people's experience and understanding of HIV stigma.

For our final research question—How can social media be used to reduce HIV stigma?—we found that social media remains a useful platform to encourage dialogue, raise awareness, and encourage publics to rethink how stigma is embedded in everyday language and acts.

To conclude, our scoping review has demonstrated that both HIV and HIV stigma are biosocial phenomena that are highly dynamic and have evolved over time. Although changes in medicine have improved outcomes for people living with HIV in many ways, HIV stigma remains firmly embedded in individual consciousness, in institutions such as the law, media, medicine, school, and work, and even within the structures of society.

Our review of campaigns suggests some promising approaches, however, long-term evidence of what ‘works’ remains elusive. It is our hope that this overview acts as a roadmap that can help inform the development of future campaigns and efforts to ensure that we can all get there together.

# Recommended Readings

**ACCHO. (2013).** Ontario HIV/AIDS strategy for African, Caribbean and Black communities 2013-2018. Retrieved from [http://accho.ca/portals/3/documents/resources/acb\\_strategy\\_web\\_oct2013\\_en.pdf](http://accho.ca/portals/3/documents/resources/acb_strategy_web_oct2013_en.pdf)

**Adam, B. D. et al. (2011).** HIVstigma.com, an innovative web-supported stigma reduction intervention for gay and bisexual men. *Health Education Research*, 26(5), 795-807.

**AFAO. (2013).** African Australian communities and HIV: Mapping HIV health promotion programs. Retrieved from [http://afao.org.au/library/topic/women/Mapping\\_web\\_final\\_august\\_2013.pdf](http://afao.org.au/library/topic/women/Mapping_web_final_august_2013.pdf)

**AFAO. (2014).** HIV & stigma in Australia: A guide for religious leaders. Retrieved from [http://afao.org.au/library/topic/hiv-education/HIVandStigma\\_2014.pdf](http://afao.org.au/library/topic/hiv-education/HIVandStigma_2014.pdf)

**Arksey, H. & O'Malley, L. (2005).** Scoping studies: towards a methodological framework. *International Journal of Social Research Methodology*, 8(1): 19-32.

**Berkley-Patton et al. (2013).** Assessment of HIV-related stigma in a US faith-based HIV education and testing intervention. *Journal of the International AIDS Society*, 16(3).

**British Columbia Provincial Health Officer. (2014).** HIV, stigma and society: Tackling a complex epidemic and renewing HIV prevention for gay and bisexual men in British Columbia. Victoria, BC: Ministry of Health.

**Brown, L. et al. (2003).** Interventions to reduce HIV/AIDS stigma: what have we learned? *AIDS Education and Prevention*, 15(1), 49-69.

**Chollier, M. et al. (in press).** STIs/HIV stigma and health: A short review. To be published in *Sexologies*.

**de Bruyn, T. (2004).** A plan of action for Canada to reduce HIV/AIDS-related stigma and discrimination Retrieved from <http://aidslaw.ca/site/a-plan-of-action-for-canada-to-reduce-hiv-aids-related-stigma-and-discrimination/>

**Donohoe, S. & Tart, B. (2012).** Fear less live more: Dealing with HIV stigma and discrimination online. *HIV Australia*, 10(1). Retrieved from <http://afao.org.au/library/topic/government/HIVA-10-1-V6.pdf>

**Goffman, E. (1963).** *Stigma: Notes on the management of a spoiled identity*. New York: Simon and Schuster.

**Heijnders, M., & Van Der Meij, S. (2006).** The fight against stigma: an overview of stigma-reduction strategies and interventions. *Psychology, health & medicine*, 11(3), 353-363.

**Herek, G. M. et al. (2007).** Sexual stigma: Putting sexual minority health issues in context. In I. H. Meyer & M. E. Northridge (Eds.), *The health of sexual minorities: Public health perspectives on lesbian, gay, bisexual and transgender populations* (pp. 171-208). Boston, MA: Springer.

**Kaiser Family Foundation. (2012).** HIV/AIDS reporting manual. Retrieved from <http://kaiserfamilyfoundation.files.wordpress.com/2013/01/7124-09.pdf>

- Krauss, B. J. et al. (2006).** Hugging my uncle: The impact of a parent training on children's comfort interacting with persons living with HIV. *Journal of Pediatric Psychology*, 31(9), 891-904.
- Lawson, E. et al. (2006).** Stigma, denial, fear and discrimination: Experiences and responses of people from African and Caribbean communities in Toronto. Retrieved from [http://accho.ca/pdf/hiv\\_stigma\\_report.pdf](http://accho.ca/pdf/hiv_stigma_report.pdf)
- Link, B.G. & Phelan, J.C. (2001)** Conceptualizing stigma. *Annual Review of Sociology*, 27: 363-85.
- Little, S. (2010).** Considering the impact of stigma on HIV prevention in relationship to national HIV/AIDS strategy. January 10, Center on AIDS and Community Health. Retrieved from <http://aids.gov/federal-resources/pacha/meetings/2010/stacy-little.pdf>
- Mahajan, A.P. et al. (2008).** Stigma in the HIV/AIDS epidemic: A review of the literature and recommendations for the way forward. *AIDS*, 22(Suppl 2): S67-S79.
- Martinez, D. A. (2013).** HIV stigma reduction and testing in the Hispanic/Latino church setting. Retrieved from <http://search.proquest.com/docview/1441061968?accountid=13800>
- Nichols, K.M. (2013).** Examining the effects of a motion comic intervention on HIV-stigma among a sample of adolescent men who have sex with men. Retrieved from [http://scholarworks.gsu.edu/iph\\_theses/299](http://scholarworks.gsu.edu/iph_theses/299)
- Ontario AIDS Bureau. (2006).** Ontario gay men's HIV prevention strategy: Gay, bi, msm situation report. Retrieved from <http://library.yorku.ca/find/Record/2227932>
- Parker, R. & Aggleton, P. (2003).** HIV and AIDS-related stigma and discrimination: A conceptual framework and implications for action. *Social Science and Medicine*, 57(1): 13-24.
- Parr et al. (2009).** Formative research for the national HIV stigma and discrimination pre-campaign development: Qualitative research report. Retrieved from [http://afao.org.au/\\_\\_\\_data/assets/pdf\\_file/0006/6486/09Report\\_Stigma\\_Research.pdf](http://afao.org.au/___data/assets/pdf_file/0006/6486/09Report_Stigma_Research.pdf)
- Pitkin Derose, K. et al. (2012).** A community-partnered intervention to reduce HIV-related stigma and promote HIV testing through African American and Latino churches. 140th American Public Health Association Conference. Retrieved from <http://apha.confex.com/apha/140am/webprogram/Paper268048.html>
- Prentice, T. & Canadian Aboriginal AIDS Network. (2005).** Developing a policy of non-discrimination: Including Aboriginal people living with HIV/AIDS : policy guidelines for First Nations, Métis and Inuit communities, businesses and community-based organizations. Ottawa: Canadian Aboriginal AIDS Network.
- Reeders, D. (2007)** Solutions to stigma. *HIV Australia*, 7(3): 29-31. Retrieved from [http://afao.org.au/\\_\\_\\_data/assets/pdf\\_file/0004/5764/HIVA-7-3-FIN.pdf](http://afao.org.au/___data/assets/pdf_file/0004/5764/HIVA-7-3-FIN.pdf)
- Rios-Ellis, B. et al. (2015).** Evaluation of a community health worker intervention to reduce HIV/AIDS stigma and increase HIV testing among underserved Latinos in the Southwestern US. *Public Health Reports*, 130(5).
- Ross, S. & Rynard, V (2007).** Gay men's BE REAL HIV prevention campaign: Final evaluation report. Retrieved from <http://library.yorku.ca/find/Record/2227938>
- Rucker, T. & Gipson, J. (2007).** Using social marketing to reduce HIV/AIDS stigma: Three year evaluation data. Presented at 2007 National HIV Prevention Conference. <http://stacks.cdc.gov/view/cdc/11543>

**Sengupta, S. et al. (2011).** HIV interventions to reduce HIV/AIDS stigma: a systematic review. *AIDS and Behavior*, 15(6), 1075-1087.

**Shimeles, K. et al., (2012).** Staying alive: Evaluation of the Keep It Alive! HIV awareness and prevention campaign for African, Caribbean and Black communities in Ontario. Retrieved from [http://accho.ca/portals/3/documents/resources/kia\\_evaluation\\_report\\_final\\_aug2013.pdf](http://accho.ca/portals/3/documents/resources/kia_evaluation_report_final_aug2013.pdf)

**Stackpool-Moore, L. (2007).** Start the press: How African communities in the UK can work with the media to confront HIV stigma. Retrieved from [http://panos.org.uk/wp-content/files/2011/03/start\\_the\\_pressSjOmQu.pdf](http://panos.org.uk/wp-content/files/2011/03/start_the_pressSjOmQu.pdf)

**Stangl, A. L. et al. (2013).** A systematic review of interventions to reduce HIV-related stigma and discrimination from 2002 to 2013: How far have we come? *Journal of the International AIDS Society*, 16(3).

**Stuart, H. et al. (2009).** *Paradigms Lost: Fighting stigma and the lessons learned.* UK: Oxford University Press.

**Stutterheim, S.D. et al.** HIV-related stigma in the Netherlands. *Aids Fonds: Netherlands.* Retrieved from <http://hivnet.org/downloads/pdf/reportplusproject.pdf>

**Thoms, J.M. (2007).** Leading an extraordinary life: Wise practices for an HIV prevention campaign with two-spirit men. Retrieved from <http://2spirits.com/PDFolder/Extraordinarylives.pdf>

**Woodward, P. (2014).** Stages of disclosure. *HIV Australia* 12(3): 33-36. Retrieved from <http://afao.org.au/library/topic/women/HIVA-12-3-ONLINE.pdf>

**Wohlfeiler, D. (2000).** Structural and environmental HIV prevention for gay and bisexual men. *AIDS*, 14(suppl 1): S52-S56.



The Community Based Research Centre for Gay Men's Health (CBRC) is a health promotion group created by and for gay men based in Vancouver, British Columbia. We are a non-profit charitable organization using community participatory research to develop knowledge about gay men's health and interventions addressing health and social issues. CBRC's core programs are currently leading a social determinants based approach to gay men's prevention through:

1. Knowledge transfer from *Sex Now* our periodic survey of gay men's health reaching eight thousand nation-wide every 2-3 years;
2. *cbrc.net*, our gay men's health theory & practice exchange website;
3. Our *BC Regional Gay Men's Health Network* prevention planning activities;
4. Our annual *Gay Men's Health Summit* conference addressing emerging themes; and
5. Our focus on gay youth with three main initiatives: *Investigaytors* our research training program for gay youth; *Totally Outright* our youth leadership program offered through local organizations across Canada; and *Resist Stigma*, a national social media campaign for gay and queer youth.

