

Opening Session

- **How Stigma is Impacting the 90-90-90 Goals**



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South Africa



# How **Stigma** is Impacting the 90-90-90 Goals

Linda-Gail Bekker

Desmond Tutu HIV Centre and Desmond  
Tutu Health Foundation



We've despaired

We've hoped

?



# HIV: We HAVE come a long way....



Treatment with HIV medicines can **prevent HIV from developing into AIDS**

WHO announces first country eliminating mother to child transmission of HIV and syphilis

**PEP**

= a treatment to stop a person becoming infected with HIV after it's got into their body

Swaziland: new infections halved in five years as HIV treatment scales up

WHAT IF THERE WERE A PILL THAT COULD PREVENT HIV?

**THERE IS.**

**U=U**

UNDETECTABLE  
UNTRANSMITTABLE

A PERSON LIVING WITH HIV WHO HAS AN UNDETECTABLE VIRAL LOAD DOES NOT TRANSMIT THE VIRUS TO THEIR PARTNERS.

The International AIDS Society is proud to endorse the U=U consensus statement of the Prevention Access Campaign.

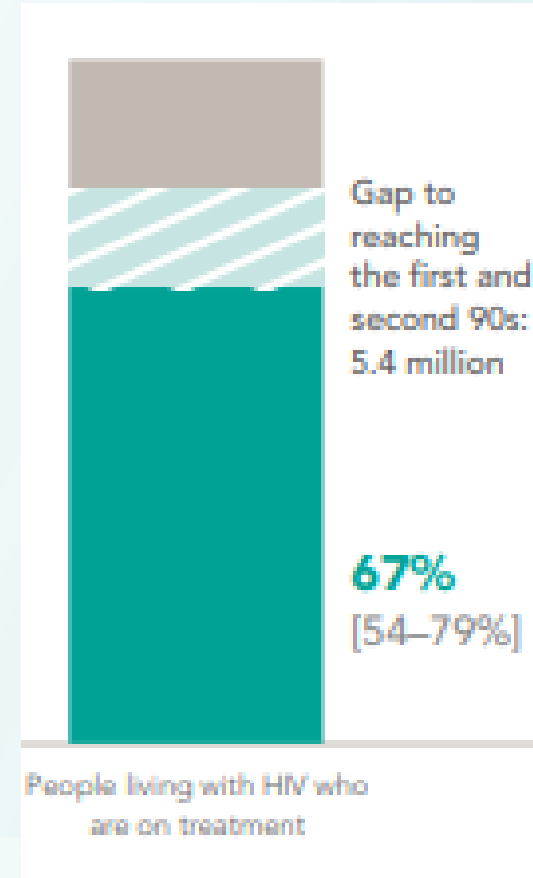
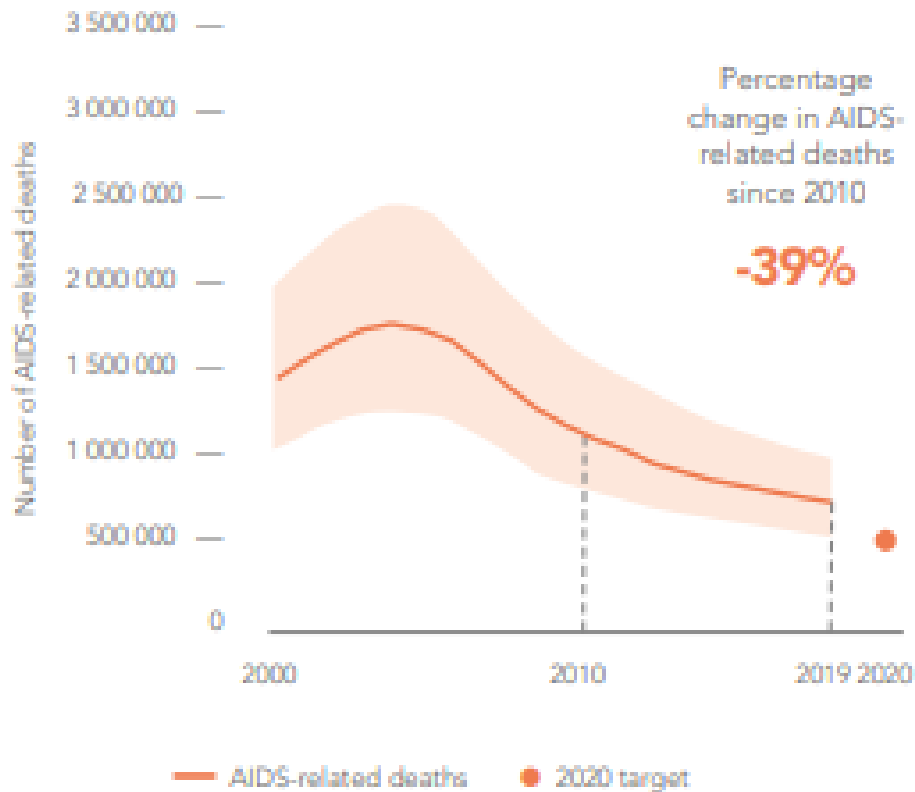






# Deaths Down!

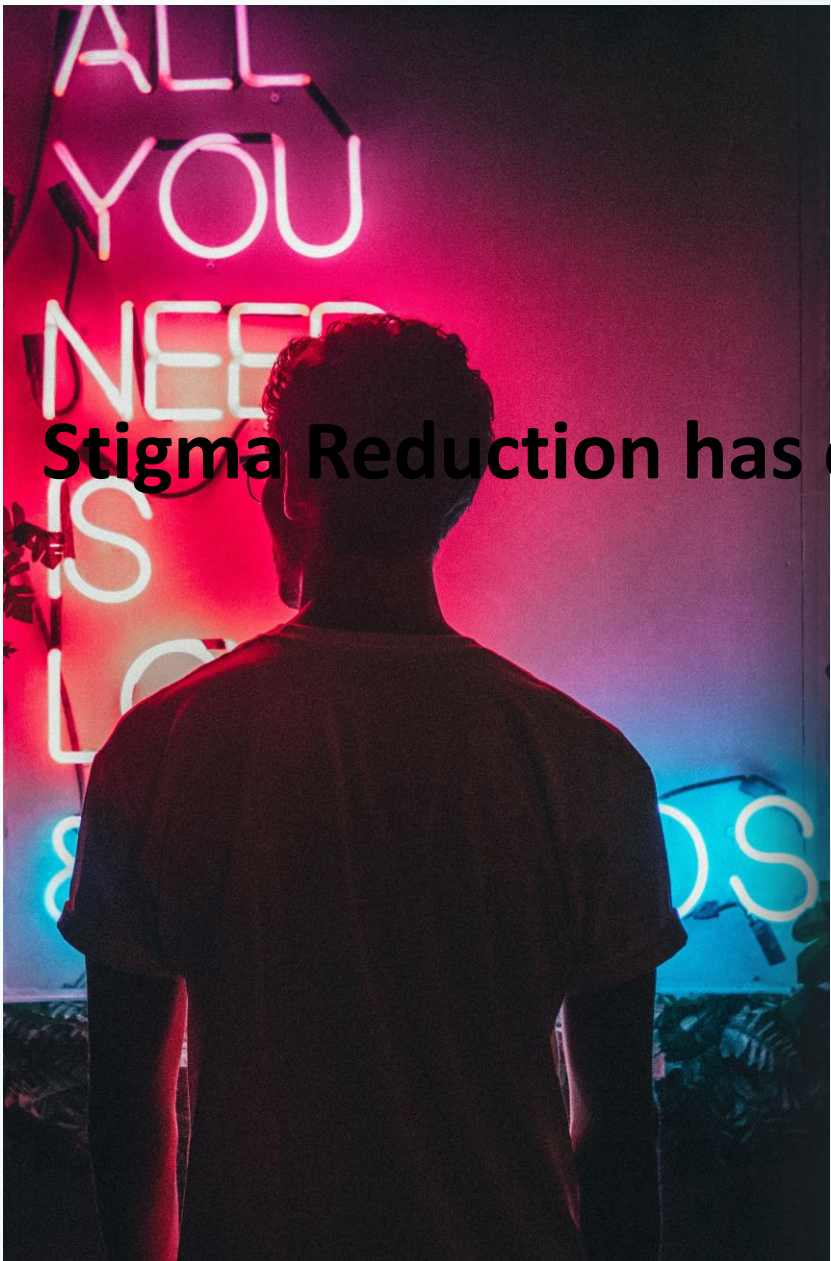
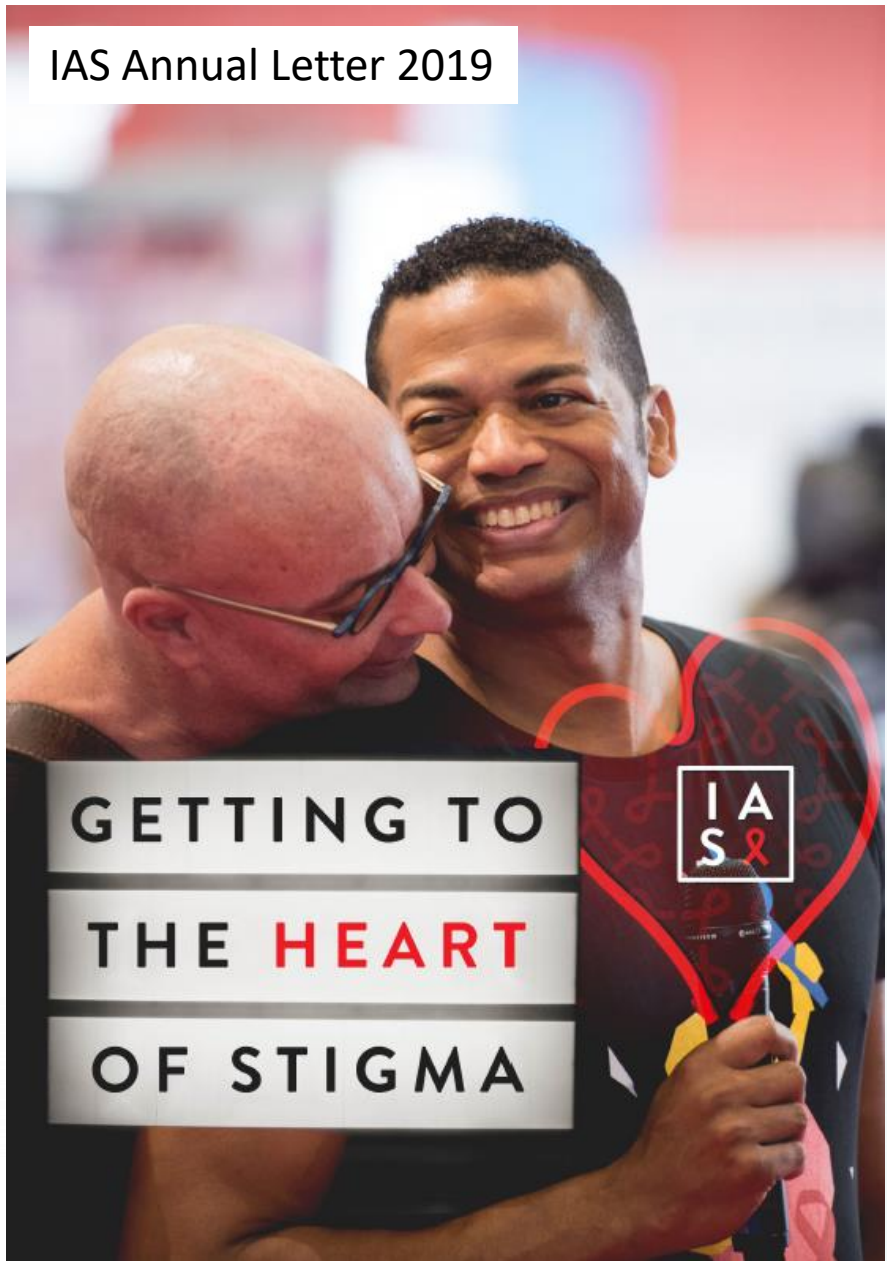
**39%** reduction in AIDS-related deaths globally since 2010  
(UNAIDS 2020)



# Treatment Up!

**Numbers of people on treatment has more than tripled since 2010**  
(UNAIDS 2020)



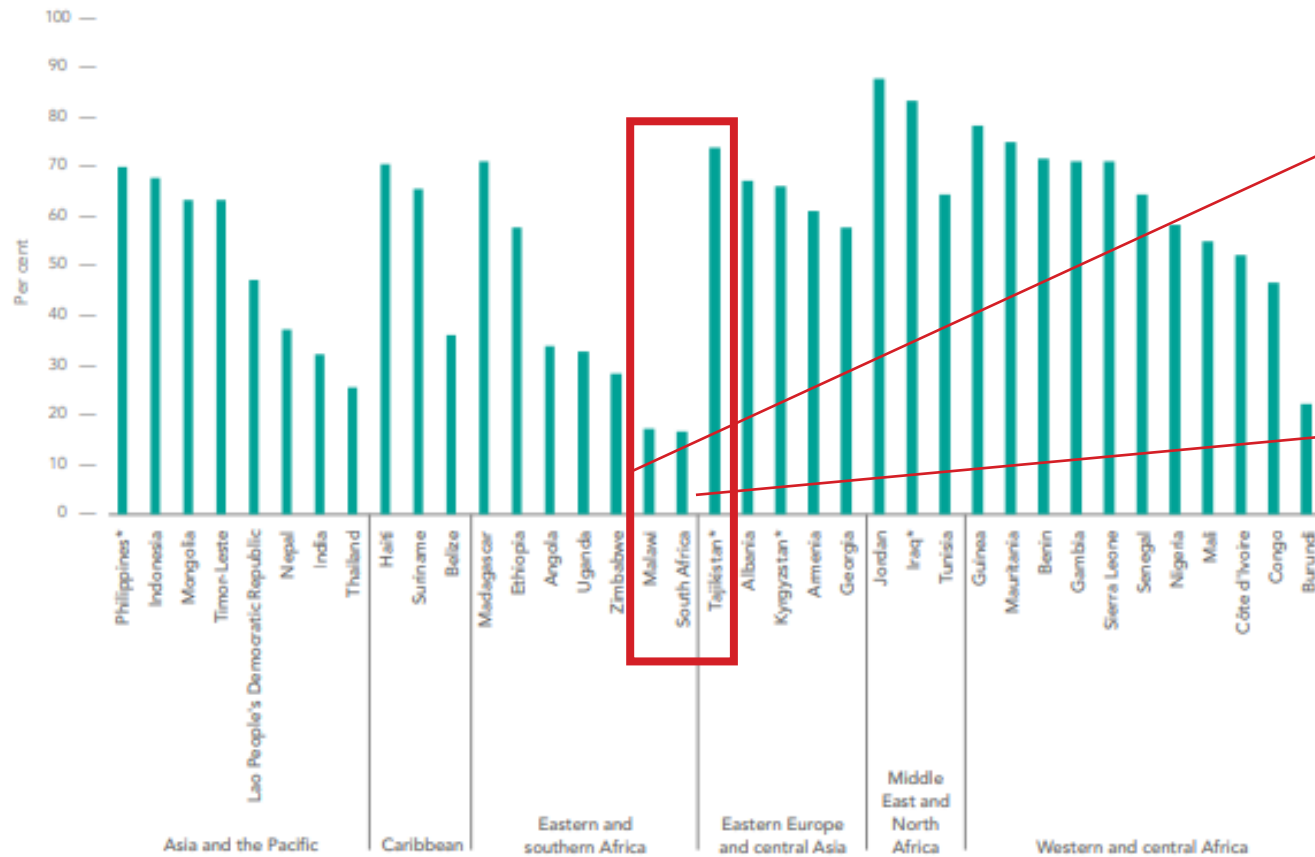


**Stigma Reduction has evaded us**

“WHAT WE ARE SEEING IN THE CASE OF HIV-RELATED STIGMA IS MIRRORED MORE GENERALLY IN THE WORLD’S SEEMING RETREAT ON HUMAN RIGHTS.”

# HIV Stigma: *high prevalence globally* (UNAIDS Global AIDS Update 2020)

Percentage of people aged 15 to 49 years who report discriminatory attitudes towards people living with HIV, countries with available data, 2014–2019



*1.7% of PLWHIV denied services because of their HIV status in Malawi*

*21% of PLWHIV denied services because of their HIV status in Tajikistan*

The ability of PLWHIV to receive ART in some countries is still conditional on contraceptive use.

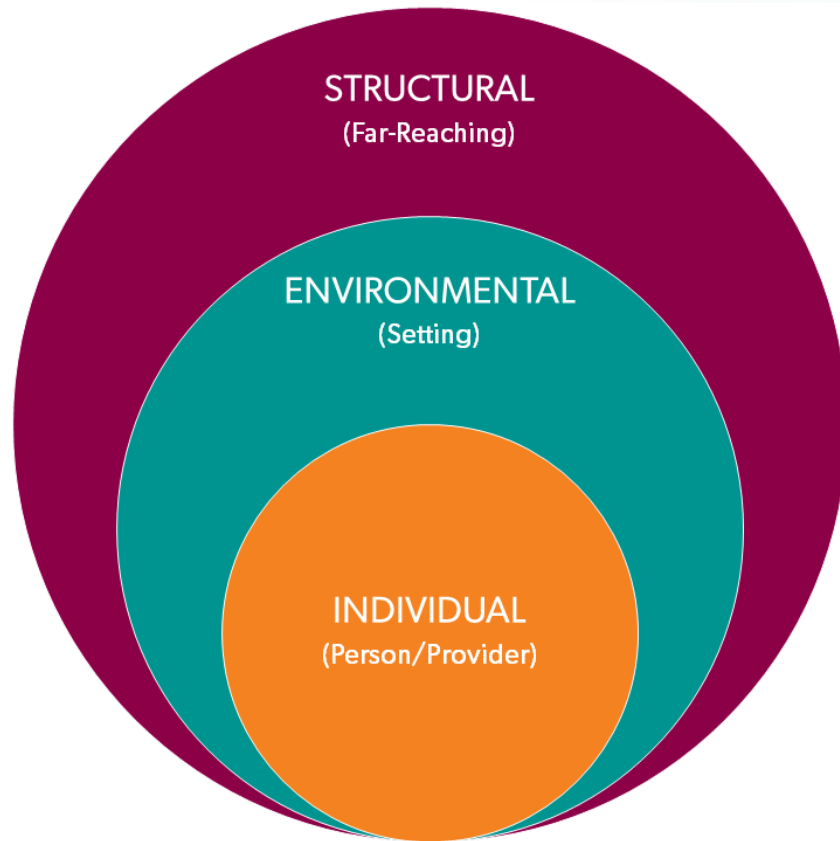
Source: population based surveys 2014-2019





# Levels of Stigma

Negative attitudes and beliefs towards a group that works to constrain their opportunities, resources, and wellbeing (*Hatzenbeuhler & Link, 2014*)



- 1. Structural Stigma:** Social conditions, cultural norms, and institutional practises
- 2. Public Stigma:** Commonly held negative beliefs amongst the general population that discredit a particular group of people
- 3. Self-stigma:** Develops when a person is aware of public stigma and internalises these beliefs by applying them to themselves (*Coorigan, Larson, Kuwabara, 2010*)





“DISCRIMINATION IS A  
DIRECT ACTION THAT  
RESULTS FROM  
STIGMA.”

# Stigma and discrimination hold the HIV response hostage

Leaders lack courage to tackle questions that effective HIV responses raise:

- ❖ Criminalisation and discrimination of key populations.  
**More than 70 countries still criminalise same-sex relationships.**
- ❖ Criminalisation of HIV non-disclosure, exposure or transmission. **72 countries still specifically allow for this.**
- ❖ Evidence-based harm reduction approaches for injecting drug users are not implemented .
- ❖ Incarcerated populations are underserviced.
- ❖ Harmful gender norms, gender-based violence, Homophobia, homoprejudice, patriarchy and poor social protection continue to be prevalent everywhere.
- ❖ Inadequate comprehensive sexual health education and adolescent-friendly services for youth



YPWU and ID



**Risk: 24 X**

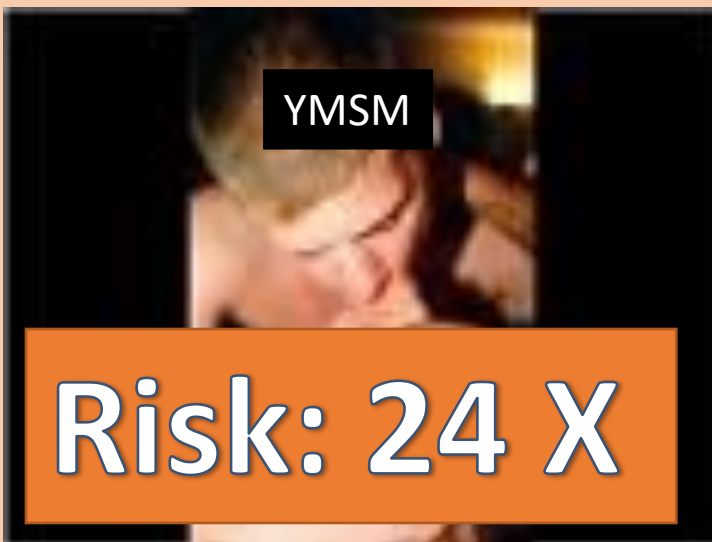
YSW



**Risk: 10 X**

Key Population: High burden and poor access

YMSM



**Risk: 24 X**

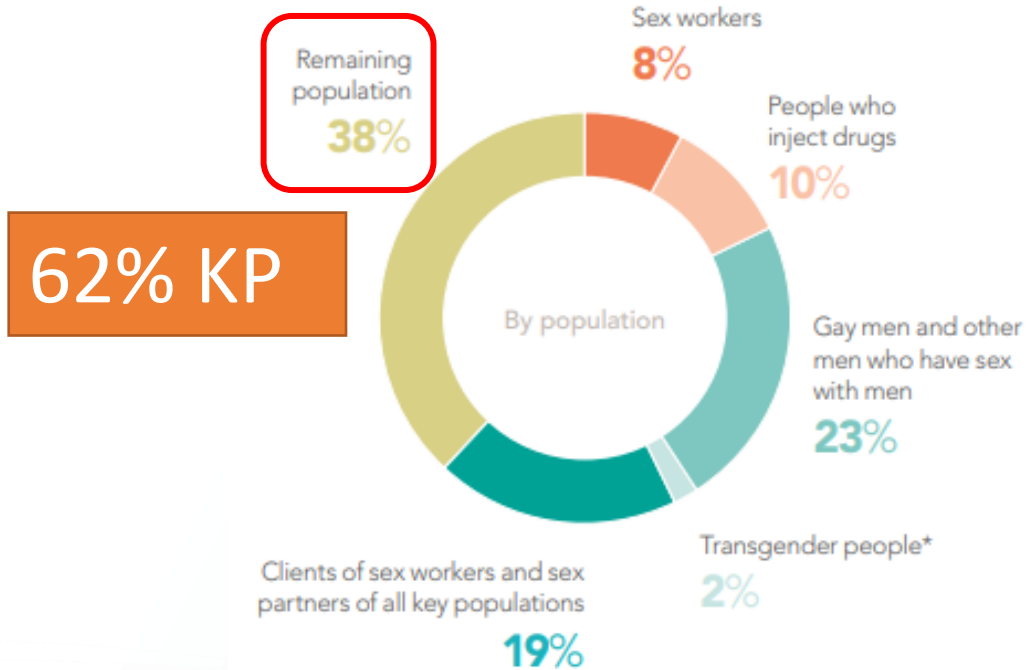
TRANSGENDER PEOPLE: 49X

INCARCERATED PEOPLE: 5X

Young refugees, migrants, detainees

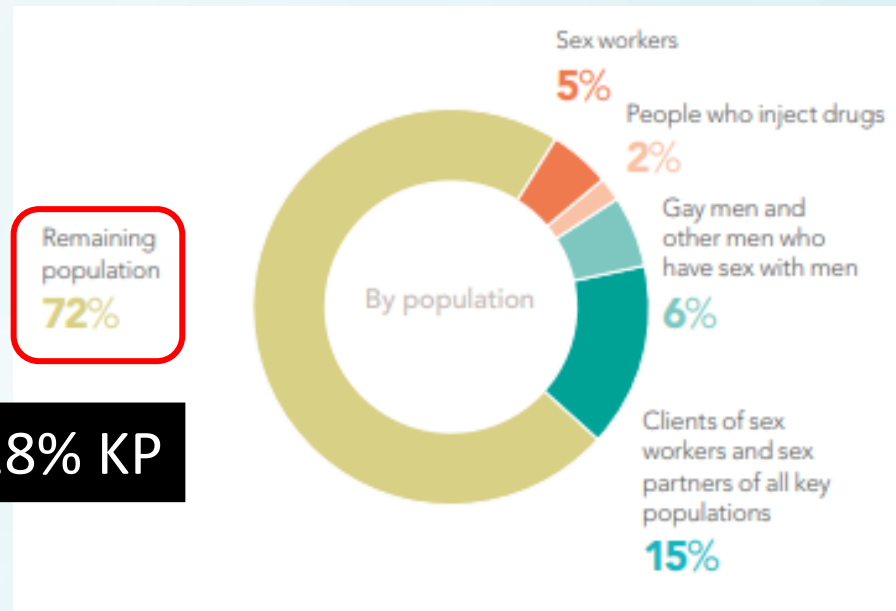
Leave no one behind.....

### Distribution of new HIV infections by gender and population, global, 2019



### Distribution of new infections in **Globally** (UNAIDS 2020)

### Distribution of new infections in **Sub-Saharan Africa** (UNAIDS 2020)





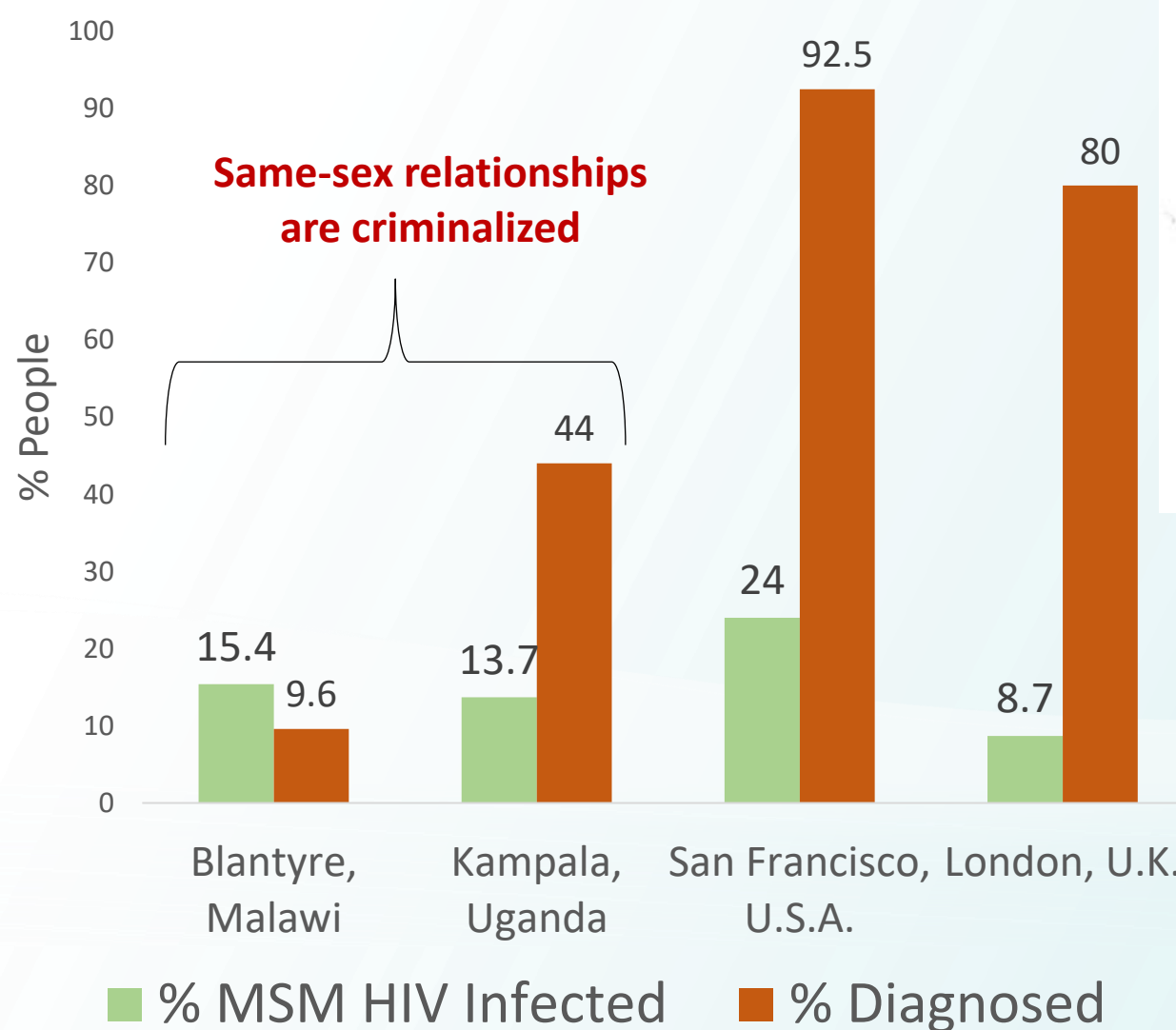
# YIDU, YSW, YMSM are Key Populations.

David  
Gillanders:  
HIV-positive  
girl in  
Ukraine



- Poor Information
- Inadequate Services
- **Stigma and prejudice**
- Criminalisation
- Poor social protection
- Violence
- Incarceration

HIV Incidence among MSM is similar, the number of HIV-infected people who **know their status** is much lower in countries where same-sex relationships **are criminalised**



Source: <https://76crimes.com/76-countries-where-homosexuality-is-illegal/>

Brown et al., 2014;  
Hladik et al., 2010;  
Wirtz et al., 2013

**43% of countries with injecting populations do not have needles and syringe exchange programs.**

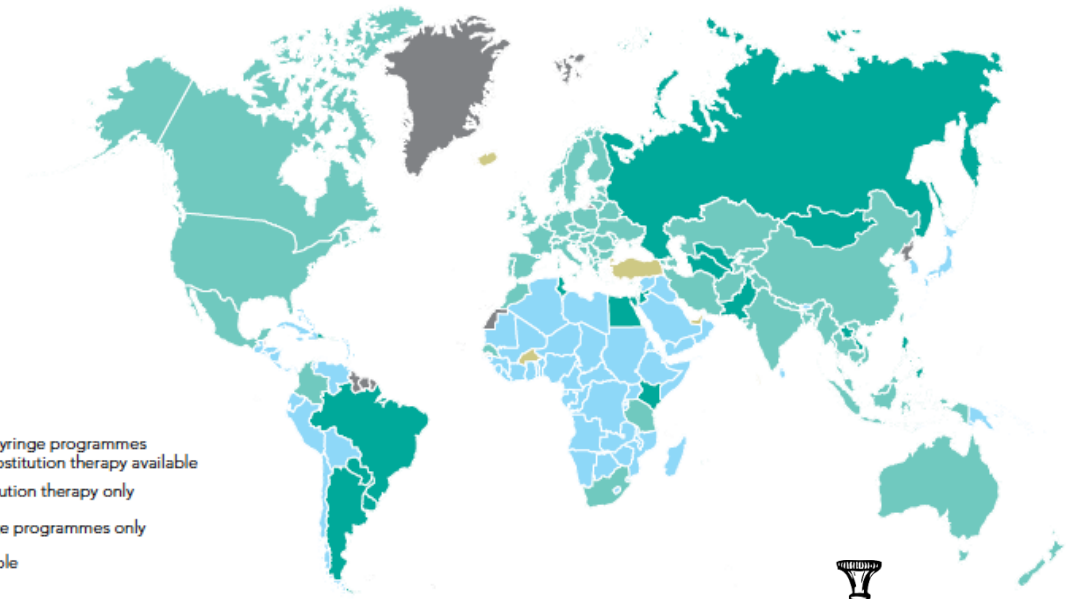


**AVAILABILITY OF NEEDLE-SYRINGE EXCHANGE PROGRAMMES AND OPIOID SUBSTITUTION THERAPY, 2014**

**Median percent of people with opioid dependence use receiving opioid substitution therapy, 2015**



Source: 2016 Global AIDS Response Progress Reporting; UNODC. World Drug Report 2016.



Source: The global state of harm reduction 2014. London: Harm Reduction International; 2014 (<http://www.thra.net/files/2015/02/16/GSHR2014.pdf>).

**Only 12 countries provide the requisite 200 clean needles/person injecting/year.**



**Young women and adolescent girls** account for **75%** of new HIV infections in sub-Saharan Africa.

**>8000** young women are infected with HIV **every week** (almost 2000 in RSA alone).





# YWAG in SSA are a Key Population



Gabra  
Kenyan Girl

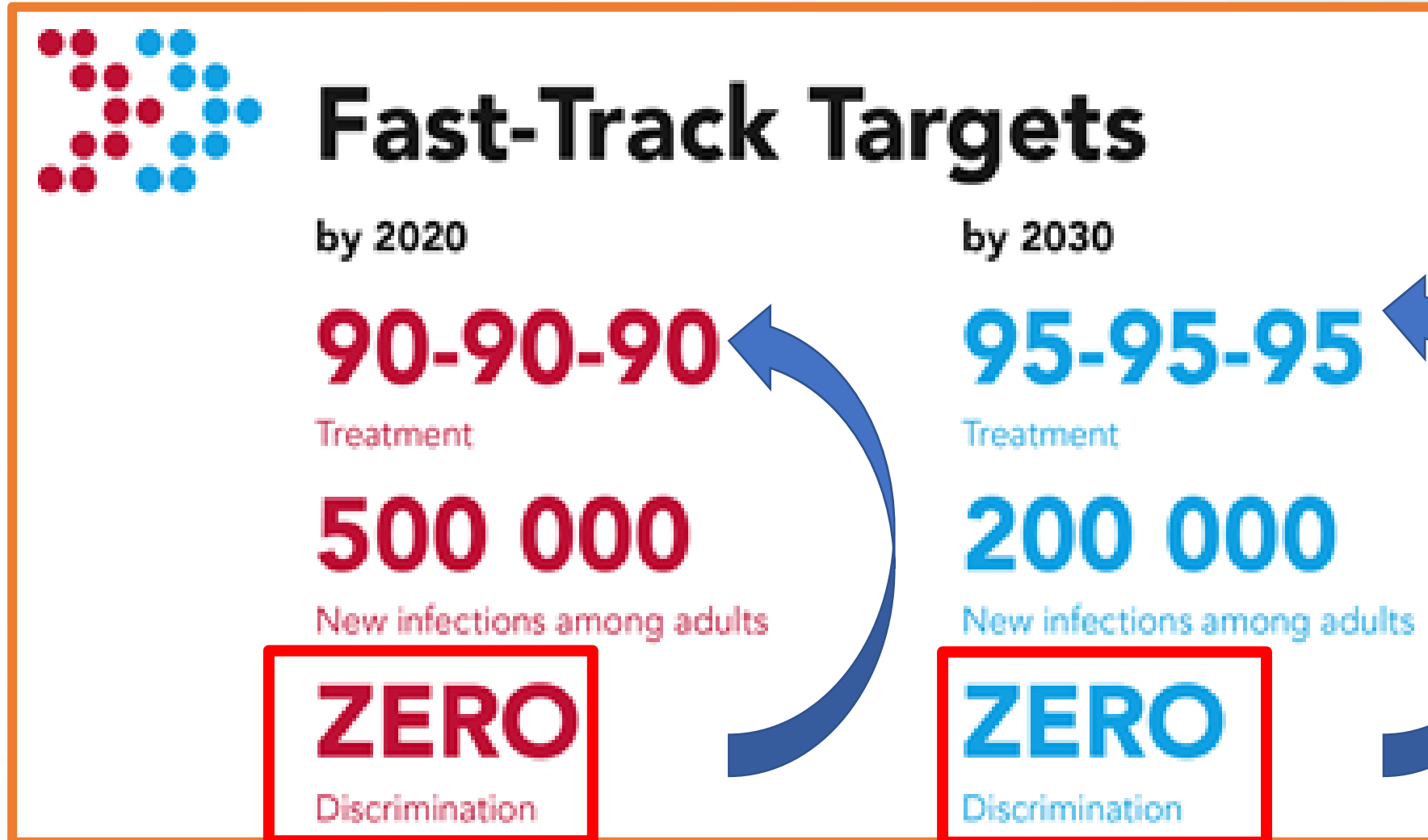
- Low levels of school completion
- Inadequate information
- High levels of Gender Based Violence
- Poor access to Sexual Reproductive health services
- Poor social protection
- **Stigma and prejudice**
- Early marriage
- Patriarchy
- Older male partners
- Child marriage



"Because of **bad policies** that reflect ideology, prejudice and bias rather than science, those most vulnerable to HIV are deterred from accessing the services they need."

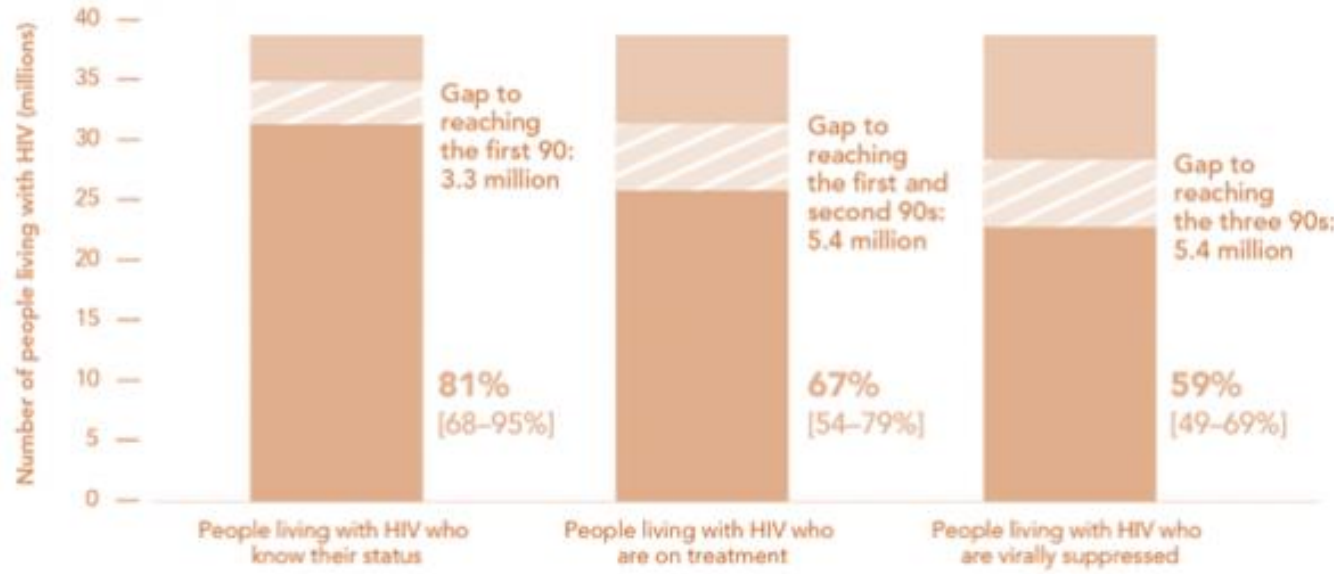
2012 Society's Child

# The targets before us.....



# 90-90-90 Progress: *gains made but still off track* (UNAIDS Global AIDS Update 2020)

HIV testing and treatment cascade, global, 2019



(UNAIDS special analysis, 2020)

- 62% of new infections occur amongst key populations and their sexual partners
- Marginalised (Key) populations struggle to access SRH services – fearing judgment, violence, or arrest
- 82 countries still criminalise some form of HIV transmission (exposure or non-disclosure)
- Key populations, including sex workers, sexually and gender diverse populations, and people who use drugs, are often criminalised:
  - 103 countries criminalise sex work
  - 108 countries criminalise drugs

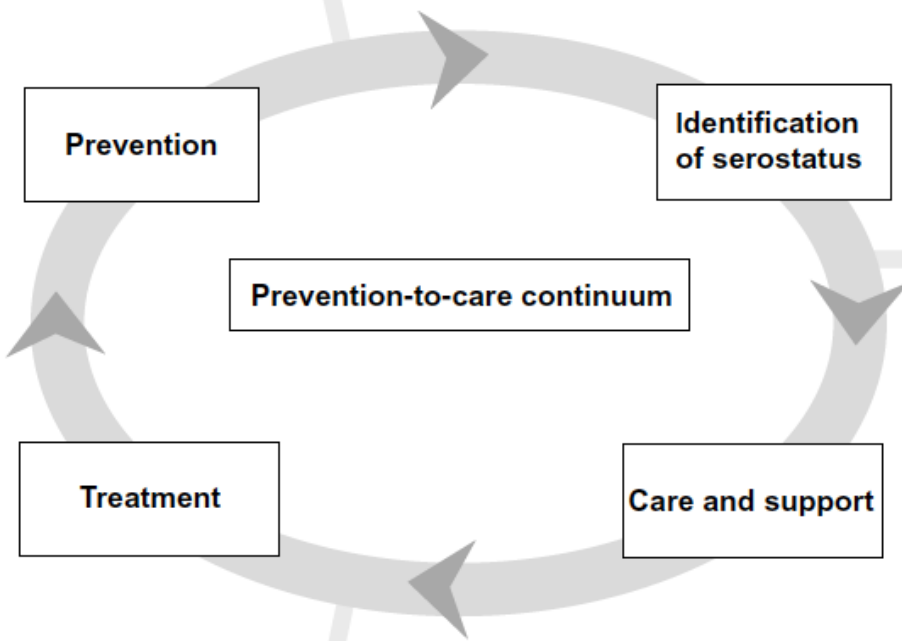
**Stigma is associated with poor health outcomes – including treatment seeking behaviour (Kane et al., 2019)**



# Stigma and discrimination impact on the cascade



- Low perception of individual risk because only stigmatized groups seen as vulnerable
- Reluctance to know one's serostatus for fear of negative repercussions
- Increased vulnerability of others



- Inadequate or inappropriate counselling and support
- Denial of appropriate health care to those living with HIV
- No care-seeking due to fears of public recognition of status.

- Stigmatization of associated behaviours (drug use, sex work) limits effectiveness of harm-reduction interventions
- Lack of forward planning



## HIV - Related Stigma, Discrimination and Human Rights Violations

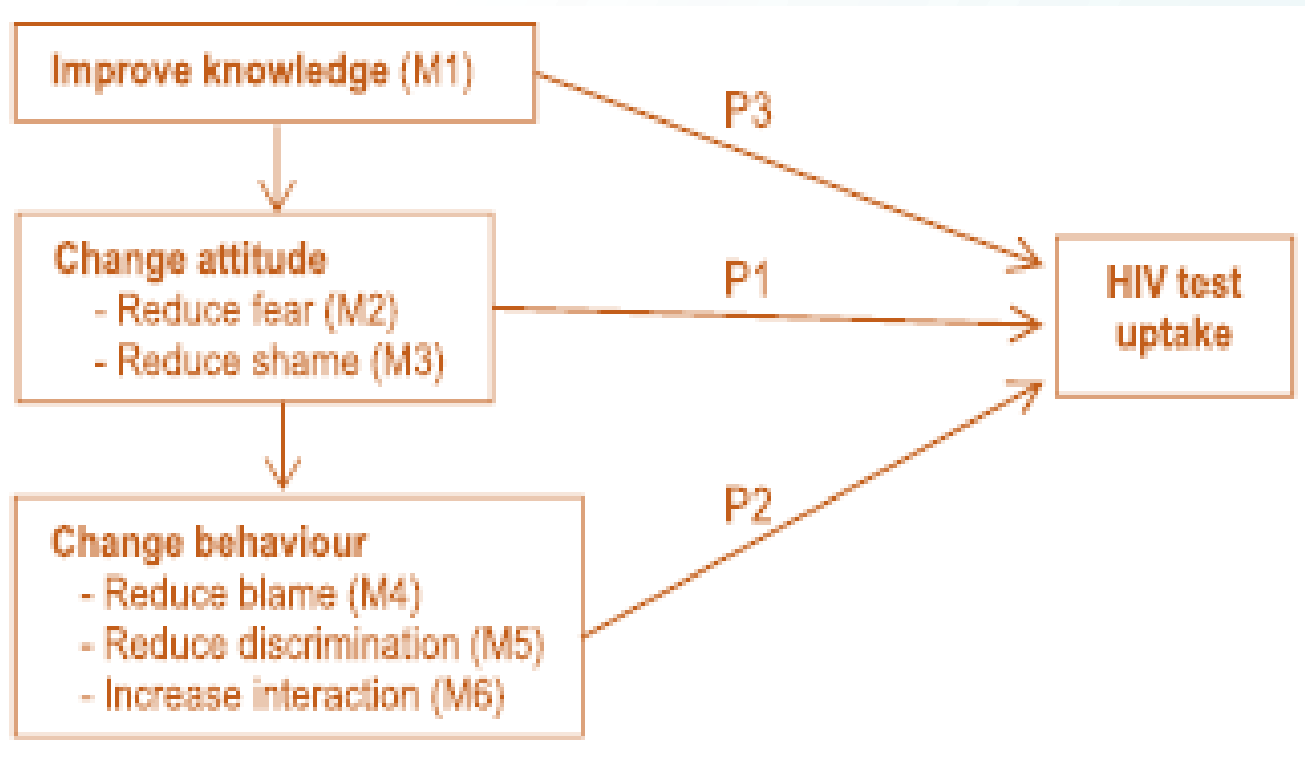
Case studies of successful programmes

UNAIDS BEST PRACTICE COLLECTION



# Stigma & HIV Testing: The first 90 (Thapa et al., 2018)

HIV stigma can drive lower rates of testing uptake. Several interventions have tried to address this – but what works and do we know the mechanisms at play? An analysis of 34 articles showed:



P1 – Increased knowledge can trigger changes to **stigmatising attitudes** = increased HIV test uptake

P2 – Knowledge and attitude improvements can trigger **changes in behaviour** = increased HIV testing uptake

P3 – Knowledge can lead to testing uptake **alone**, even when it does not change stigmatizing attitudes and behaviours

# Potential of HIV-self-testing kits to combat stigma?

*“It’s better because you can take this and go home. Nobody sees your results. Only you know. I prefer that it’s confidential. I know that I do have HIV but nobody saw me, it’s me alone. Now it’s my duty to go there and take the ARVs.” - 20 year old male*

Perez et al., PLoS ONE, 2016



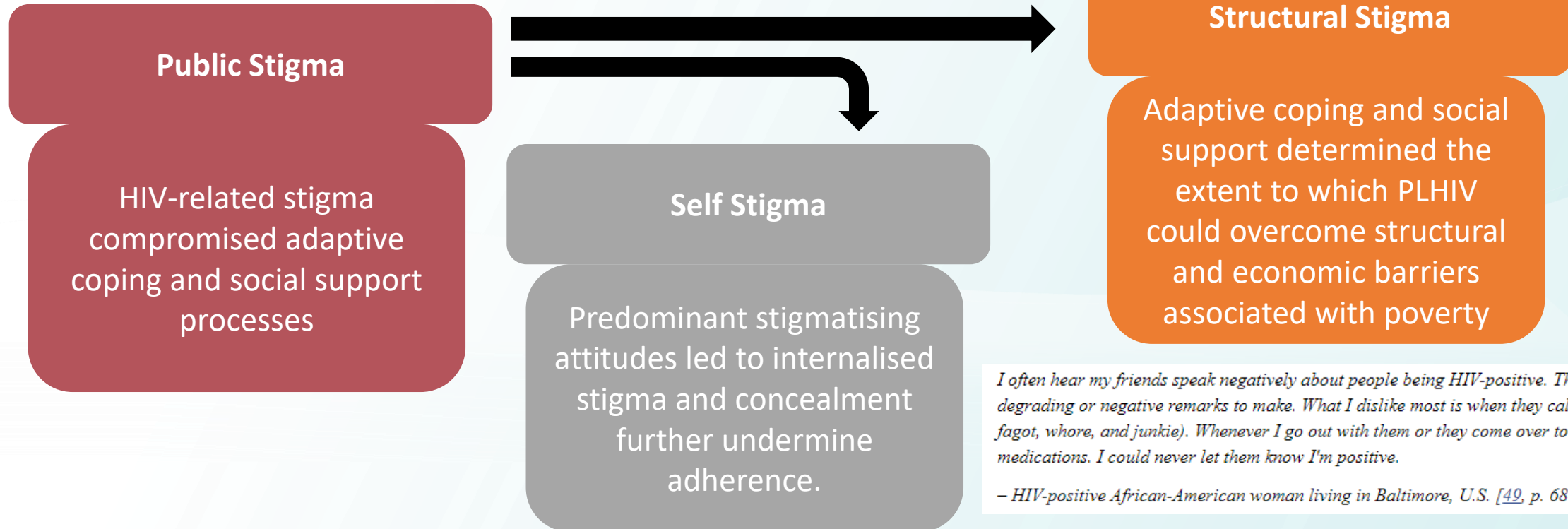
- SA qualitative study on the use of oral self-testing kits in informal settings
- Reason for use of self-testing kits incl.
  - Fear of community stigmatization
  - Being the subject of community gossip
- Acceptability of testing was increased, particularly among male and youth groups – **the missing millions to reach the first 90?**



# Stigma compromised adherence to HIV Treatment (the 2<sup>nd</sup> 90): need to tackle all levels of stigma to improve ART adherence (Kats et al., 2013)

*These days when people come to know that you have AIDS they don't want to come near you, as if you are an abominable thing ('bakwenyinyala'). You cannot feel free. Wherever you go they start talking, 'See that one, she is sick'. [57, p. S88]*

Kampala, Uganda



# Stigma during treatment (The 3<sup>rd</sup> 90): *Focus on healthcare facilities*



**Stigma reduction approaches in Healthcare Facilities: (Nyblade et al., BMC Med, 2019)**

1. Spend more time providing patients **with information** about the condition
2. Upskill healthcare providers to **sensitize them** to working with stigmatized groups
3. **Contact and peer-based learning** – involving members of a stigmatised group in the delivery of healthcare
4. Empower clients by providing them with potential **coping mechanisms** to overcome stigma in health facilities
5. **Structural changes** through policy change or changes to clinical guidelines

# Differentiated care addresses stigma

It is a **client-centred** approach that simplifies and adapts HIV services **across the cascade**, in ways that both serve the needs of people living with HIV PLHIV better and **reduce unnecessary burdens** on the health system. It doesn't discriminate.

Grimsrud A et al. *Journal of the International AIDS Society* 2016, 19:21484  
<http://www.jiasociety.org/index.php/jias/article/view/21484> | <http://dx.doi.org/10.7448/IAS.19.1.21484>

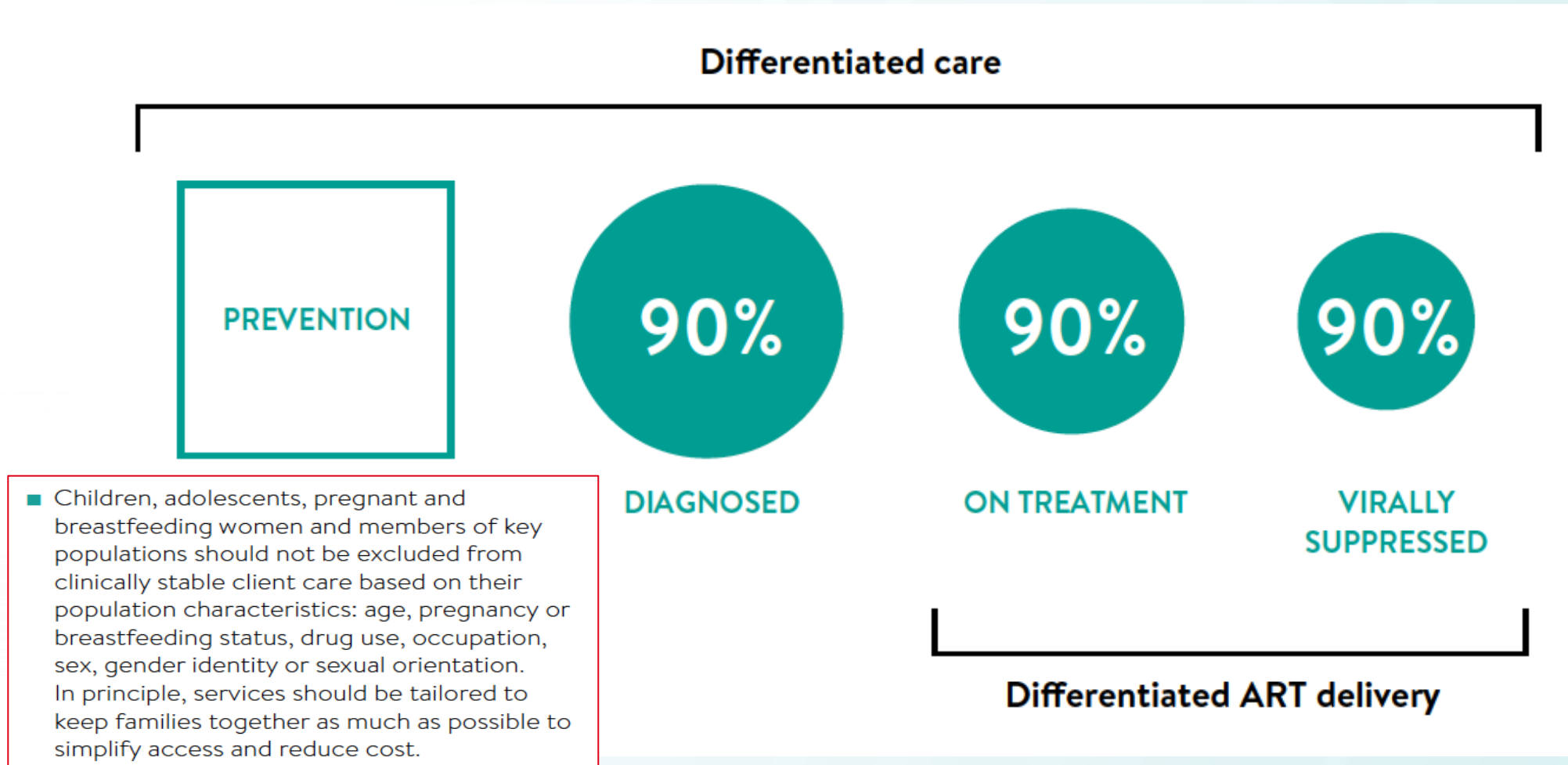


## Viewpoint

### Reimagining HIV service delivery: the role of differentiated care from prevention to suppression

Anna Grimsrud<sup>5,1</sup>, Helen Bygrave<sup>2</sup>, Meg Doherty<sup>3</sup>, Peter Ehrenkrantz<sup>4</sup>, Tom Ellman<sup>2</sup>, Robert Ferris<sup>5</sup>, Nathan Ford<sup>3,6</sup>, Bactrin Killingo<sup>7</sup>, Lynette Mabote<sup>8</sup>, Tara Mansell<sup>1</sup>, Annette Reinisch<sup>9</sup>, Isaac Zulu<sup>10</sup> and Linda-Gail Bekker<sup>1,6,11</sup>

# Differentiated care is applicable across the HIV care continuum





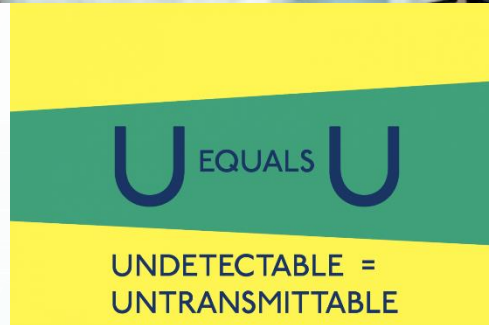
# U=U: A opportunity to de-stigmatize HIV

UNINFECTIOUS

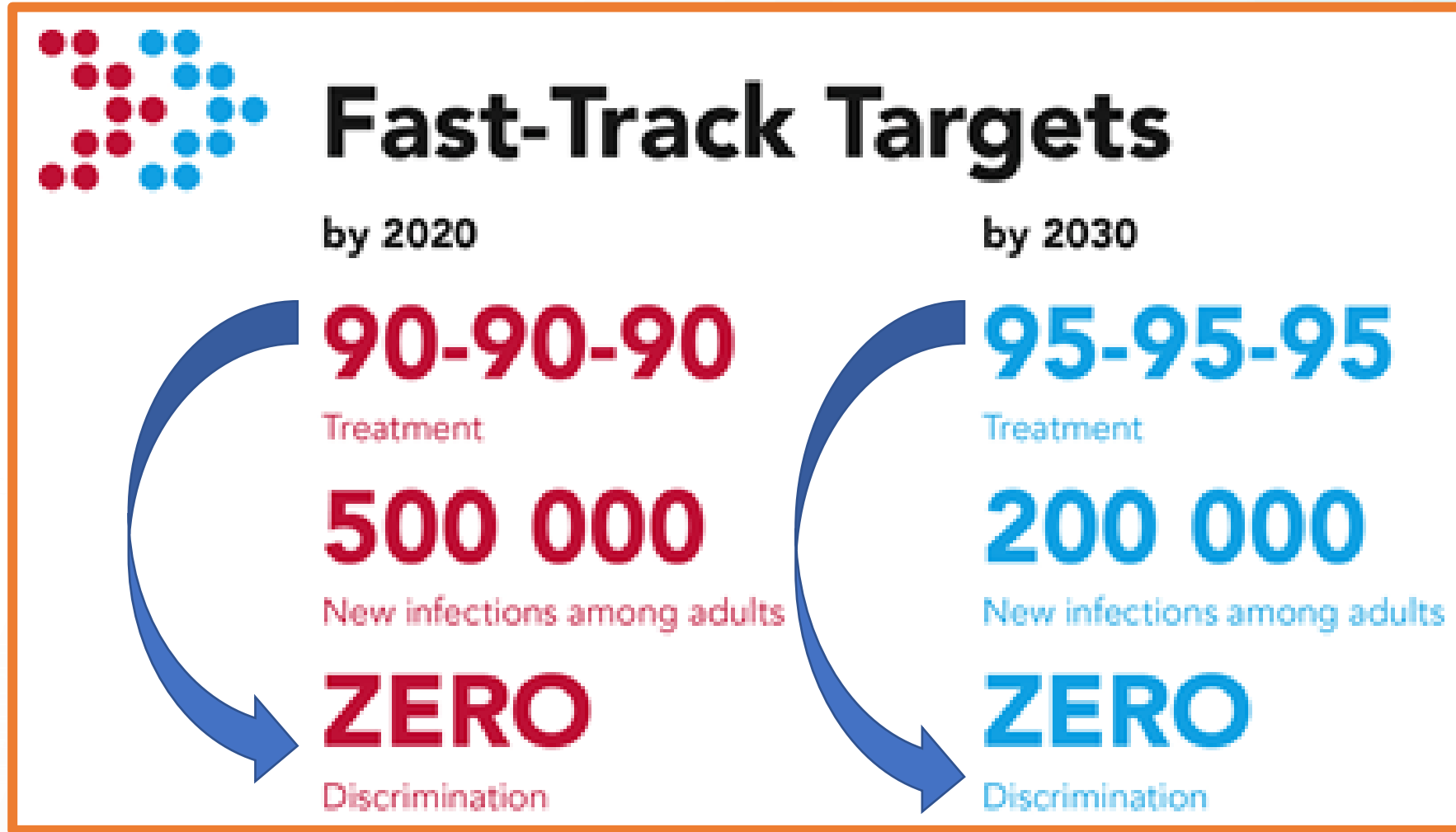


UNDETECTABLE Equals UNTRANSMITTABLE

VIRAL LOAD <40-400cpm



The targets can work for us.....



# Approaches to reducing Stigma: *What works in other health domains such as substance use and mental illness*

Particularly good for adolescents: school-based programmes & the internet



## Education:

*Correct misinformation & counter inaccurate stereotypes using factual evidence.*

**Effective?** Self-stigma, but mixed evidence for public stigma & limited ability for sustained impact

## Protest & Advocacy

*Advancing civil rights agenda and formally rejecting stigma – support for Grassroot movements & community stakeholders*

**Effective?** Mixed results on stigma (can strengthen negative public stigma)



## Contact

*Meaningful interactions with PLHIV who can share their lived experience (in person or virtually)*

**Effective?** Public & self stigma 2x as effective as educational campaigns (Corrigan et al., 2012)

## Peer Services

*Use of people who openly share the stigmatized experience as part of the health management team*

**Effective?** Well known strategy for HIV services



*Ironically – the need to reduce social distance*

*Source: Ending Discrimination Against People with Mental and Substance Use Disorders: The Evidence for Stigma Change. Washington (DC): National Academies Press (US); 2016*





## HIV - Related Stigma, Discrimination and Human Rights Violations

Case studies of successful programmes



UNAIDS BEST PRACTICE COLLECTION

UNAIDS 2005



# A concrete agenda (IAS) and some best practices (UNAIDS)

- Global Partnership for Action to Eliminate all forms of HIV related stigma (GNP+)
- Role of governments to repeal stigmatizing laws and policies and ongoing advocacy for this
- New funding to scale up research for stigma mitigation
- Prioritise stigma mitigation in national plans
- HCWs should also tackle stigma and hold each other accountable
- PLHIV and others find the resilience to continue to advocate



IAS Annual letter 2019





# Stigma reduction efforts remain chronically underfunded:

National budgets and large grants are used up in the purchase of commodities

## **But funding critically needed for:**

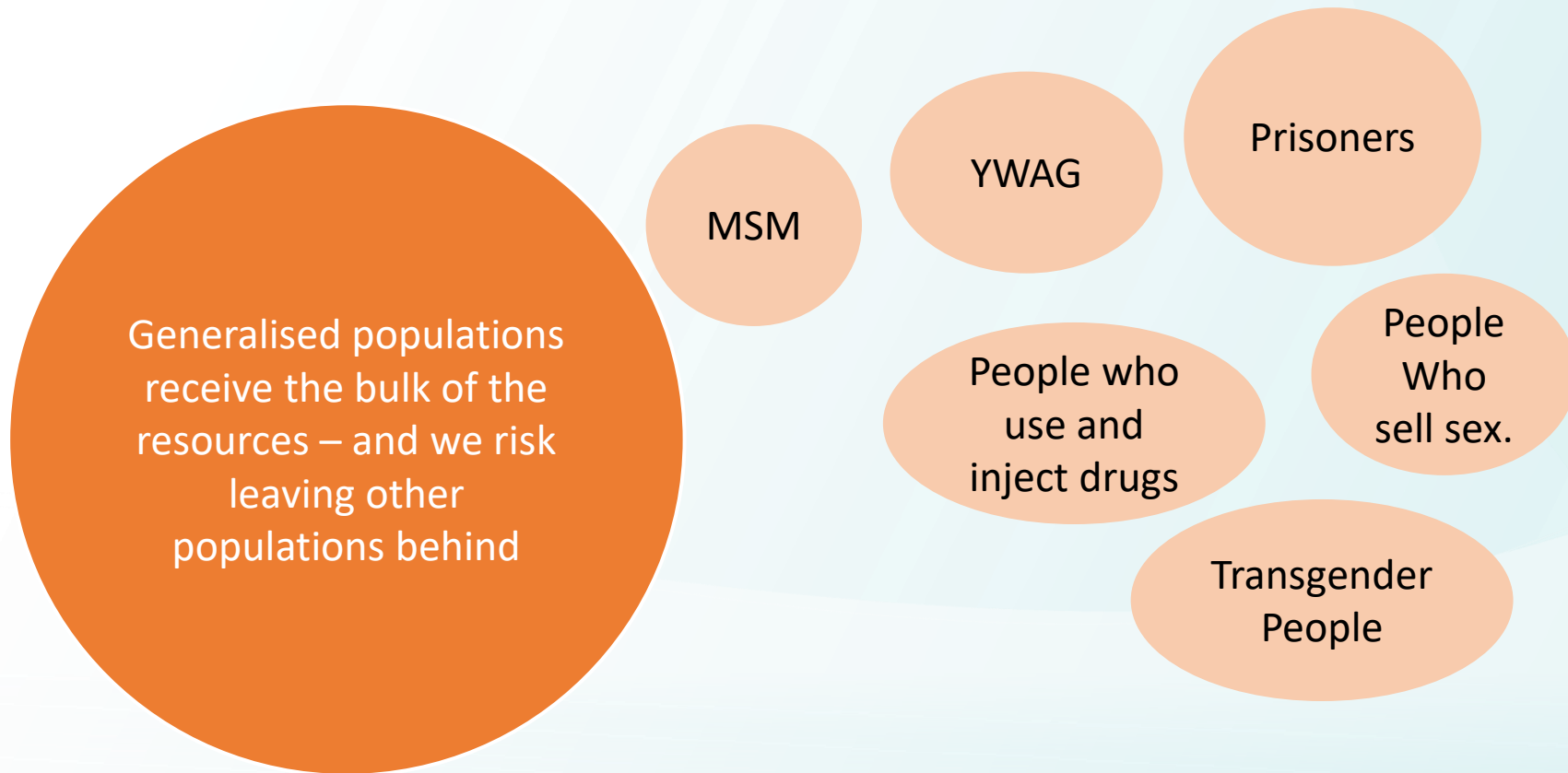
- Community mobilisation and information dissemination
- Interpersonal communications
- Civil society support
- Peer led programs

These elements are required to reduce stigma and make large-scale treatment and prevention programmes have a meaningful impact.



Gains are being made within generalised populations, but there is an alarming shift in disease burden towards key populations.

**We can't afford to leave them behind.**



**FRAGILE, UNDERFUNDED, FRAGMENTED, STIGMATISING AND INEFFICIENT HEALTH SYSTEMS**

**WE WILL NOT  
REACH 95-95-  
95 and  
CONTROL HIV  
UNTIL WE  
END  
HIV- RELATED  
STIGMA**



The tools exist. HIV/AIDS can be **treated** and **contained**.

But in many communities, social, political and economic obstacles **get in the way**.

### **STIGMA CONTINUES UNABATED**

**In those places, the epidemic is far from over.**

Science

<http://www.sciencemag.org/news/2018/06/nigeria-has-more-hiv-infected-babies-anywhere-world-it-s-distinction-no-country-wants>

<http://www.sciencemag.org/news/2018/06/russia-s-hiv-aids-epidemic-getting-worse-not-better>

<http://www.sciencemag.org/news/2018/06/face-misguided-response-hiv-aids-russia-these-bright-stars-are-taking-charge>

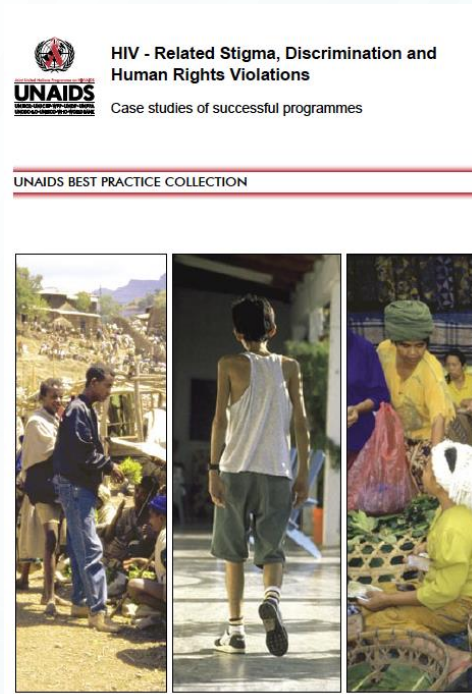
PBS NewsHour

<https://www.pbs.org/newshour/features/end-of-aids-far-from-over/>

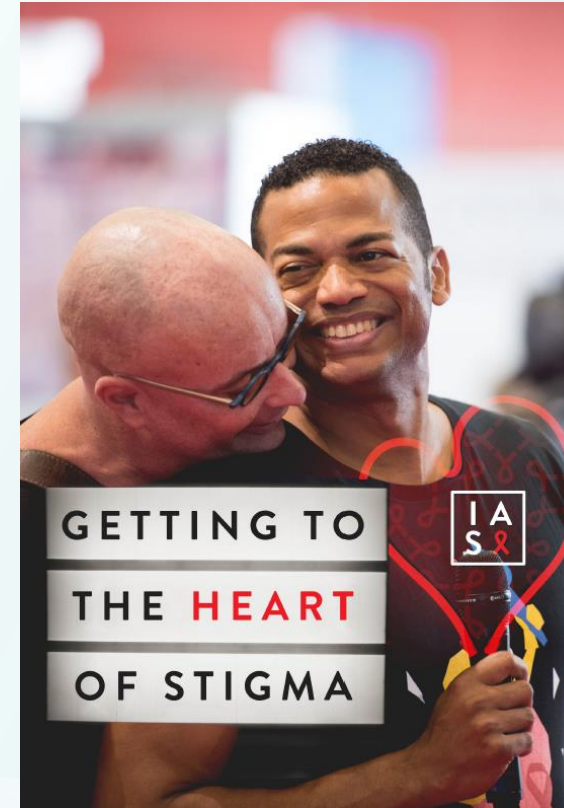


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- IAS



UNAIDS 2005



IAS 2019 annual letter