

On the role of a sustained community response to HIV: Measuring promises against reality

Brent Allan, Senior Advisor Policy and Programs 4 May 2018

At the recent [IAPAC conference in May 2018](#), where the conference theme was mirrored in the title of the conference “Controlling the HIV Epidemic”, the session topics covered a range of issues, including:

- **Setting the metrics for success** – where the panel discussion focused upon the question of “are we measuring what matters”?
- **Facilitating HIV epidemic control** – where innovative program models, new therapeutic developments, and policy discussions about comprehensive prevention and differentiated care were put forward.
- **Leaving no one behind** – where the reoccurring theme of stigma and discrimination was interrogated and was followed by regional, national and subnational examples of how progress towards HIV epidemic control is being achieved around the world.

[Dr. Laurel Sprague](#) from the Global Network of People living with HIV ([GNP+](#)) presented in three different panel discussions with her focus being the perspectives that people living with HIV and their representative organizations have on community engagement, stigma and metrics.

This blog post looks at these three presentations and draws out some of the recurring themes that permeated the conference discussions and deliberations with specific attention to the sustainability of a community response to HIV.

The role of community engagement in the global response to HIV has been highly valued across the partners involved. And certainly, the vitality of people living with HIV as part of those engagement strategies has been hailed as a hallmark of the response to HIV.

However, the role of communities in the response was described by Dr. Sprague as essentially existing to “shine a light on the gap between what is often promised and what is actually delivered”. It describes both an accountability role as well as an advocacy position that is required by effective and engaged community responses. This dual role that community representatives assume is one which is widely appreciated, although sometimes begrudgingly when inaction is called out. But more importantly, the role of community exists because there is a wide-spread understanding that any complex multi-system and multi-lateral response requires that someone must take the advocacy and accountability position to ensure that promises translate into action.

Dr. Sprague then illustrated her analysis by taking three global commitments which have been made in the past on (1) HIV treatment for all (2) human rights and HIV criminalization and (3) dedicated funding allocations for an effective community response.

On the promise of [Treatment for All](#), it is clear that even with outstanding examples of community engagement there is still a far way to go with donor support constantly in

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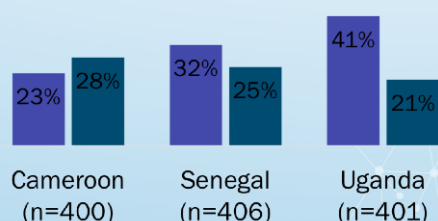
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jeopardy and emerging vulnerable and marginalized communities still being the ones left behind.

On the promise of protecting human rights, the response is mixed. Successes in one country or jurisdiction for example on [HIV criminalization](#) are offset by a regressive policy momentum in another. This is played out again and again in a country like the United States where one state enacts progressive reform while another moves towards greater criminalization.

Stigma Affects HIV Care Cascade (2017)

- Hesitated to get tested due to fears
- Delayed entering care



Delayed entering care because:

- Not ready to deal with HIV infection (16–33%)
- Worried others would find out status (11–13%)
- Afraid health workers would treat me badly or disclose status without consent/had a bad experience with a health worker previously (4–11%)

2018 CONTROLLING THE HIV EPIDEMIC SUMMIT

However, the greater attention being paid to understanding how [HIV stigma and discrimination](#) negatively affects the entirety of the global HIV response and its potential to disable the efficacy and effectiveness of this response is being better understood.

It is abundantly clear that the key political and legal determinants of the continued vulnerability to HIV exist in a macabre policy and public health situation where life experiences of violence (which includes both one-off and repeated experiences of violence across the range of types and formats which manifest) intersect with the fear of punitive laws and policies and drive people living with HIV to feel as if they have to hide in the dark corners of society. It is in these dark places where HIV stigma and the discrimination against people living with HIV continue to exist so profoundly.

Actions such as the [HIV Stigma Index](#), established by the People Living with Global Network of People Living with HIV ([GNP+](#)), International Community of Women Living with HIV ([ICW](#)) and UNAIDS, and the more than 90 countries who have calculated the index across their communities as well as discussions across other presentations on the development stigma related indicators are commendable and this begins to open up and shine a light on the impacts of HIV stigma across communities and countries.

In the conference session entitled '*Leaving No One Behind*', the development of The Global Compact to End HIV-related stigma and discrimination in all its forms currently being co-convened by UNAIDS, UN Women, UNDP and GNP+ is a practical example of the level of awareness and understanding that HIV stigma and discrimination needs to be given. If we are truly committed to ensuring that [Zero HIV Discrimination](#) can be more than just an

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awareness day in the global schedule of issue based awareness days but an actual reality for all key populations affected by HIV we must do more than just talk we must act.

Finally, on the promise of better funding for a meaningful community response, the reality is that this is not even close to being recognized with

[high level reports](#)

lamenting the woeful

[state of funding](#)

[availability](#) to community

led response around the

world and the effect has

been devastating. In

some countries,

[dwindling donor funding](#) for HIV (and more community responses in particular) has meant service delivery cuts, advocacy and policy reform stalled, and some community-based organizations facing the reality of closure. It is difficult to take on the dual roles of being an advocate and monitoring accountability if the funding to support these roles no longer exist.

If we believe that community engagement is a vital part of the picture that has led us to recognize fantastic advancements to HIV disease testing, treatment and care, then Dr. Sprague left us with three key actions which should be made a priority across city, region, national and international jurisdictions being:

1. **Community-led research, monitoring, and advocacy** need to be funded and recognized
2. **Legal barriers to organizing**, especially for most marginalized populations, need to be removed
3. **Commitment to Zero Discrimination** across sectors (laws, education, employment, health facilities, etc.) needs to be realized

With thanks to Dr Laurel Sprague from GNP+ and the conference organizers IAPAC