

WHERE'S THE EQUITY?

Including People with Disabilities in HIV Prevention Programming and Research

Monday, August 5
9:00 AM – 10:30 AM ET

Welcome all!

Image: Miles Peacock via Unsplash



**THE
CHOICE
AGENDA**



HIV prevention research - a new forum for advocacy on the latest

avac.org/project/choice-agenda

- **Yebo Lapho
(Gogo) Edit
[feat. DJ Maphorisa
& Djy Biza]**
Felo Le Tee, Scotts Maphuma, Thabza Tee

- **Don't You
(Forget About Me)**
Simple Minds

- **Remember**
Asake

- **Si Antes Te Hubiera Conocido**
KAROL G

**Aug 5
Playlist**

DJ JIMBERLY

Today's Agenda

WHERE'S THE EQUITY?

Including People with Disabilities in
HIV Prevention Programming and Research

Monday, August 5
9:00 AM – 10:30 AM ET

More info/register
tinyurl.com/wherestheequity



Moderators

- JD Davids, Strategies for High Impact / Long COVID Justice
- Patriciah Jeckonia, LVCT Health

Speakers

- Dr. Hannah Kuper, London School of Hygiene & Tropical Medicine
- Sarah Mwikali, Gifted Community Centre
- Tafadzwa Maseva, Zimbabwe Network for Disability
- Brian Minalga, Office of HIV/AIDS Network Coordination (HANC)
- Commentary: Maria Bakaroudis, UNFPA

Disability and HIV – what is the link and why does it matter?

Professor Hannah Kuper

London School of Hygiene & Tropical Medicine

Missing Billion Initiative

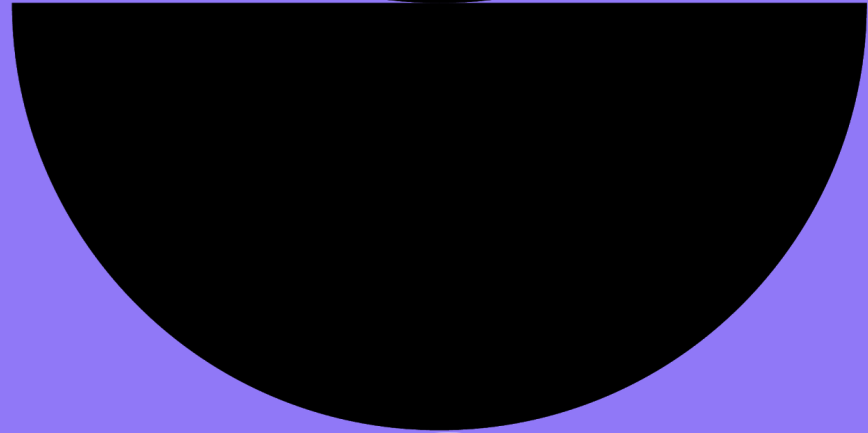
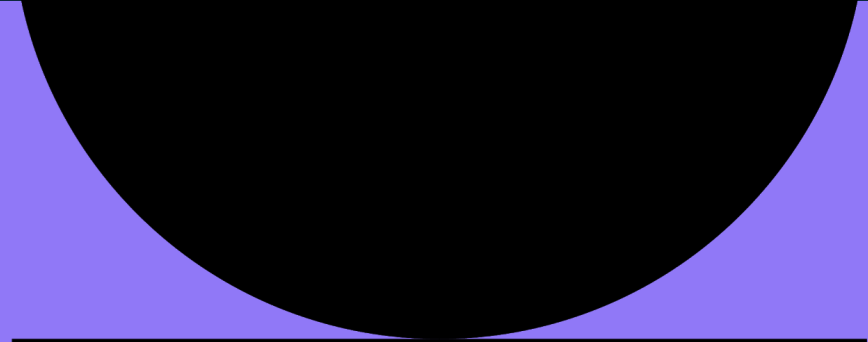
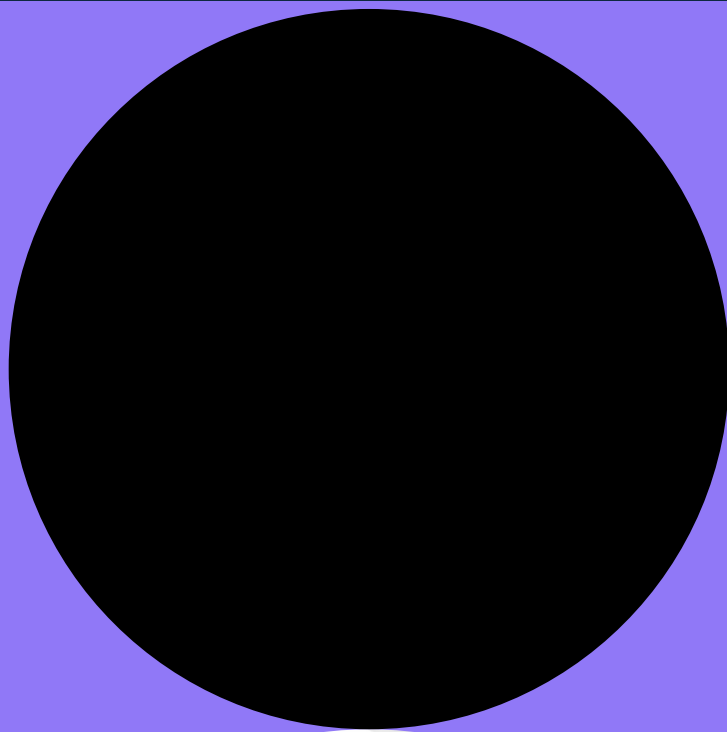
LONDON
SCHOOL of
HYGIENE
& TROPICAL
MEDICINE



16%

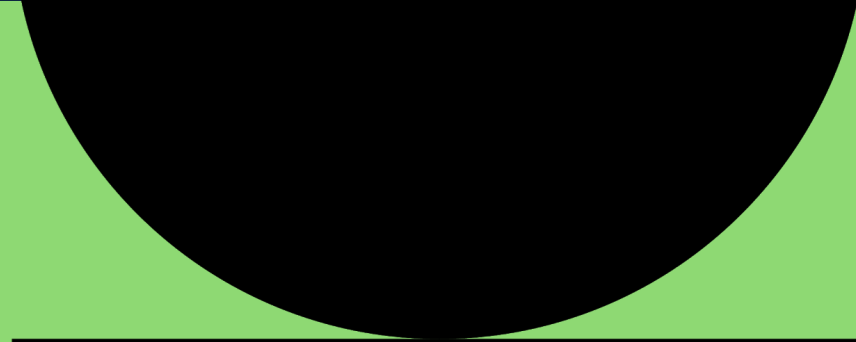
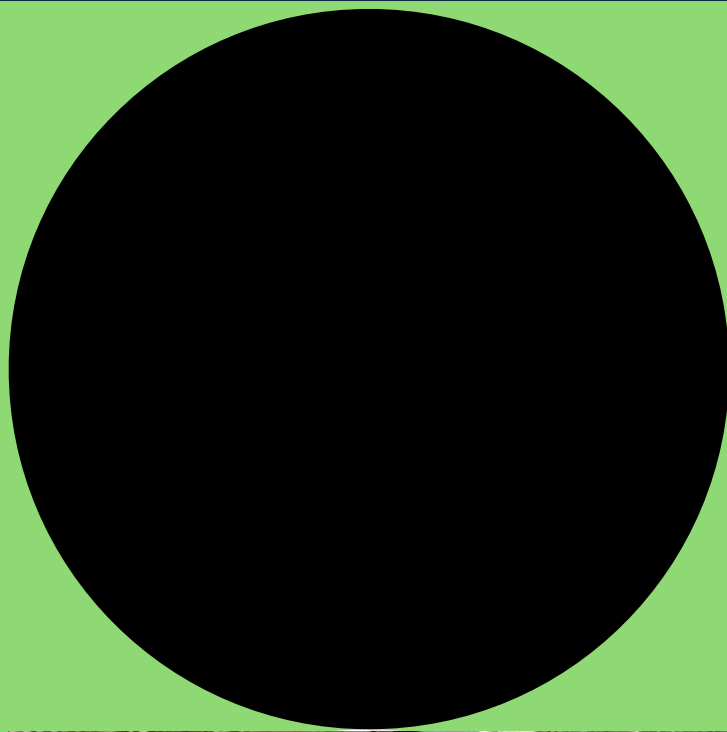
Of the world's
population has a
disability





**Disability
is diverse**





**Poverty, exclusion
and stigma are
common**



These are also social
determinants of HIV!

Risk factors for HIV higher among people with disabilities

Exclusion from information and programs

- Less knowledge and information
- Lower school attendance

More behavioural risk factors

- Younger age at first sex
- More STIs
- More sexual partners
- More sex for money

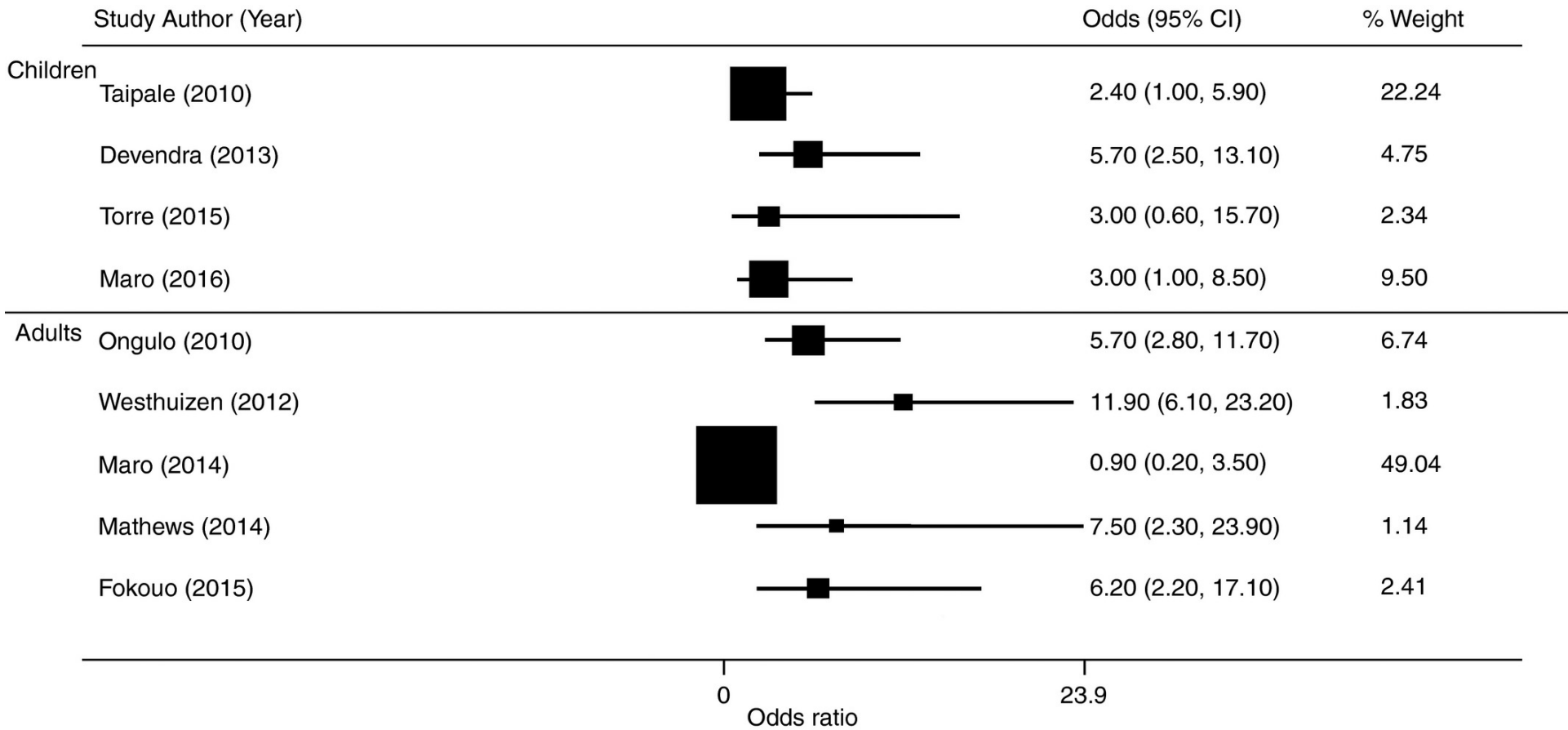
More structural determinants of HIV

- More violence
- More poverty
- Less education

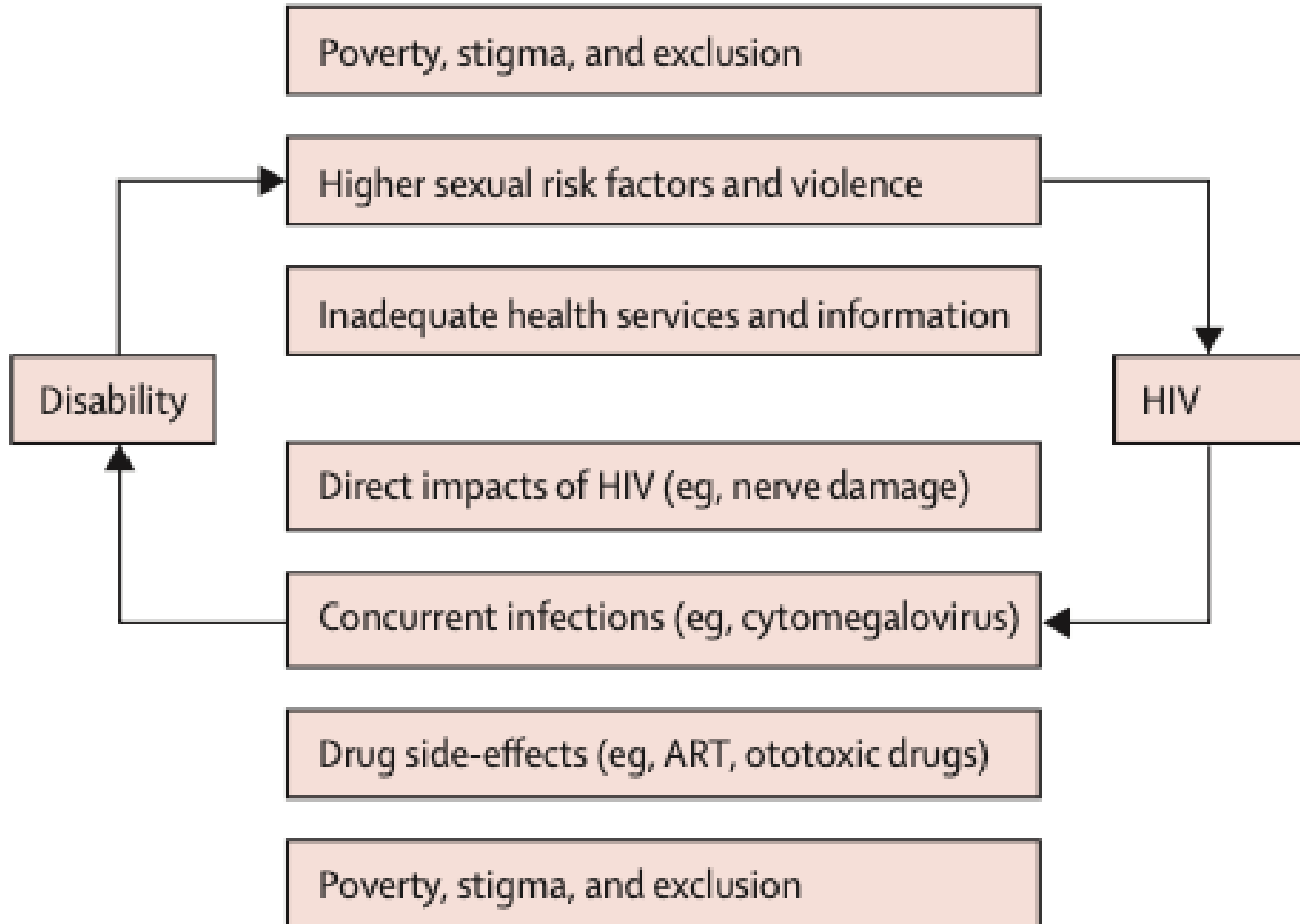
HIV can also cause
impairments



HIV can cause impairments – like in hearing



Two-way direction between disability and HIV

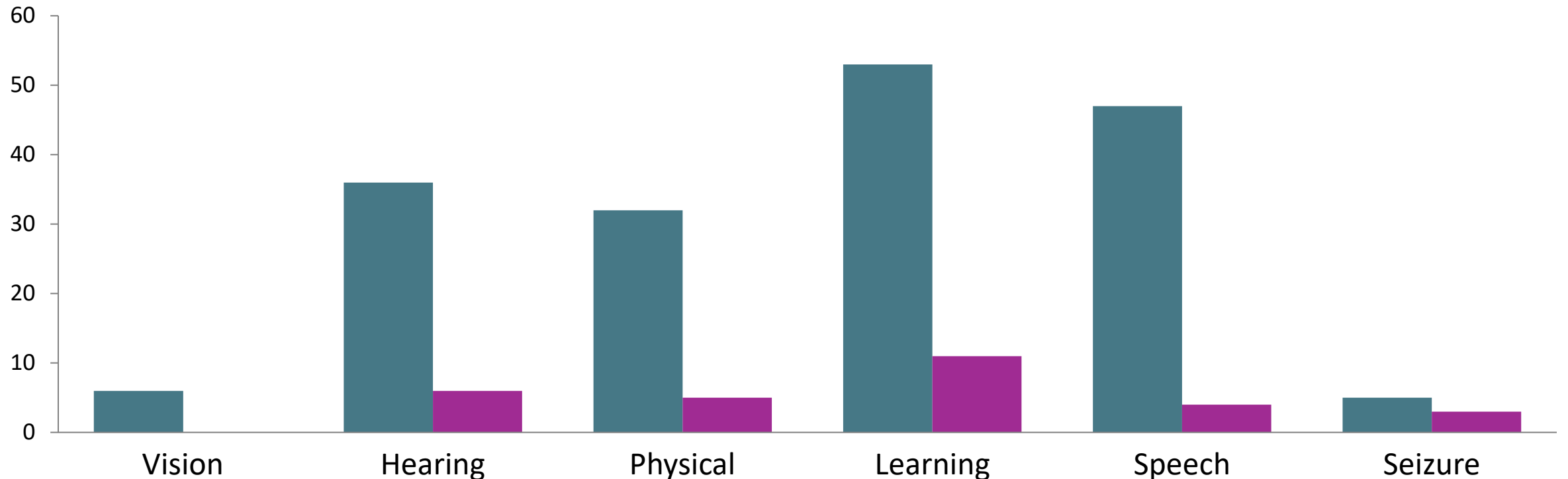


Disability is common among
people with HIV

Overall, 33% of HIV positive children had disabilities, compared 7% of controls

Children reporting disability, In % of all surveyed

Case Control



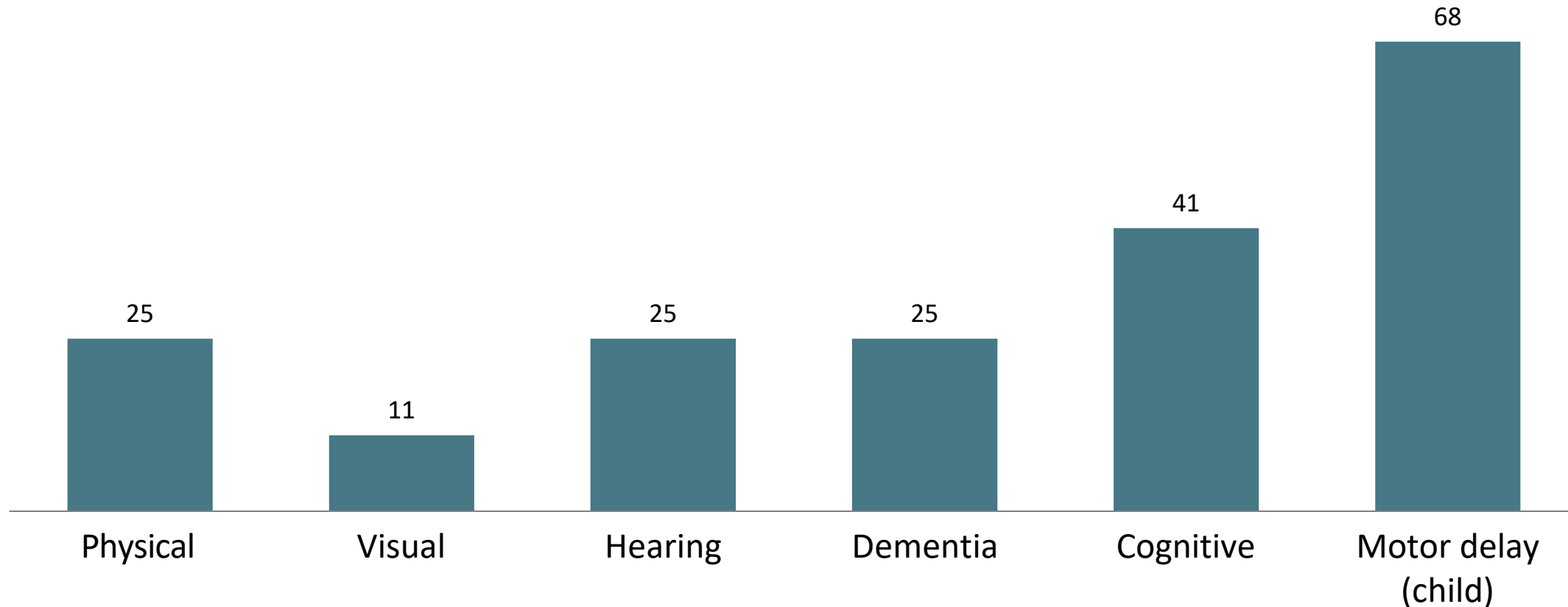
SOURCE: Devendra A, Makawa A, Kazembe PN, Calles NR, Kuper H (2013) HIV and Childhood Disability: A Case-Controlled Study at a Paediatric Antiretroviral Therapy Centre in Lilongwe, Malawi. PLOS ONE 8(12): e84024

**MISSING
BILLION**

Cross-country review from SSA showed high prevalence of impairments

Number of people with HIV experiencing an impairment

In % of total people with HIV surveyed



HIV-related disability creates a “double burden”

Category	Measure	Country	Example
Quality of life	PEDSQL	Malawi	Worse emotional functioning
Mental health	Depression, anxiety	Zimbabwe, South Africa	4 x more depression and anxiety
School inclusion	Missing days, repeating year, social exclusion, lower grades	Zimbabwe, Malawi	Worse school functioning
Social inclusion	Forming friendship	Zimbabwe	15 x greater difficulties forming friendships



People with disabilities face additional barriers in accessing healthcare

- Accessibility
- Informational
- Attitudinal
- Financial
- Lack of services

**MISSING
BILLION**

Exclusion from HIV services among people with disabilities

Barrier	Example studies	Country
• Exclusion from HIV education / prevention ²	• 14% reached by prevention activity	• Cross-country
	• More likely to have incorrect knowledge on modes of transmission	• Nigeria ⁴
• Lack of access to prevention ²	• 55% access condoms • (85% Sexually active)	• Cross-country
• Lack of access to testing ²	• 27% tested for HIV	• Cross-country
	• 53% tested for HIV	• Ethiopia ³
• Lack of access to drugs	• 9% lower adherence to HIV drugs	• South Africa

Direct challenge to HIV goals

1 Reference: van Egeraat et al. Afr J AIDS Res. 2015;14:285-94.; Schenk KD. Disabil Rehabil. 2018 Oct 3:1-14.

2 Global fund report

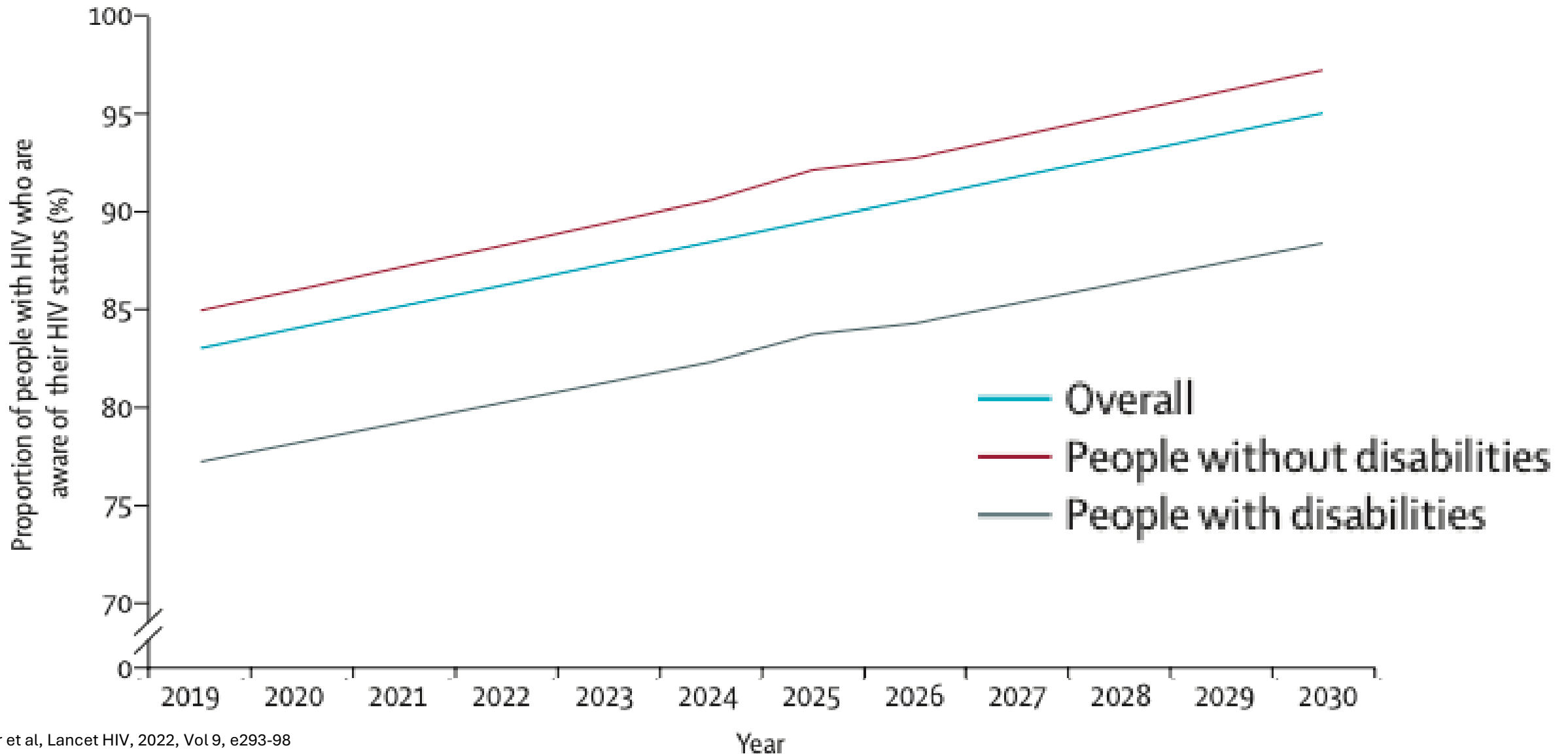
3 Aderemi et al, 2013, Predictors of voluntary HIV counselling & testing services utilization among people with disabilities in Addis Ababa, Ethiopia

4 Carpenter et al. Disabil Rehab 2020; 42: 806-13

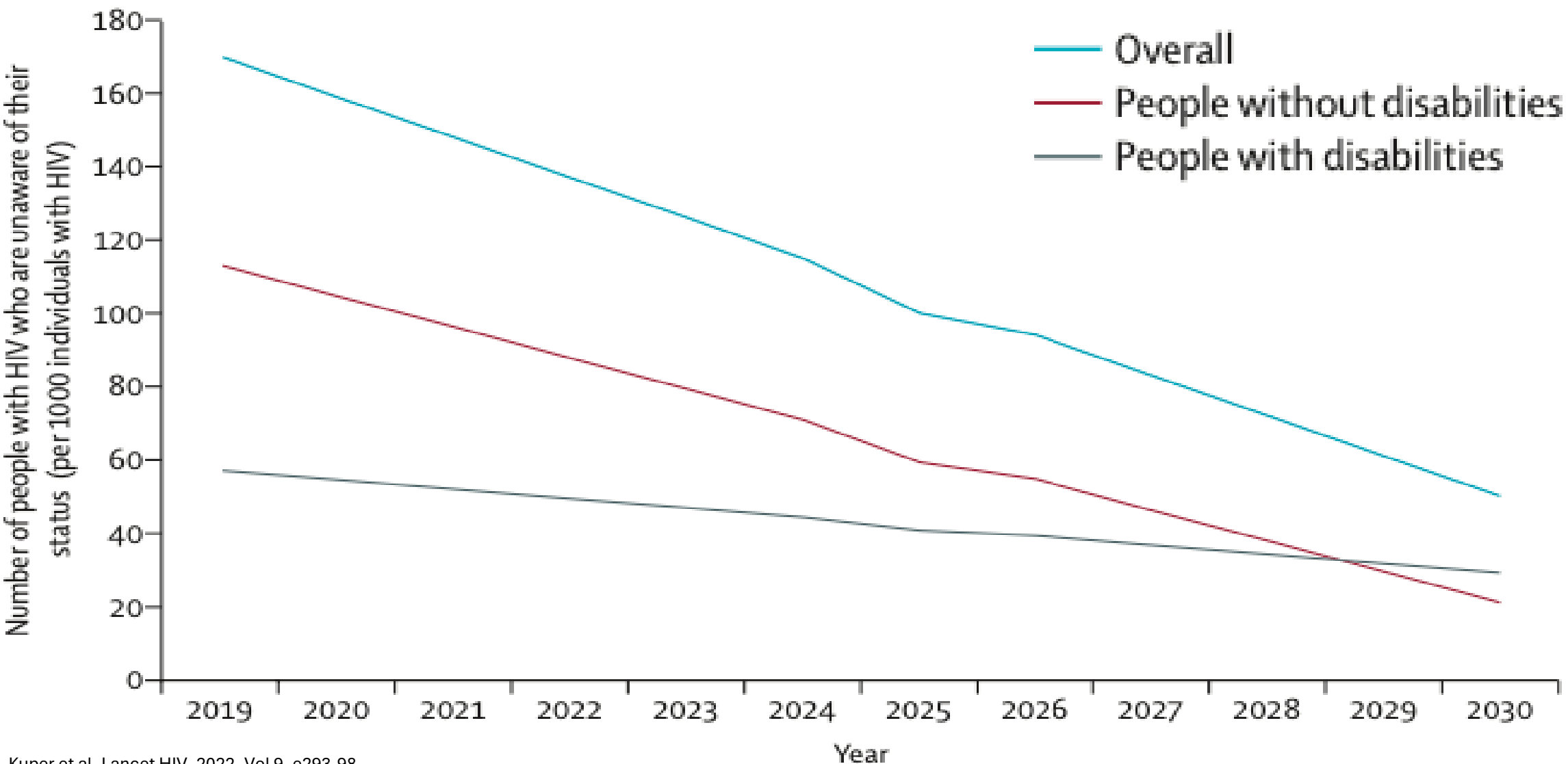


What are the implications for
this inequity in healthcare
access?

Proportion of people with HIV aware of their status

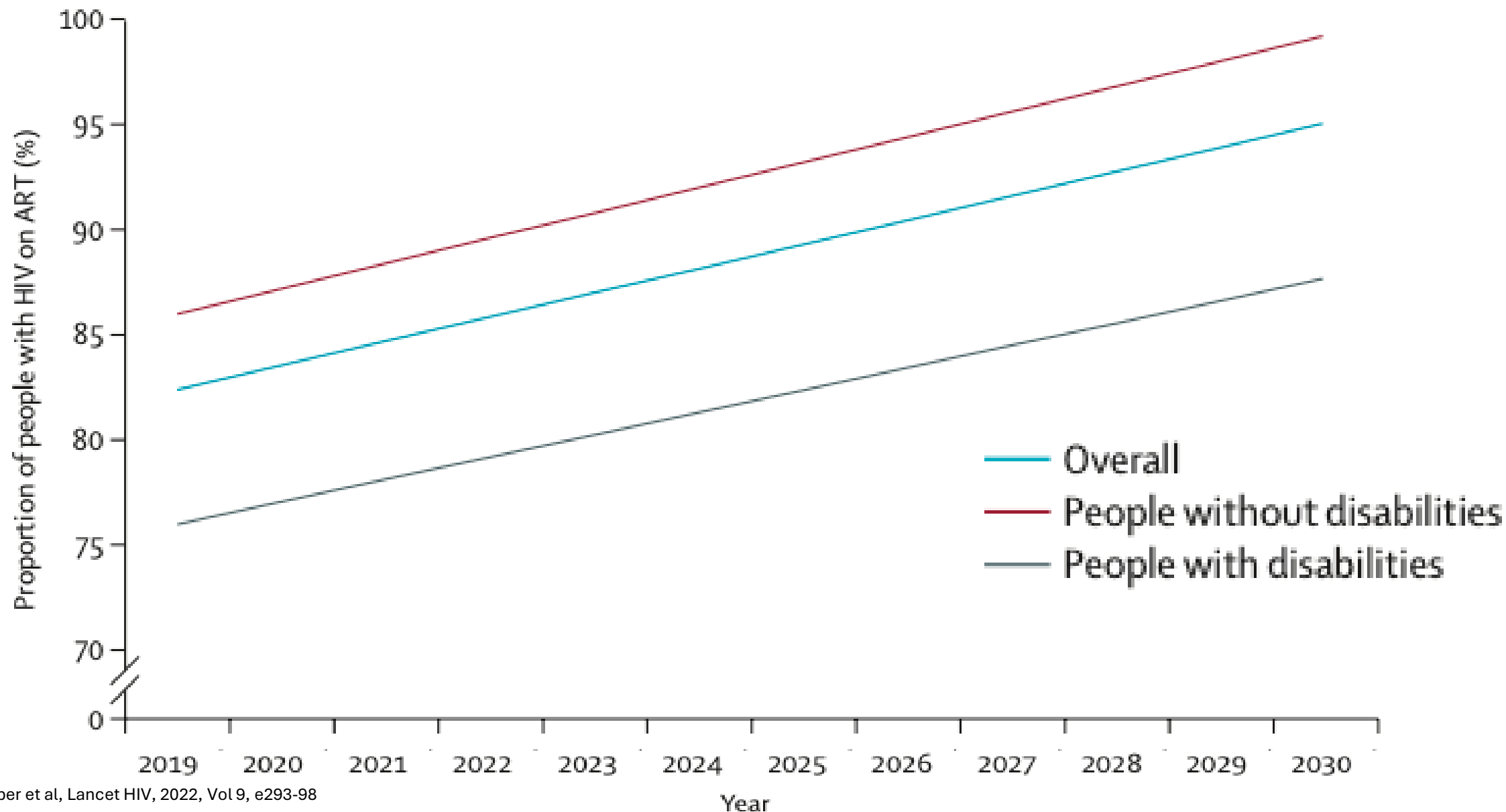


Number of people with HIV unaware of their status

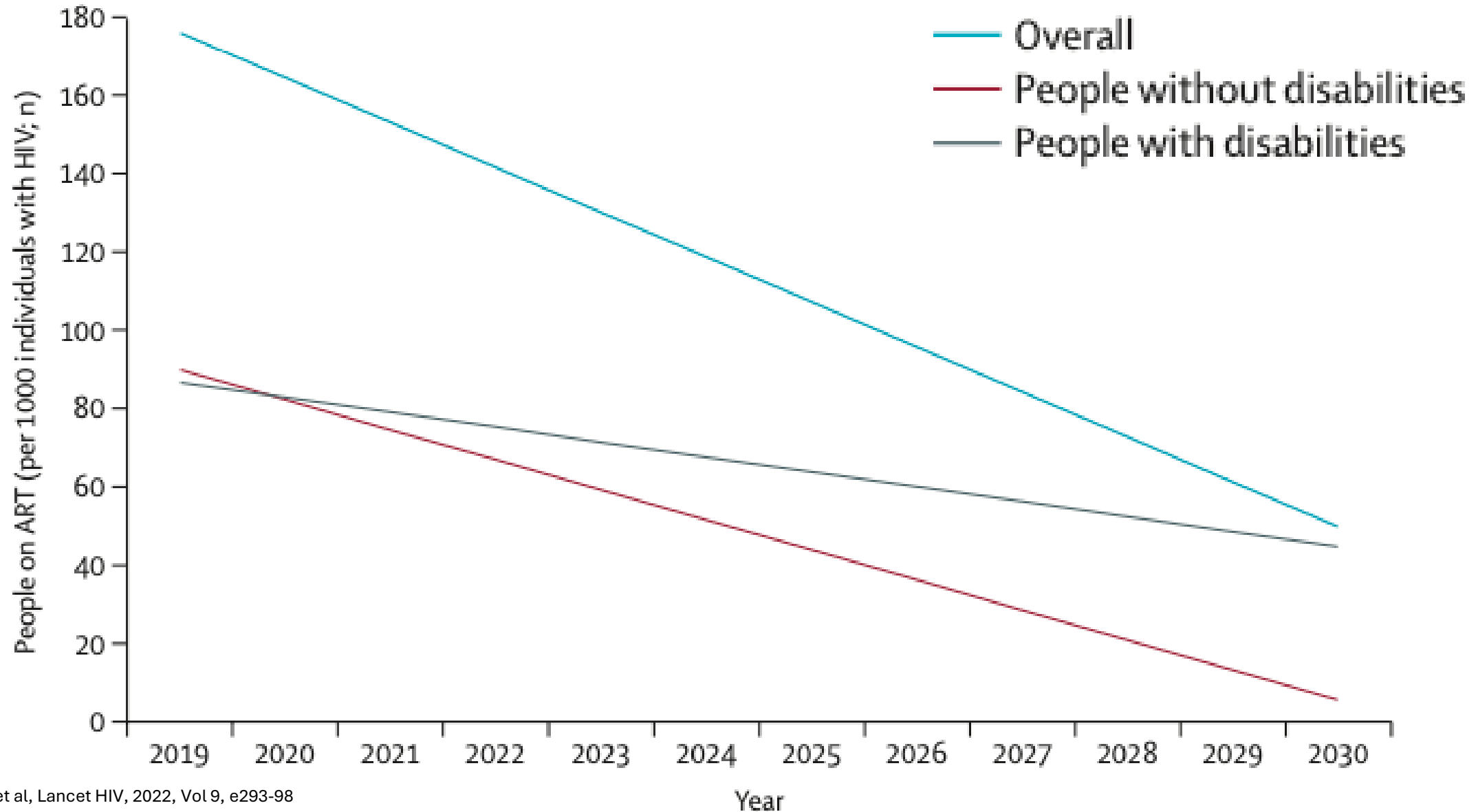


Kuper et al, Lancet HIV, 2022, Vol 9, e293-98

Proportion of people with HIV on ART

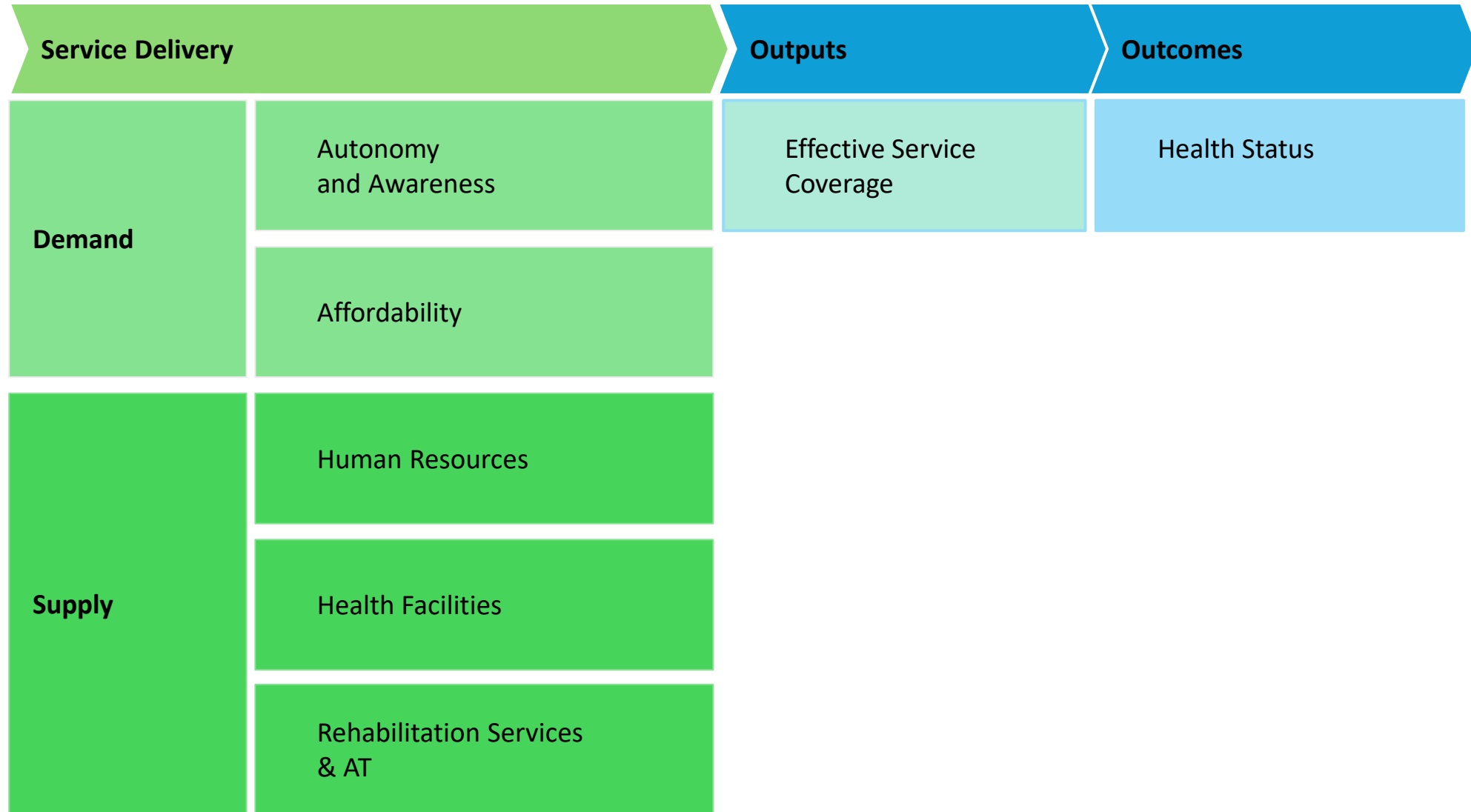


Number of people with HIV not on ART

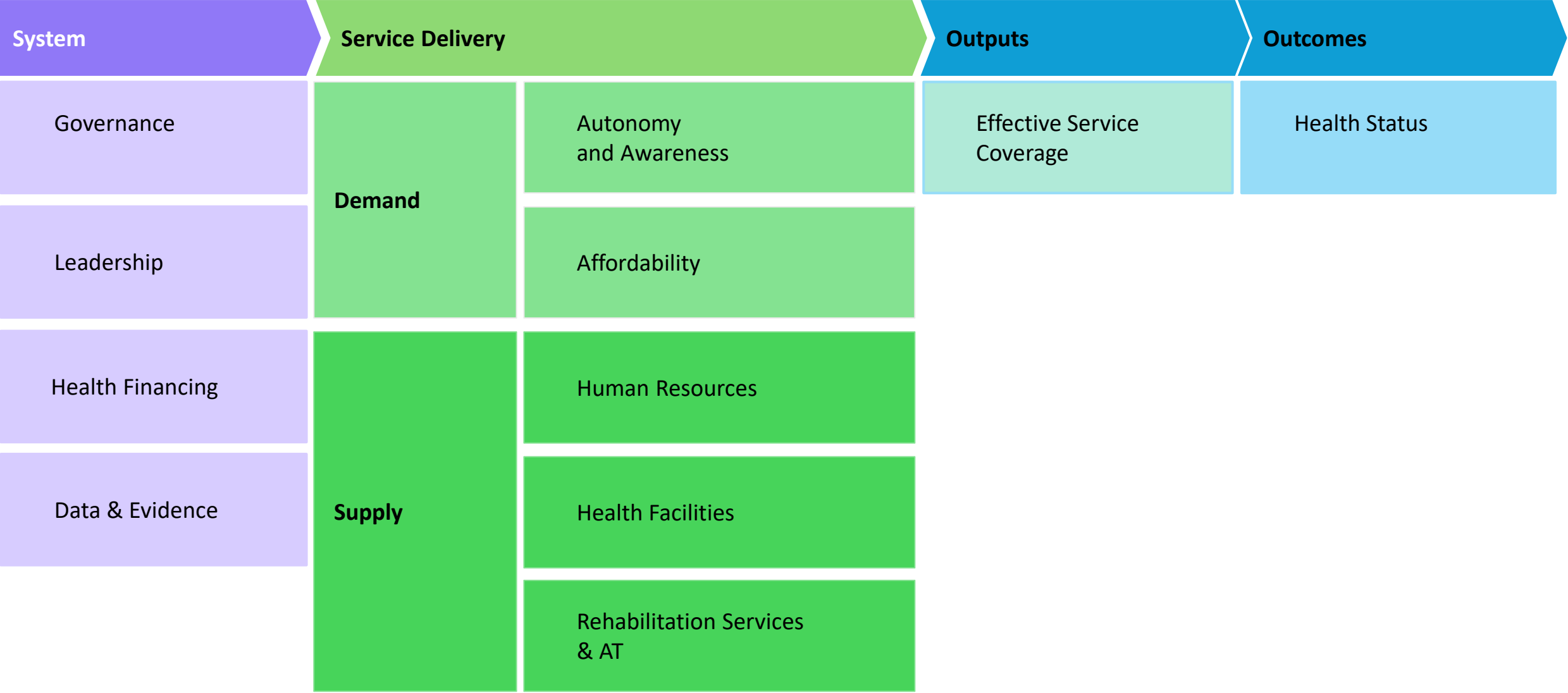


Global HIV targets unachievable
without inclusion of people with
disabilities

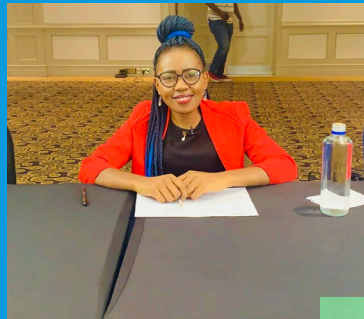
HIV programmes must become disability inclusive!



HIV programmes must become disability inclusive!



Thank you for your time and
attention



Co-founders

Gifted Community Center-GCC

- Founded by 2 individuals with lived experience of disability to empower themselves and other youth with disabilities.
- Organization for and by youth with disabilities (caregivers) – informal settlements / colleges
- Operationalized in 2019 in Kibera
- Identify as a Leadership hub for/of youth with disabilities

CONT...D



- Peer to peer model
- 500 Ambassadors – students / graduates with disabilities in other counties / colleges
- Self help groups/ orgs / associations
- Empower, educate, inform, mentor, and advocate

“Nothing for us without us”



Visible and invisible disabilities, 15-40 years

GCC PILLARS / STRATEGIC FOCUS

- Sustainable livelihoods
 - Health programming (SRH, Mental health, GBV, and HIV Prevention programs)
 - Leadership and Governance
- Research and advocacy- cross cutting – informs projects / policy advocacy

PAST RESEARCH (2019-)

- A Research on the uptake of SRH/HIV Prevention services among young girls and women with invisible disabilities in Kibera, 2019- ViiV Healthcare, UK
- A Research on the Impact Of COVID-19 among Youth with Disabilities in Kenya, 2020-2021, Leonard Cheshire, UK (only org in Kenya)
- A Research on food and nutrition security (Right to Food) among persons with disabilities, 2020-2021, African Population and Health Research Centre, APHRC
- A Research on the uptake of SRH/HIV/GBV services among adolescents and young people with disabilities in the 13 villages of Kibera, 2021, LVCT
- Global Disability Summit national youth consultations among youth with disabilities, 2021, Leonard Cheshire, UK
- GBV response mechanisms for girls and women with disabilities in Nairobi

HIV and Disability ISSUES

- Lack of disaggregated data – no resource allocation – no accountability
- Diversity of disabilities – deaf, VI, PD, Speech, etc – customized interventions
- Access to HIV information / platforms – lateness of info
- Access to HIV services
- Accessibility – SLIs, confidentiality, caregivers, infrastructure
- Community perception of PWDs- negative attitudes, ignorance-parents withholding their children from HIV testing/seeking services

CONT...D

- Background – drugs/alcoholic parents – unbothered with their children
- Vulnerability predisposes them to HIV- nature of disability, defenseless, inability to see/recognize the violator; inability to communicate/report; lack protection – e.g., by being left alone at home
- Reporting mechanisms and processes / treatment- from community level- unclear, not known, - some do not know where to go, whether there is anything like HIV,
- Service providers attitudes towards PWDs – little knowledge on disability and HIV, confidentiality,

Recommendations

- Deliberate research on disability and HIV – disaggregated
- Deliberate/ intentional allocation of resources to disability and HIV
- Collaboration with organizations of persons with disabilities
- Customized and accessible channels on HIV for PWDs
- Accessible facilities / service delivery points
- Policy for all medical personnel learn SLI
- Continuous awareness and education on HIV and disability from school level to community level
- Customized IEC materials on HIV and disability



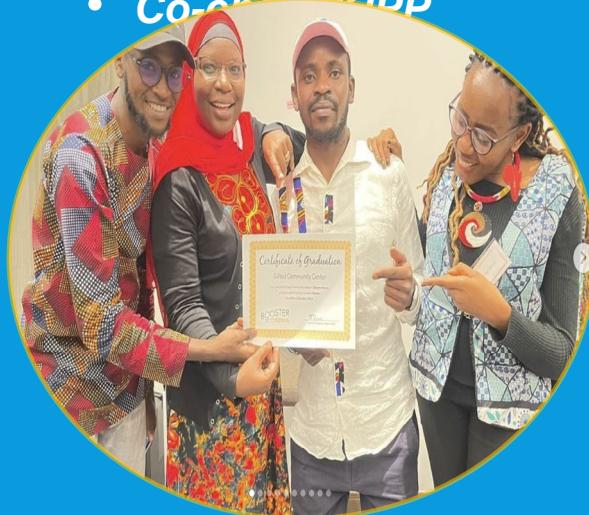
Policy Advocacy

Review /influence of policies:

- Nairobi County Disability Act,
- PWDs Amendment Bill 2023, CIDP,
- Minimum Standards on Inclusion of Persons with Disabilities in Political Parties,
- Reproductive Health Bill (EAC Petition - *Endorse and implement treaties against gender-based violence in East African Community (EAC)*),
- Kenya Sign Language Bill, NGEC SP, etc.
- Children's ACT 2022

Awards and recognition

- **AWARD WINNER: Path Finder by Segal Family Foundation**
- **Organization of the year 2023, IK**
- **Political inclusion of PWDs award by WFD**
- **Co-chair, Commonwealth Children and Youth Disability Network**
- **Co-chair, KIPP**



PART OF GCC TEAM



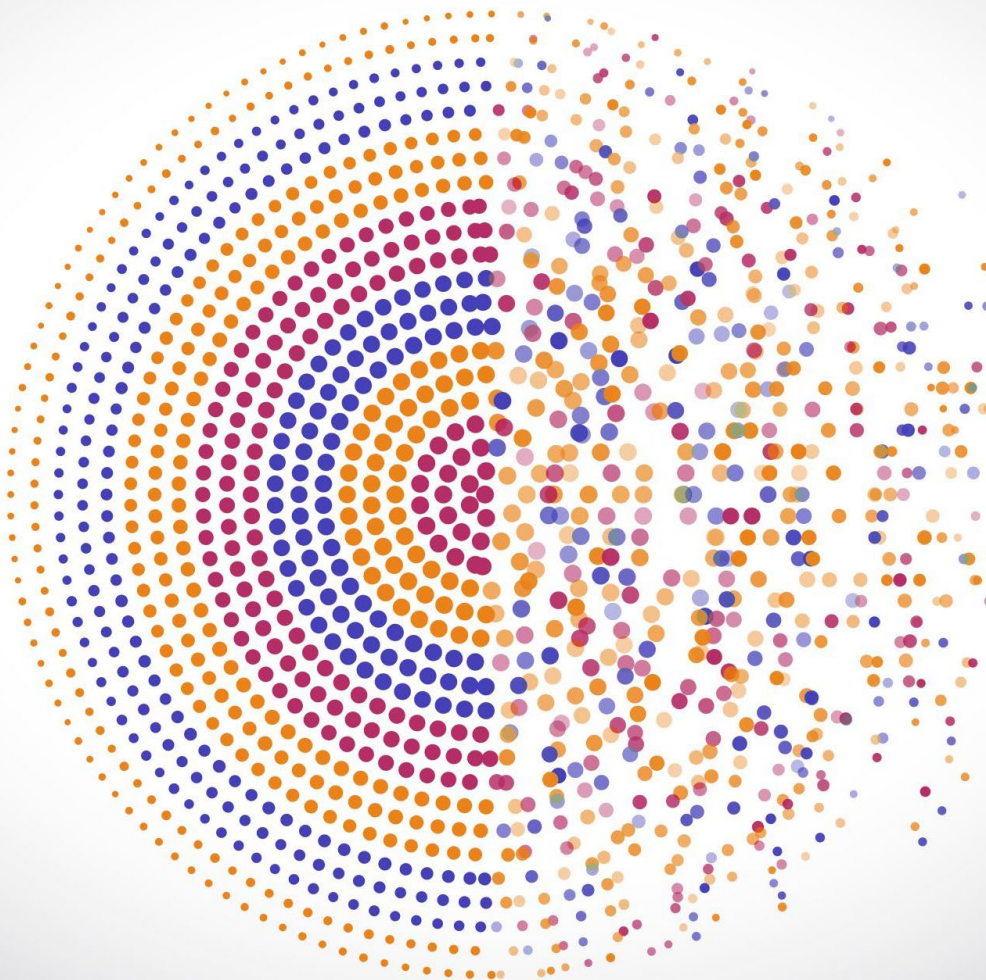


THANK YOU



THE END





People with Disabilities in HIV Research

Expanding the Conversation

Brian Minalga, MSW
HANC Deputy Director



How are “disabilities” defined?

Scope of Disability

- US Interagency Committee on Disability Research found that 67 separate laws define disability for federal purposes alone.
- CDC: “any condition of the body or mind that makes it more difficult to do certain activities and interact with the world around them.”
- WHO: “impairment in body structure or function, activity limitation, and participation restrictions in normal daily activities.”
- ADA (also used by NIH): “physical or mental impairment that substantially limits one or more major life activities” or “history or record of such an impairment” or “a person who is perceived by others as having such an impairment.”
- NIMHD: “61 million people living with disabilities in the US, accounting for more than 27% of the US population or 1 in every 4 persons.”
- NIH designated people with disabilities as a “health disparities population” in 2023

“People with Disabilities”

- Immensely broad
- Poorly represented in research
- Urgent health needs

The RSR

- Age, Ethnicity, Gender, Drug Use, Pregnancy, Race, Sex Assigned at Birth

Are people age 0-12 included? Yes/No

Are transgender men included? Yes/No

Are there enrollment goals set for Black participants? Yes/No

Are people with disabilities included? ...



Possible Solution: Link to External Guidance

- RSR Item 11: Does the study correctly apply the DAIDS Cross-Network Trans and Gender-Diverse Working Group’s “Guidance on the Use of Gender-Inclusive HIV Research Practices”?
- RSR Item 12: Does the study correctly apply the *NIAID HIV Language Guide*?

RSR Item 4: People who use drugs

- Substance use disorders are included as disabilities in Affirmative Action regulations
- HPTN 094 designed specifically for people with opioid use disorder
- Many HIV research studies exclude people with substance use disorders (The RSR is designed to correct this).
 - Statistical rationale may still be used to exclude people who may contract HIV through injection drug use

People with Disabilities in HIV Research

- HIV is a disability!
- Many ACTG and IMPAACT studies are designed to examine and address health complications (disabilities?) in PLHIV (a disability):
 - Heart disease
 - HIV-associated neurocognitive disorder (HAND)
 - Inflammation
 - Liver function
 - Obesity
 - Reservoir reduction
 - TB



FDA to Require Diversity Plans

- FDA distinguishes 3 types of diversity:
 - Demographic characteristics (age, gender, race...)
 - Clinical characteristics (comorbidities, disease etiology...)
 - Other characteristics (access to care)
- RSR primarily focused on demographic diversity, but includes
 - Pregnancy (Item 7)
 - Sex and gender-based analysis (Item 10)
- Disability may fit into all 3 FDA categories of diversity
- Submit comments to FDA by September 26, 2024!



Expansion Point: Research Ethics

- *Belmont Report, Common Rule, Federal Policy for the Protection of Human Participants* specify the need for protections for “vulnerable populations”:
 - Pregnant people
 - Minors
 - People in prison
 - People with diminished decision-making capacity
- Inclusion criteria: “Willing and able to provide informed consent.”
- *Research Involving Individuals with Questionable Capacity to Consent: Points to Consider* (2009)

Expansion Point:

NIH Language Access Program (LAP)

- Requires “reasonable accommodations for people with limited English proficiency.”
- However, rooted in Title IV of the Civil Rights Act, which prohibits discrimination based on national origin (not disability).
- What about “reasonable accommodations” for people with disabilities that limit their sight and/or hearing?
- Are NIH-funded studies in compliance with the NIH LAP as it is?



Expansion Point: Further NIH Policy

- Policies and guidelines for inclusion of women, racial and ethnic minorities, people in different age groups, people from different socioeconomic backgrounds.
- What about people with disabilities?
- Again, are we in compliance to begin with?
- NIMHD designation of people with disabilities as a population with health disparities