



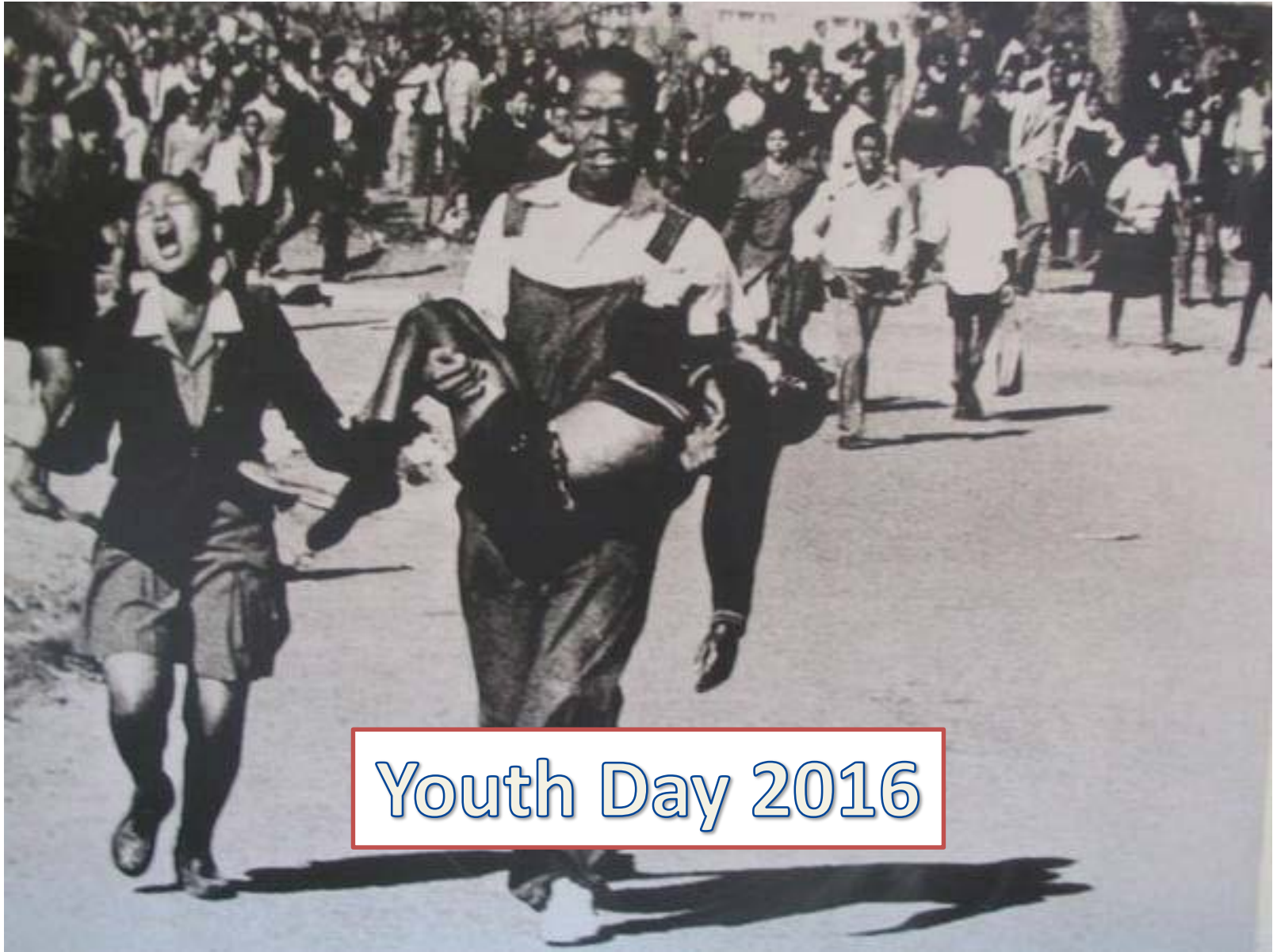
Sex and secrecy :

Disclosure to intimate partners among YPLWH



Linda-Gail Bekker
The Desmond Tutu HIV Centre
HPTN/IMPACT joint plenary
June 2016

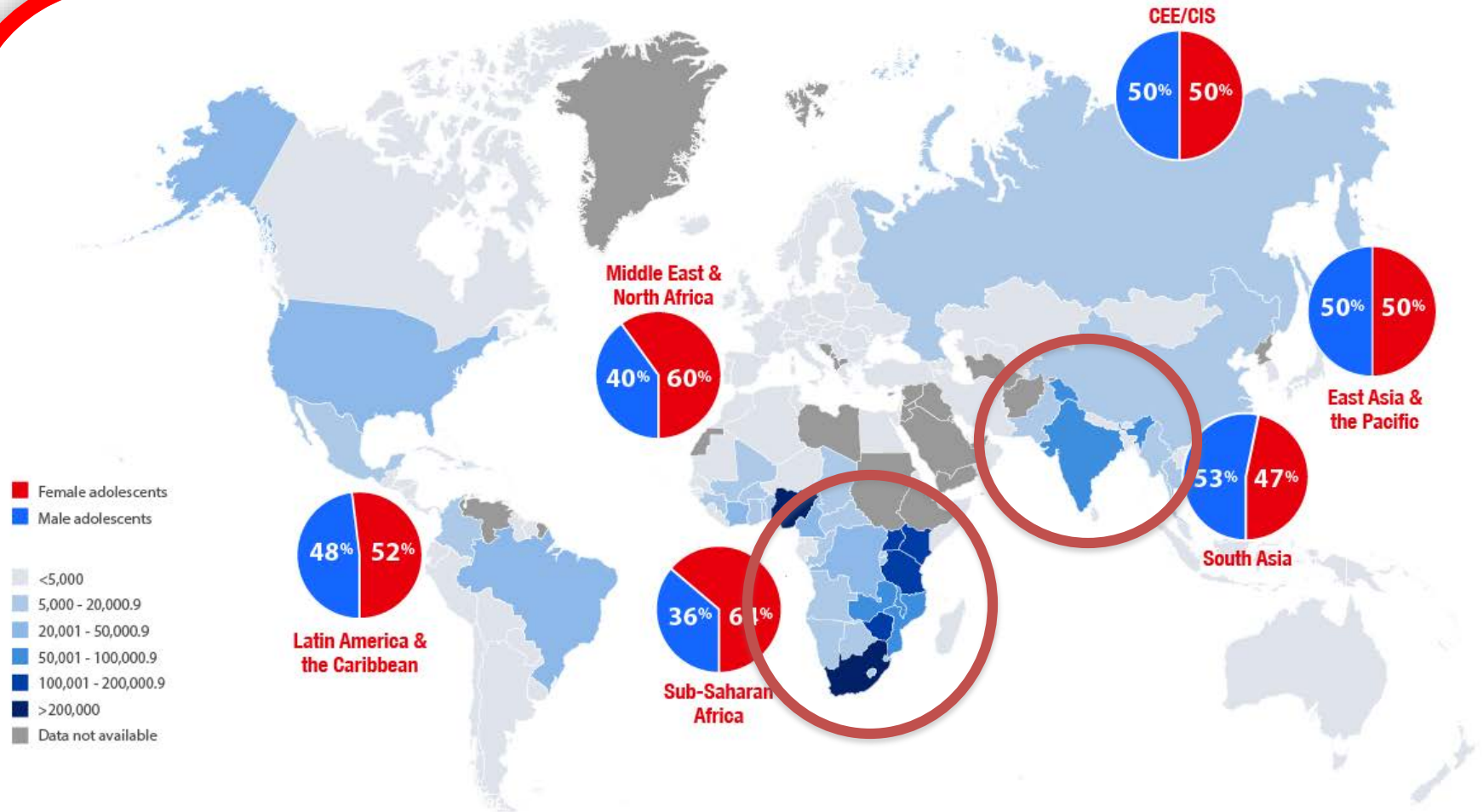




Youth Day 2016

Adolescents (10 – 19) Living with HIV

2.1 million [1.6 million – 2.6 million] of whom 60% are girls (2011)



Note: The map is stylized and not to scale. It does not reflect a position on the part of UNICEF on the legal status of any country or territory or the delimitation of any frontiers.

Source:

- Regional summaries by gender: UNICEF, Progress for Children, 2012 derived from 2010 estimates
- Country data: UNAIDS 2009 estimates



Two populations-



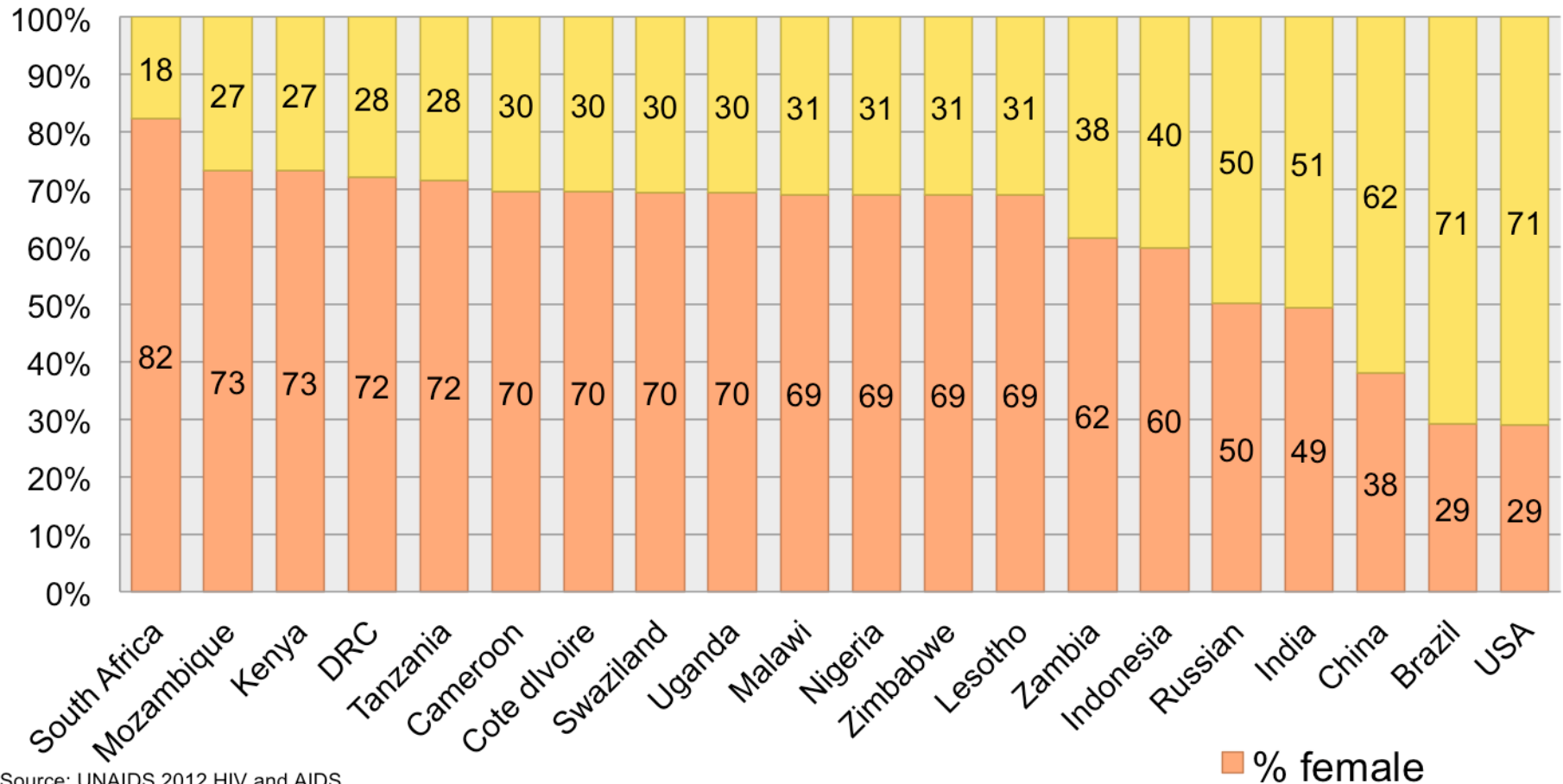
Perinatally infected youth, pHIVa

- F=M
- Younger
- Developmental stunting
- >treatment experienced
- Unaware of status
- Transitioned ex Paediatric Care
- Transition into Adult Care

Sexual and IDU Transmission, bHIVa

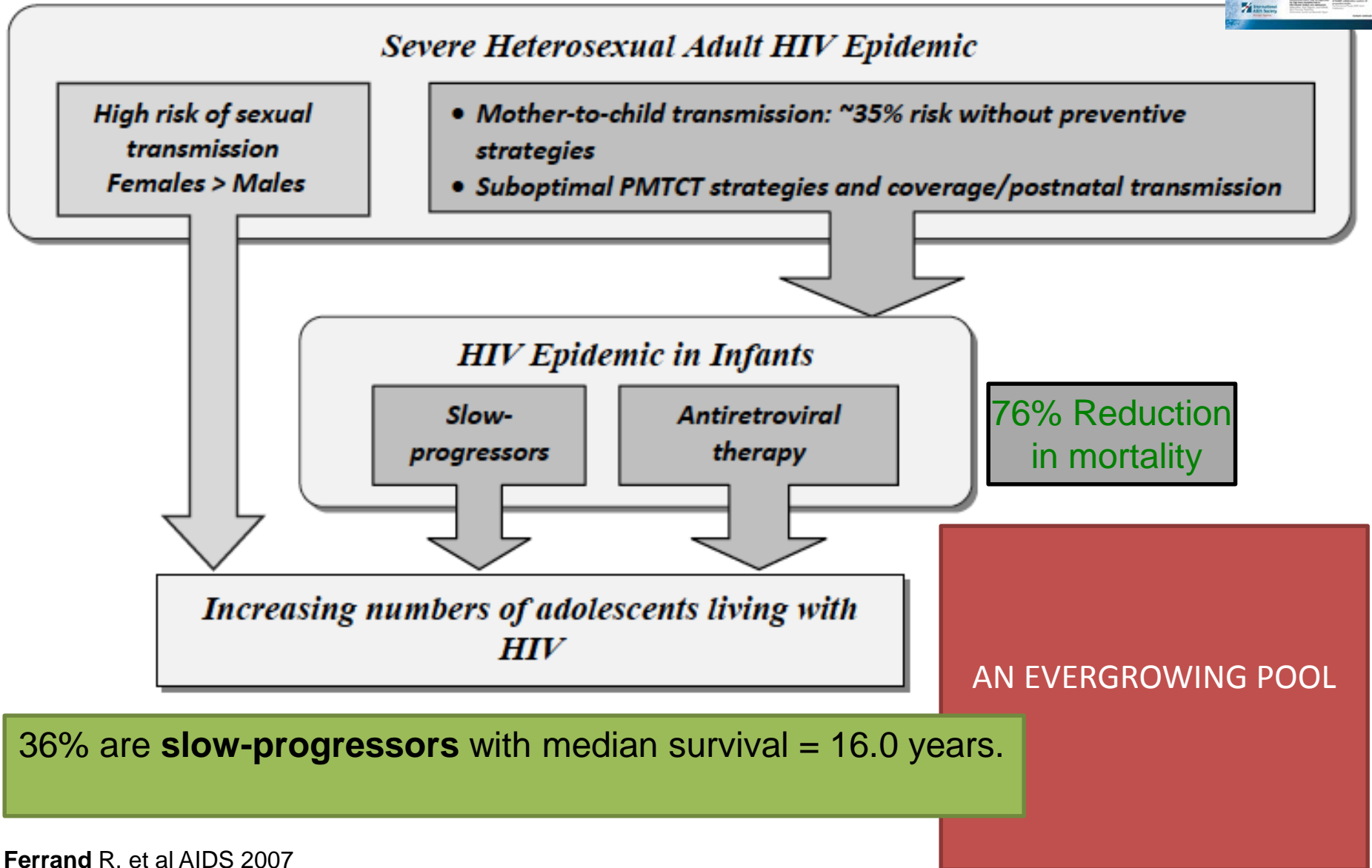
- F > M in Africa
- M>F elsewhere
- Older
- Treatment naïve
- Aware of status
- Transition into adult care

New HIV Infections in Adolescents in 20 Countries with Highest Number of New HIV Infections, 2012



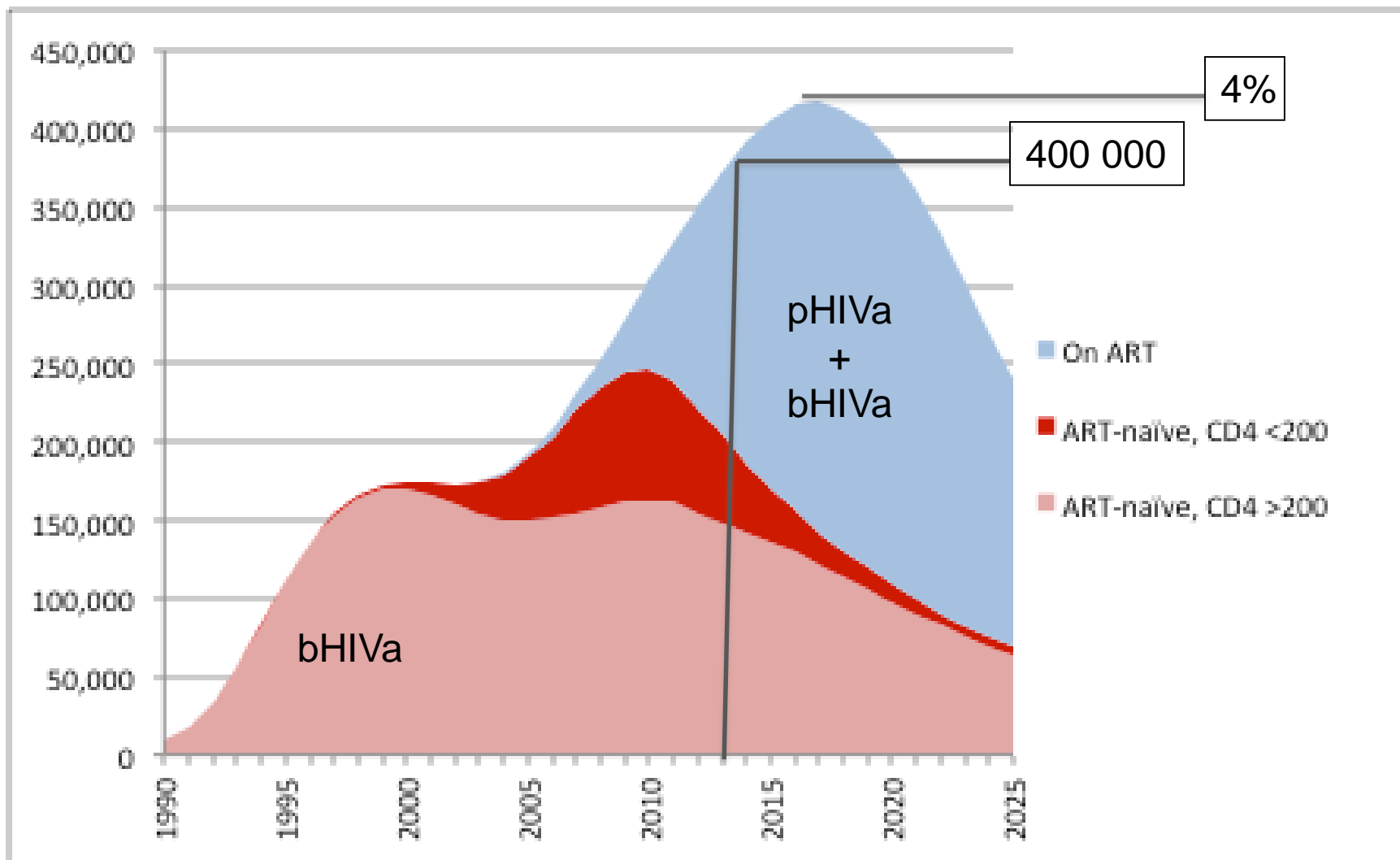
Source: UNAIDS 2012 HIV and AIDS estimates

Figure 1: Evolution of the paediatric HIV epidemic in sub-Saharan Africa (3)



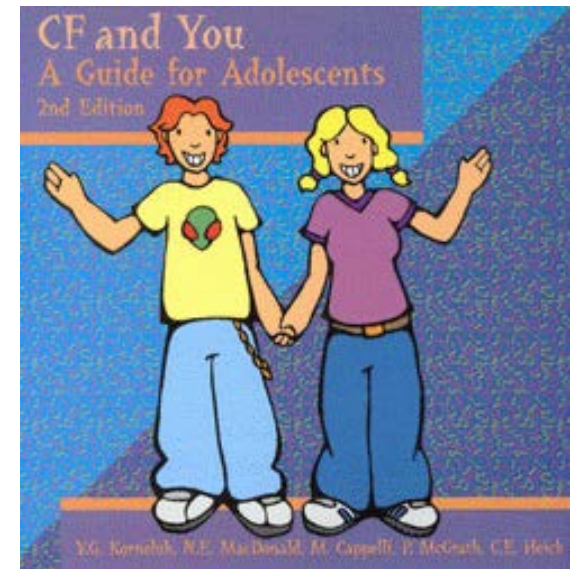
Adolescents (10-19yo) living with HIV: South Africa.

Leigh Johnson 2013



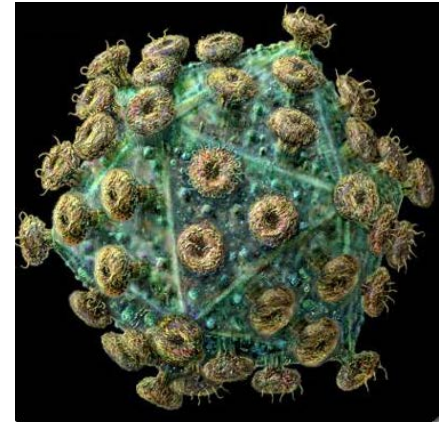
Adolescents with chronic disease...

- Developmental delays
 - Psychosocial, emotional, physical
- More social isolation, suicide and depression
- More likely to take risks that impact health
- Poor adherence to have greater impact
- Concerns about body image overshadowed/exaggerated
- Feelings of isolation when all adult focus on condition.





Additional issues with HIV infection.



- Cognitive, physical, emotional delays
- Parental loss, family sickness.
- Increased perceptions of stigma and discrimination
- Issues with disclosure to HCW, partners, others
- Issues with sexuality, fertility intent.

Positive youth

- Take treatment, be retained and virally suppressed- for the next 50 years.
- Sexually active?
- Safer Sex
 - Condoms all the time
 - No casual partners
 - Partner testing
 - Partner disclosure
 - Safer conception

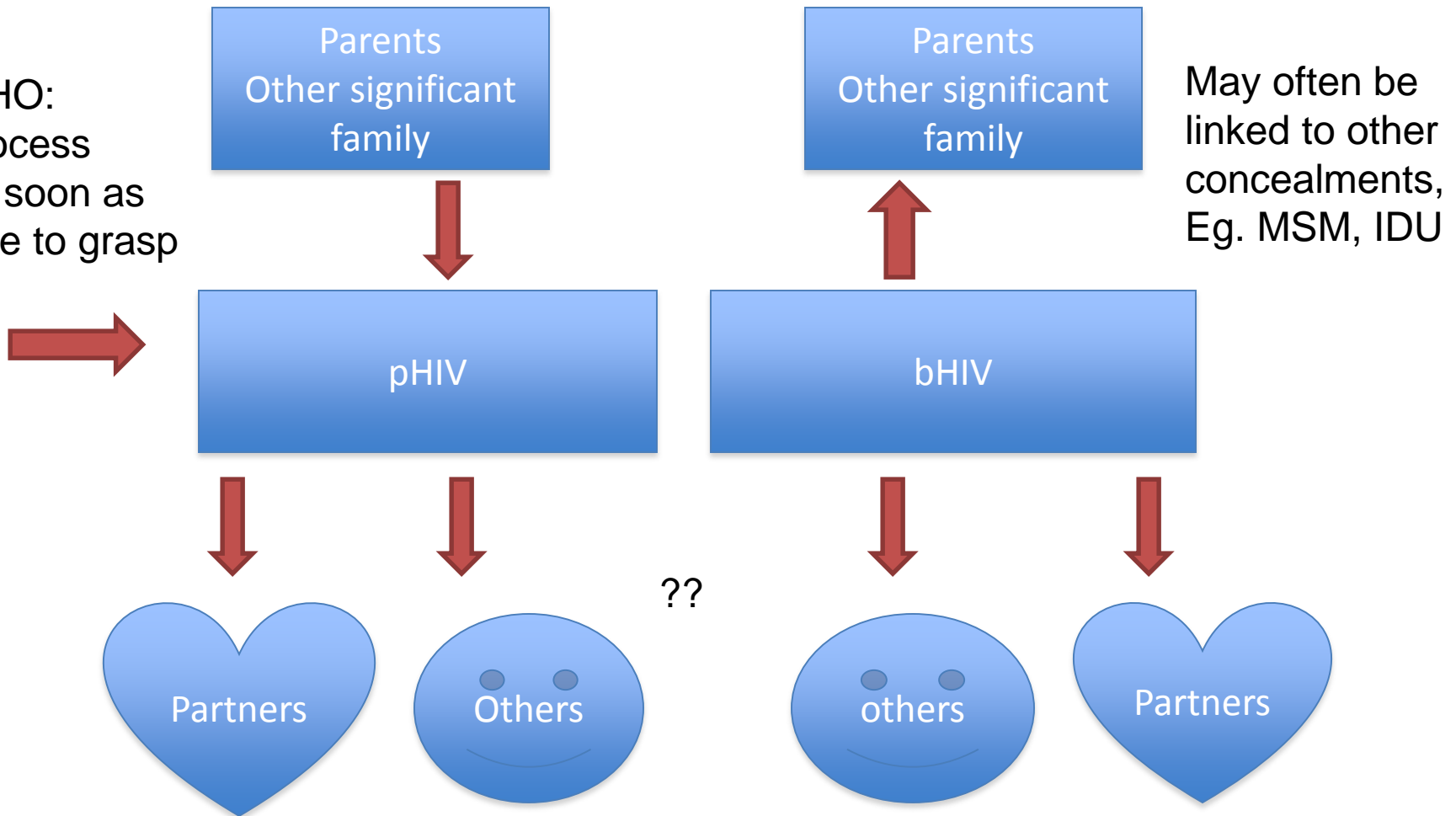


REALLY?????



Disclosures : a tough rap

WHO:
Process
As soon as
able to grasp



A NARRATIVE : Thanda (16yo)

- Thanda met her boyfriend at church, exchanged some messages over social media and have been dating for 2 months.
- She considered it **too early** in the relationship to disclose her status
- In addition, since they were both from a “moral community” where premarital sex is frowned upon, Thanda feared being **exposed and stigmatised**.
- Whilst pre-marital sex was one thing, Thanda considered her HIV status a **marker** of deeper immorality
- Since she was using the injectable contraceptive and felt she wasn't at risk of pregnancy, she **concealed her HIV status**, prioritising the pleasure of sexual and romantic intimacy and **avoiding rejection, exposure and ostracism she feared HIV disclosure could bring**.

(16yo F; Eastern Cape)

Disclosure

Is a critical aspect of the experience of people who live with concealable, stigmatised identities.

Self-disclosure is the sharing of personal information by verbal communication.



Benefits of disclosure

Mburu G, et al JIAS 2014

- Better relationships
 - » Rochat T , et al 2013
- More likely to get ART and join support group
 - » Mitbe T et al 2012
- May improve adherence to ART, retention, survival
 - » Blasini 2004; Arive 2012; Ferris 2007
- May boost self esteem and cope better with stigma
 - » AAP1999; Mditibi 2012
- May increase feeling of cohesion and support
 - » Hosek, et al 2000
- May improve coping abilities and autonomy
 - » Mburu 2013
- May adopt safer sex practices
 - » Fair 2012; Marques 2006.

Laws and mandatory disclosure

- 2011, a total of 67 laws that focus on PLWH had been enacted in 33 states.
- In 24 states, laws require persons who are aware that they have HIV to disclose their status to sexual partners.
- 25 states criminalize one or more behaviors that pose a low or negligible risk for HIV transmission.

All of the individuals named are members of Sero's Advisory Board, have become advocates to combat criminalization and are identified with their permission.

None of them has been accused of transmitting HIV.



IOWA - Nick Rhoades used a condom, had an undetectable viral load and was sentenced to 25 years for non-disclosure. The judge reconsidered the sentence and released him after a year, but he must register as a sex offender for the rest of his life.

Used condom, suppressed VL. Sentenced to 25 yrs



IDAHO - Kerry Thomas used a condom, had an undetectable viral load and is now serving a 30 year sentence for non-disclosure.

Used condom, suppressed VL. Sentenced to 30 yrs



LOUISIANA - After a contentious breakup, Robert Suttle's former partner accused him of not having initially disclosed. He served 6 months and must register as a sex offender for 15 years. He is Sero Project's Assistant Director.

Accused of non-disclosure after break up- 6 mnths

Condom + Viral suppression: 2.5 years.



ARKANSAS - Mark Hunter used a condom, had an undetectable viral load and served two and a half years for non-disclosure.

Suppressed VL, told partner to use a condom



SOUTH CAROLINA - Monique Moree had an undetectable viral load and told her partner to use a condom. She faced up to 10 years, but the U.S. Army ultimately dropped the charges.



TEXAS - A man (name withheld) is serving 35 years for spitting at a police officer.



NEW YORK - When a judge ruled that his saliva was "a dangerous instrument", David Plunkett was sentenced to 10 years for assault and served 6 before being released after winning his appeal.



On the down side

- Associated with at least short term anxiety
- May result in MORE risky behaviours
- A bad experience may lead to greater fears and isolation
- Can lead to increased stigma and discrimination
- Disclosure to intimate partners- the most difficult

I have a boyfriend now but it isnt sexual. He doesn't know my status. I'm scared of telling him because he might leave. (Zambian 19 yo)

I only disclosed my status to one of my boyfriends. He understood me because we never had sex. When he started asking for sex we broke up. (Cape Town 18yo)

My (HIV) didn't affect anything in my health but in my relationship, it's not easy for me to tell someone I'm dating that I'm HIV. ... But if I'm dating that person I am using protection.. I'm scared like, of disclosing to my boyfriend about my status and then he runs away or makes fun about it (CT 19yo)

How are adults doing?

- Study of 630 adults in 5 ART clinics in Cape town (8% : 18-24 yrs)
- 1/5 had not disclosed status to intimate partner
- 1/2 didn't know partner's status
- 1/4 didn't use a condom at last sex
 - Younger people less likely to disclose
 - Partner HIV status, stability of partnership, low perception of stigma: strongly associated with disclosure

Sex and Secrecy: How HIV status disclosure affects safe sex.

- 858 positive youth (10-19) from 41 ART clinics Eastern Cape (52% F; 68% pHIV)
- 68% knew their own status
- 15% had ever had sex (85% had current partner)
 - 41% knew partner status; 35% disclosed
- Knowing own status associated with safe sex
- Neither knowing partner's status nor disclosure to partners were associated with safer sex.
 - Adolescents feared rejection, stigma and public exposure
 - HCW counseling focused on benefits of disclosure but didn't address these fears nor impart any skills.

HCW attitudes

- *She [counselor] doesn't tell you about having goals, you can get married, you can be in love, you can have other children in future . . . she's insisting that you're HIV-infected and there are things that you cannot do, and if you want other things then you look like a stupid person. (YW, focus group)*
- *. . . there are [doctors] who put pressure on you [to disclose] You must not be forced . . . After you have disclosed you live a life of persecution . . . Everything that you do is being noted. (YM, focus group)*

Lit review : Reproductive Health behaviours of young US women

Carter MW, et al AIDS Patient Care 2013

- 32 articles 2001-2012
- Substantial proportions of YW+ were sexually active
- Most sought sexual or romantic involvement
- Disclosure was difficult and most (50-80%) had not done so
 - “a major hurdle and a major concern” Leonard AD, 2010
- Most YW hoped to have children but many wanted to avoid pregnancy until later
- Condoms were a primary method of contraception

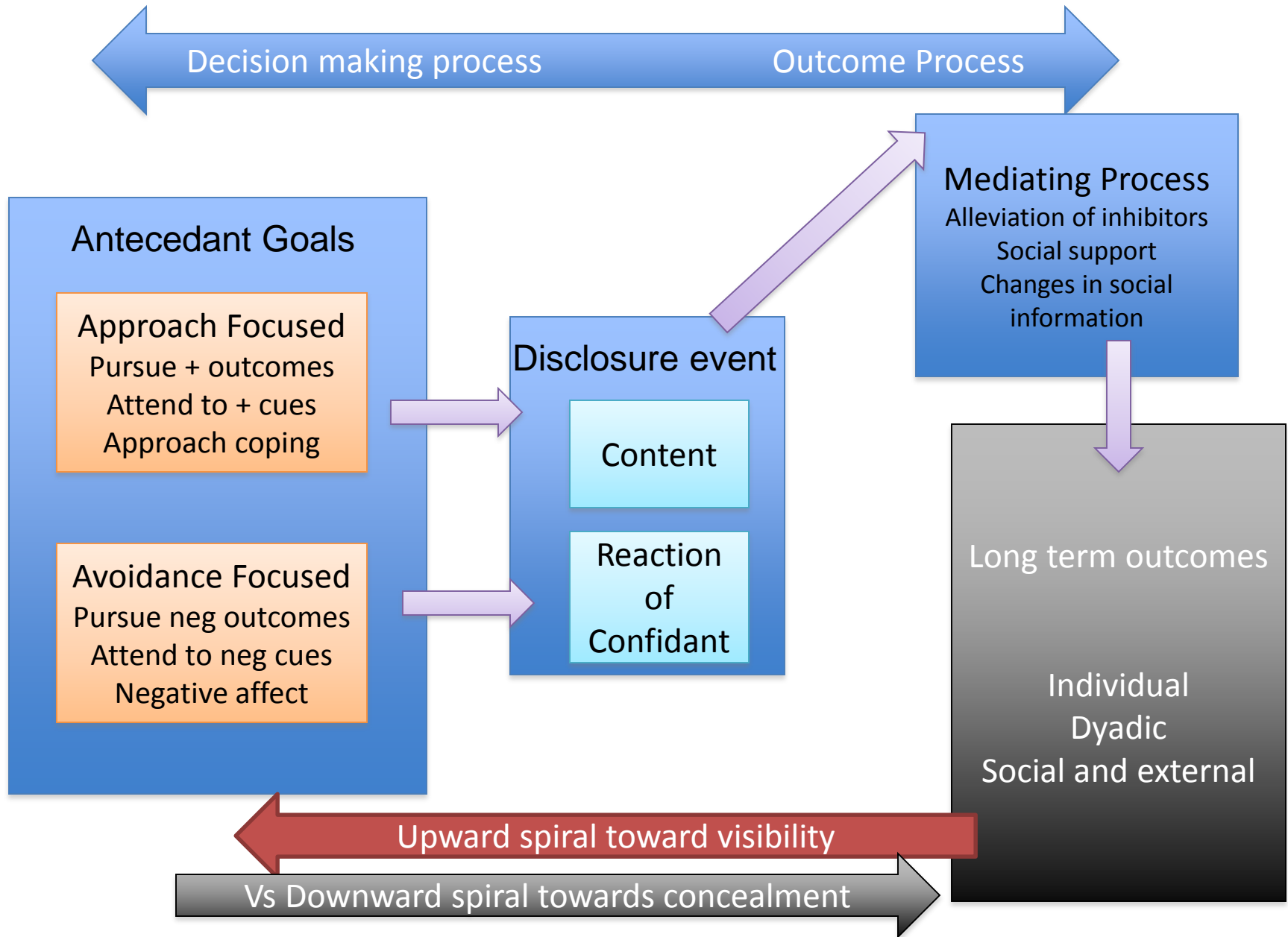
In 5 studies

Carter MW, et al AIDS Patient Care 2013

- Disclosure to sex partners was positively associated with
 - The partner being main
 - The partner confirmed or believed to be positive
 - A greater number of sex acts
 - A longer time of known HIV diagnosis
 - Disclosure to family and/or friends
- Disclosure was negatively associated with
 - High number of partners
 - Partner being negative or of unknown status
 - Youth

The Disclosure Processes Model

Chaudoir S, Fischer J: Psychol Bull 2010 136(2);236-256





- Group Intervention to engage newly diagnosed youth
 - Conducted interviews & focus groups
 - Identified key messages/outcomes for new groups
 - Modified CBI tools to suit youth
 - Held practice sessions

**General opinion of experts interviewed:
“This is needed but it won’t work.”**



Feasibility Pilot Study

[March to December 2010]

- Inclusion criteria: ages 16-24, HIV dx within year
- Three group sessions led by lay facilitators:
 - 1) Coping & Support : ‘**5 Ws to TELLING**’
 - 2) HIV Health (focus on CD4)
 - 3) Positive Prevention/Sexuality “**SAFE SEX**”
- Held in variety of venues: clinics, libraries, youth centres

Our 10 tips: Then practice!

1. Be selective.
2. Consider the five "W's" when thinking about disclosure: who, when, where, what, and why.
3. Easy does it. In most situations, you can tell them in a way that is easy to tell and how to tell them.
4. Consider whether there is a support person.
5. Telling people indiscriminately can lead to more questions you haven't considered.
6. Having feelings of embarrassment is a very common reaction.
7. Keep it simple.
8. Avoid judgment.
9. Even if a specific situation doesn't go the way you'd hoped, your life will go on.
10. Millions of people have dealt with this experience and have found their way through it.

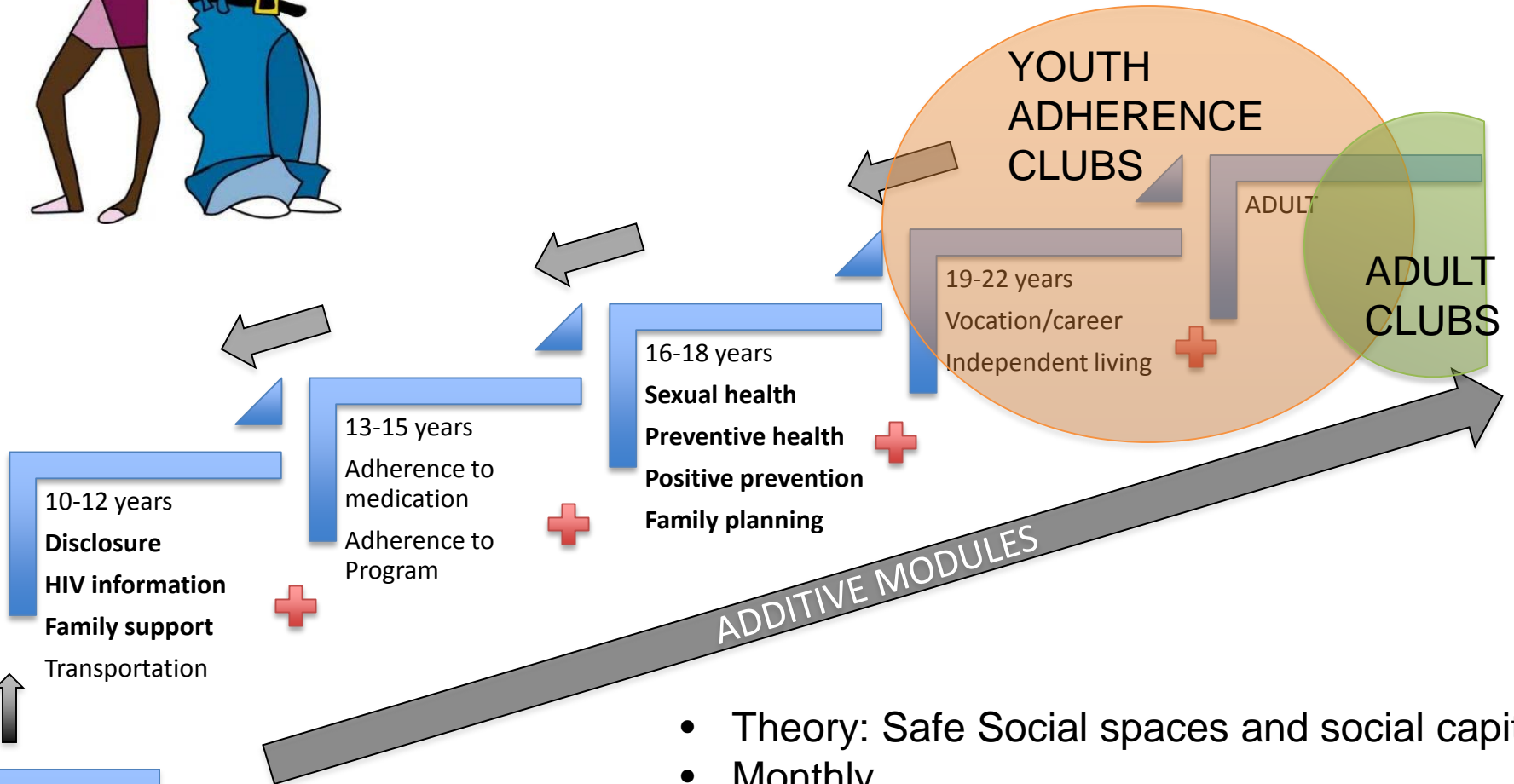
**IF a sexual partner
Then, SAFER SEX!!!**



**Hannan Crusaid,
Gugulethu**

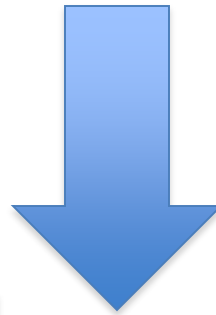
Hlanganani HCT model

Based on Hlanganani LTC Program.



Paediatric
Service

- Theory: Safe Social spaces and social capital
- Monthly
- Group based
- Trained Lay Facilitator led
- interactive



Direct referral to ART services

Referral to Hlanganani Plus Adherence clubs

Viral suppression, retention in care, contraception, condom use.

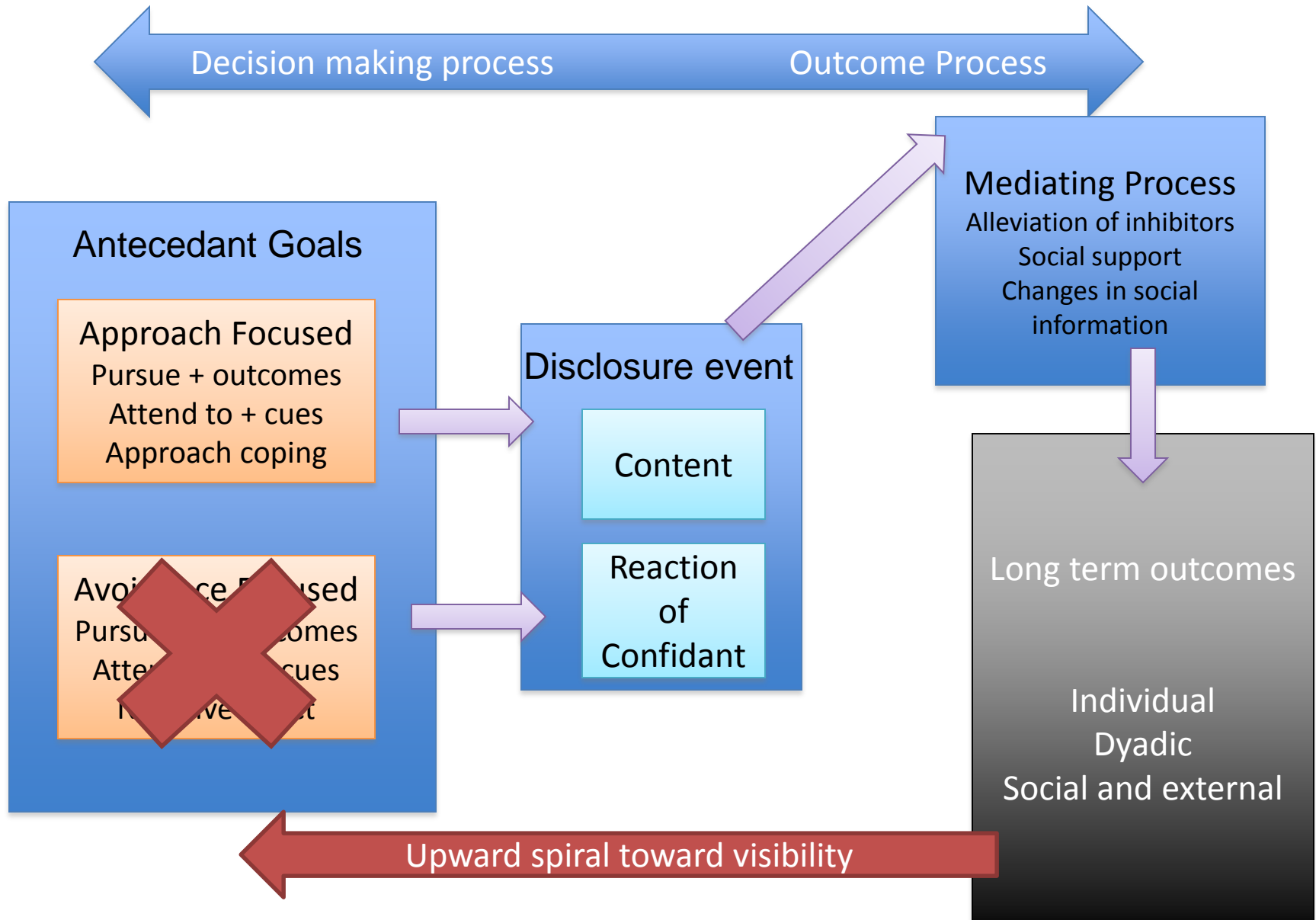
The final word.....

Some recommendations:

- **EVERY YPLWH NEEDS TO KNOW THEIR OWN DIAGNOSIS**
- Every YPLWH needs **appropriate safer sex** information
- Every YPLWH needs **access** to adolescent friendly(non prejudicial, confidential) SRHs including condoms, lube, contraception, safer conception, etc
- **Skills** on disclosure need to be learned and practiced through role play, etc. (practice content)
- Frank information (antecedant) on **pros** (approach) and **cons** (avoidance) of disclosure should be shared
- First disclosure should be “low hanging fruit” to ensure good outcome (ensure good confidant reaction)
 - Ensure positive feedback loop with resulting positive outcomes.

The Disclosure Processes Model

Chaudoir S, Fischer J: Psychol Bull 2010 136(2);236-256



Hope for the future....



(Future Fighters- DTHF)

***“These pills can help me. I will finish school.”
(14yo F).***

***“I will finish school and find work”
(11yo M).***

“I want to marry and have children” (13yo F).

Acknowledgements

Archbishop Tutu

The Adolescent Centre of Excellence:

Millicent Atujuna

Philip Smith

Elzette Rousseau

Rebecca Marcus

Cathy Matthews

Leigh Johnson

Hanan-Crusaid clinic

Cathy Kalumbo

Phyllis Orner ; Diane Cooper

Lucie Cluver; Rebecca Hodes

Rashieda Ferrand

Adolescents and their families



Desmond Tutu HIV Centre

Masibambane Ngezandla



Future Fighters CAB

Funders:

ViiV Health Care

Chevron

PEPFAR

IAVI

Discovery Health

MHG

NIH(USA)

BMGF

SA MRC