



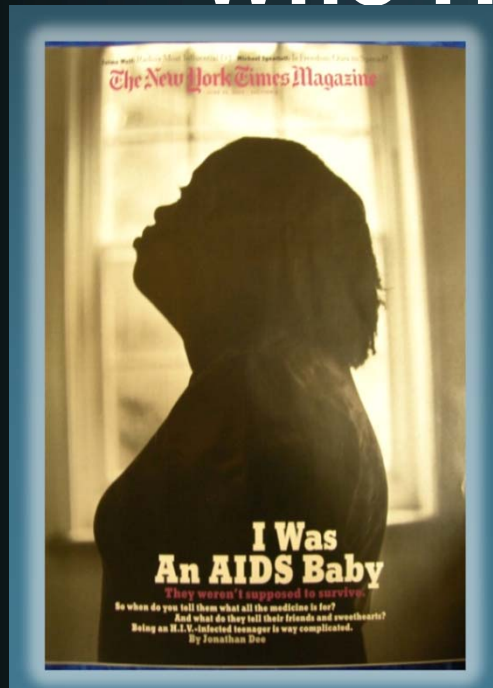
ICAP

GLOBAL. HEALTH. ACTION.

Columbia University
Mailman School of Public Health

GRANDROUNDS

Promoting the Health and Behavioral Health of Adolescents Who Have Grown up with HIV



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Case of AC: Mental Health, Adherence, and Substance Use

- AC is a 16 year old African American teen who has been hospitalized for most of the past year due to complications related to his antiretroviral regimen.
- He has decided to stop taking his medications.
- AC lives with his grandmother.
- His mother, after a long history of cocaine abuse, died from AIDS-related complications.
- AC alternates between being flat in affect, sad or angry.
- He argues that he does not want to live his short life in the hospital.
- He feels “less sick” when he is not taking the medication.
- When not in the hospital, he is smoking “weed” and drinking with friends.
- His Grandmother is furious and argues with him daily.

Pediatric HIV (PHIV) is an Adolescent Global Epidemic (UNAIDS 2016)

- **1.8 million** children <15 years are currently living with HIV, majority are perinatally infected
- With scale up of PMTCT - new HIV infections have declined by 50% since 2010 → fewer babies and young children
- ART scale-up led to improved case finding → prolonged lives → growing population of PHIV+ adolescents and young adults
- High risk group: HIV+ youth are the **only age-group in which HIV-related deaths have not gone down**

Adolescence, Risk, and Resilience

- **Adolescence is a period of challenge**, with significant physical, cognitive, emotional and social changes.
- **“Adolescence is an age of opportunity for children**, and a pivotal time for us to build on their development... navigate risks... and set them on the path to fulfilling their potential”(UNICEF, 2011).
- Research with PHIV+ youth has prioritized identifying risk behaviors and poor health outcomes.
- Understanding risk is helpful in identifying problems for treatment and targeting vulnerable populations for prevention efforts, but....
- It does not tell us how to intervene

Adolescence, Risk, and Resilience

- **Resilience:** Children who despite great adversity have successful outcomes.
- Understanding pathways to resilience has been helpful for defining the components of interventions most likely to promote positive youth development in other populations (Luthar, 2000; 2006).
- As PHIV+ children across the globe reach adolescence and young adulthood, there is an urgent need for both risk and resilience research to inform evidence-based interventions to promote Behavioral Health and ultimately health and wellbeing outcomes.
- But we also can't lose sight of the normative every day tasks

Adolescence: transitioning from childhood to young adulthood

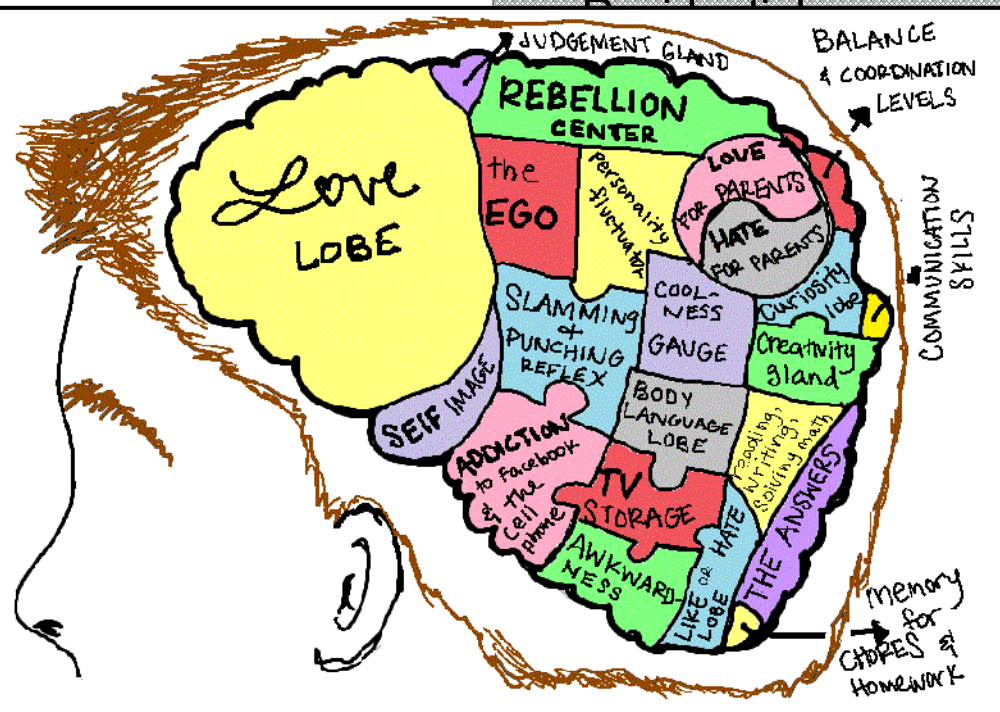
Childhood

- Dependence on parent/family/adults
- Physical and emotional

Adulthood

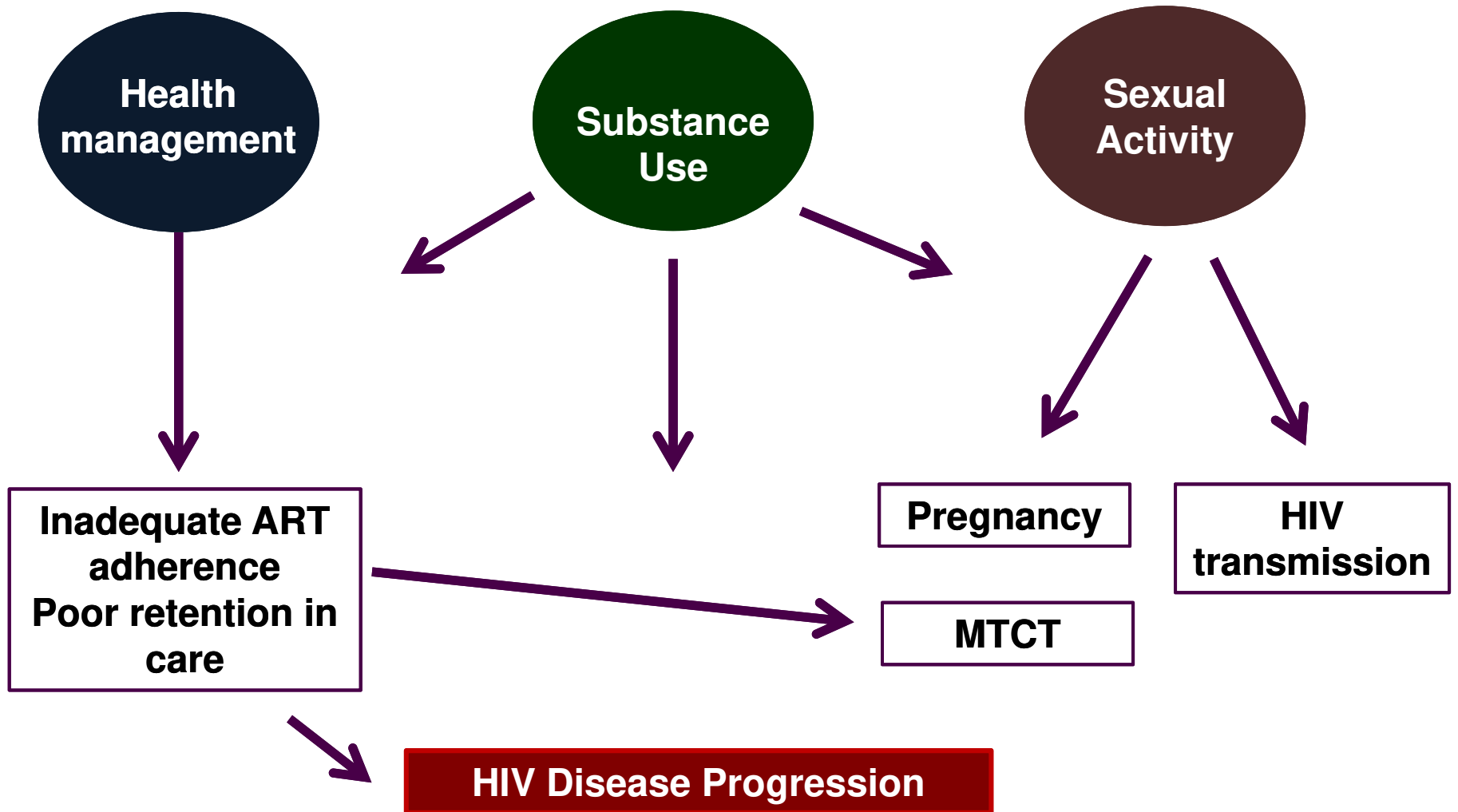
- Independence
- Education complete
- Employment

**THE
AVERAGE
TEENAGE
BRAIN**

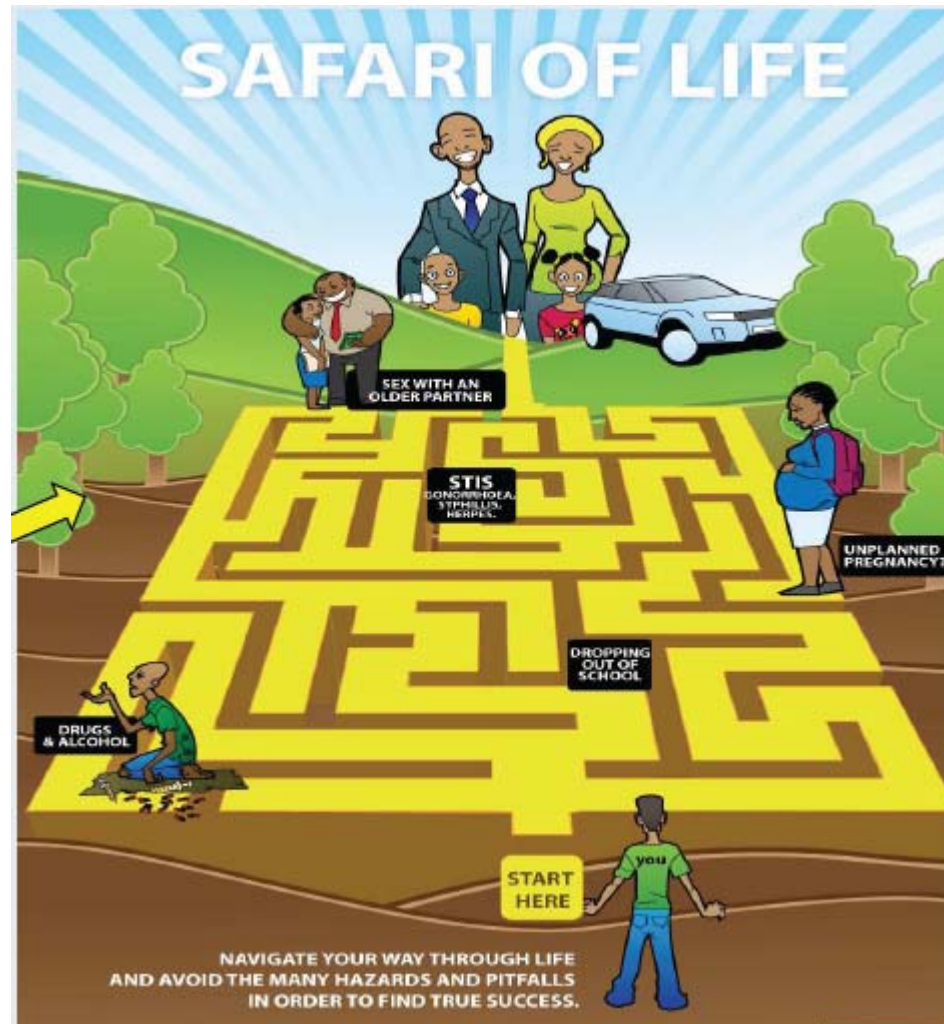


- Risk taking and experimentation

Consequences of 'normative' adolescent risk-taking in 3 critical domains for PHIV+ youth



Brighter Futures Facilitator Handbook



Demographic Profile of Youth with Perinatal HIV Infection (PHIV+) (UNAIDS; CDC)

- Globally, vulnerable families, typically affected by poverty, violence, limited health care and educational resources
- Disruptions in caregiving due to poverty, parental illness, death
- In some countries, parental substance abuse and untreated mental illness have decimated families
- In many countries, PHIV+ youth are from ethnic minority and other disenfranchised populations who have coped with racism and discrimination, and now must cope with *HIV stigma*



Why Are Youth with Perinatal HIV-Infection at Risk (cont.)?

- Experienced many environmental and social stressors (Kang 2011)
- In some countries: genetic and environmental risk for substance abuse and mental health problems (Havens and Mellins, 2008)
- Experienced an extended period of less than optimal treatment (pre-HAART; no access)→ health and neurocognitive effects (Sohn & Hazra, 2013; Phillips, 2016)
- Aging into developmental stage of (Mellins and Malee, 2013)
 - ▶ Presentation of psychiatric disorder (if at risk)
 - ▶ Normative challenges related to experimentation with sexual and substance use behavior
 - ▶ Social need to fit in with peers and feel “normal”
 - ▶ Increased risk for non-adherence across conditions

What do we know about neurodevelopmental and cognitive functioning?

- **Early data on infants and children showed significant impact of HIV on neurodevelopmental and cognitive function**
 - ▶ Particularly in children who had early severe disease (AIDS-defining) and HIV-related encephalopathy.
- **cART → reduced incidence of AIDS-defining illnesses**
 - ▶ However, youth with early disease may continue to experience cognitive deficits, even with immune recovery
- **Even for those youth without AIDS-defining conditions and on cART, cognitive deficits have still be seen, even with viral suppression**

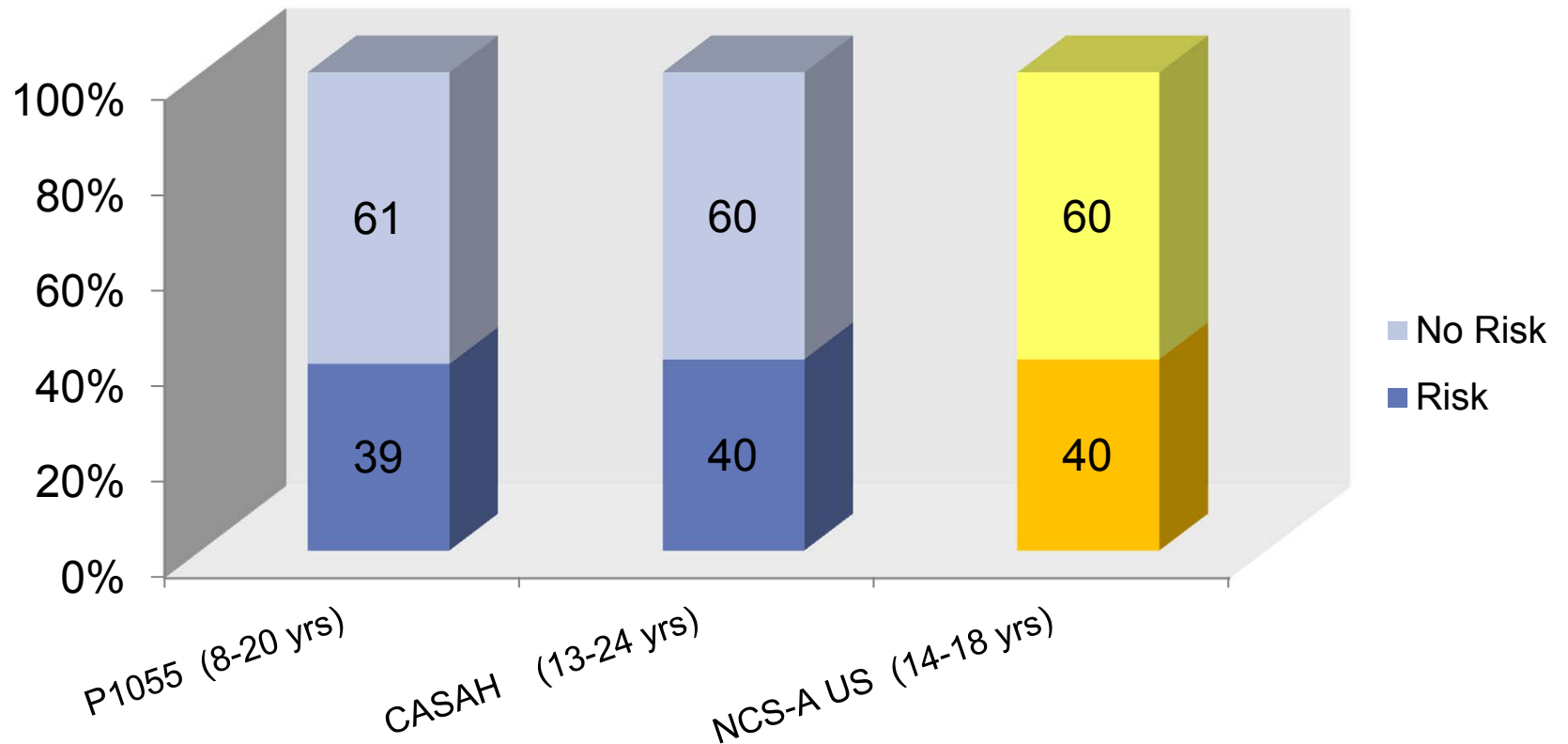
(Chiriboga, 2005;; Smith et al., 2013; Puthanakit, 2010; Van Rie 2011)

Psychosocial/Behavioral Profile

Lessons from 3 Longitudinal US Cohort Studies:

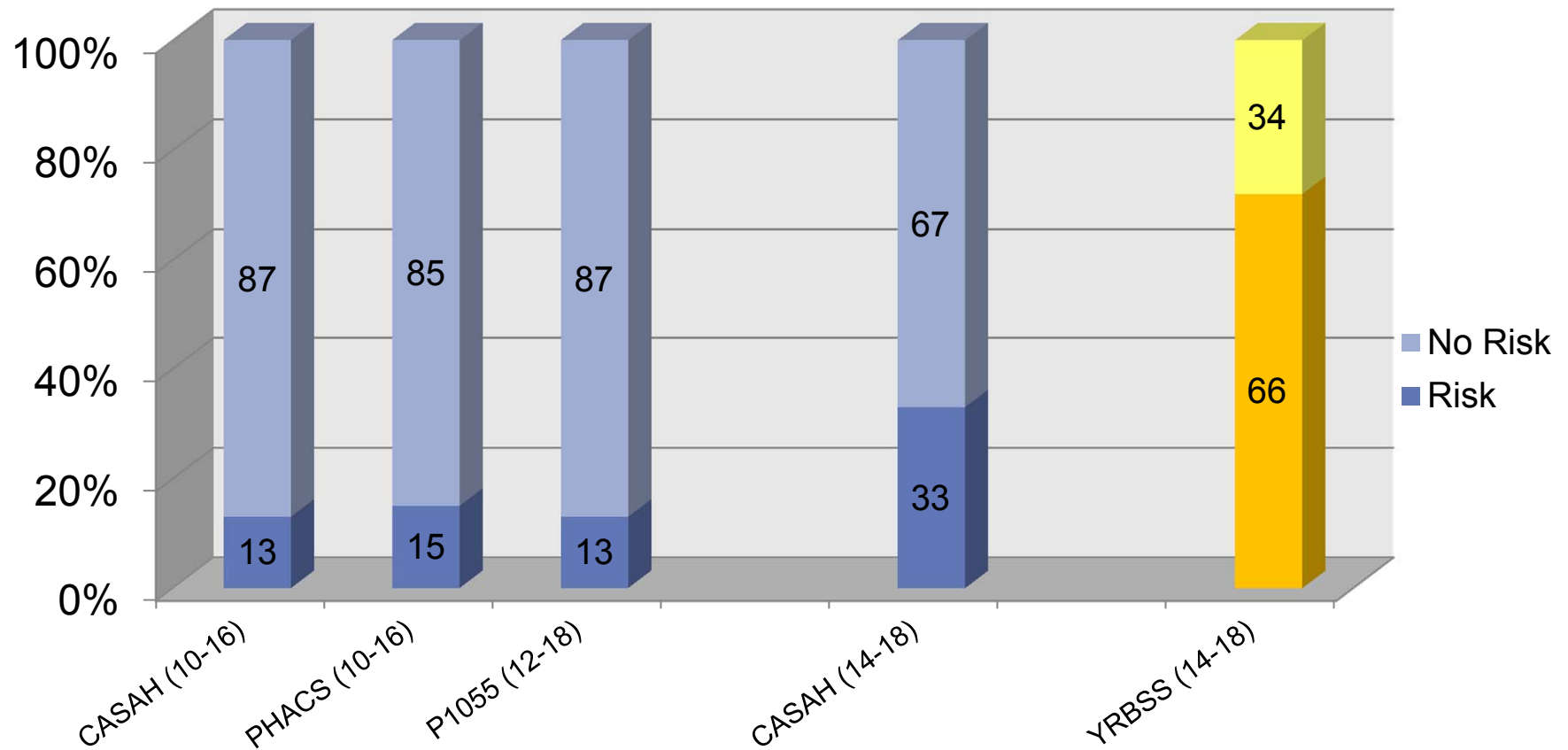
Project, Funder, References	Sites	Baseline Age (Follow up Age)	Control Group
<p>CASAH (NIMH R01-MH069133; PI Mellins)</p> <p>Mellins et al., 2009; 2011 Elkington et al., 2009; Bauermeister et al., 2009; 2012</p>	<p>4 NYC sites, US</p>	<p>9-16 yrs (13-24 yrs)</p>	<p>Perinatally HIV-exposed, uninfected (PHIV-)</p>
<p>PHACS (NIH: U01-HD052104: PI Van Dyke; U01-HD052102: PI Seage)</p> <p>Mellins et al., 2011 Tassiopoulos et al., 2013 Alperin et al., in press Usitalo et al., 2013</p>	<p>12 US sites</p>	<p>7-16 yrs (10-18 yrs)</p>	<p>PHIV-</p>
<p>IMPAACT P1055 (NIAID: U01-AI068632; PI: Nachman)</p> <p>Gadow et al., 2010; 2012</p>	<p>29 US sites</p>	<p>7-17 yrs (8-20 yrs)</p>	<p>HIV-affected (PHIV- and HIV-)</p>

PHIV+ Youth: Current Psychiatric Disorder



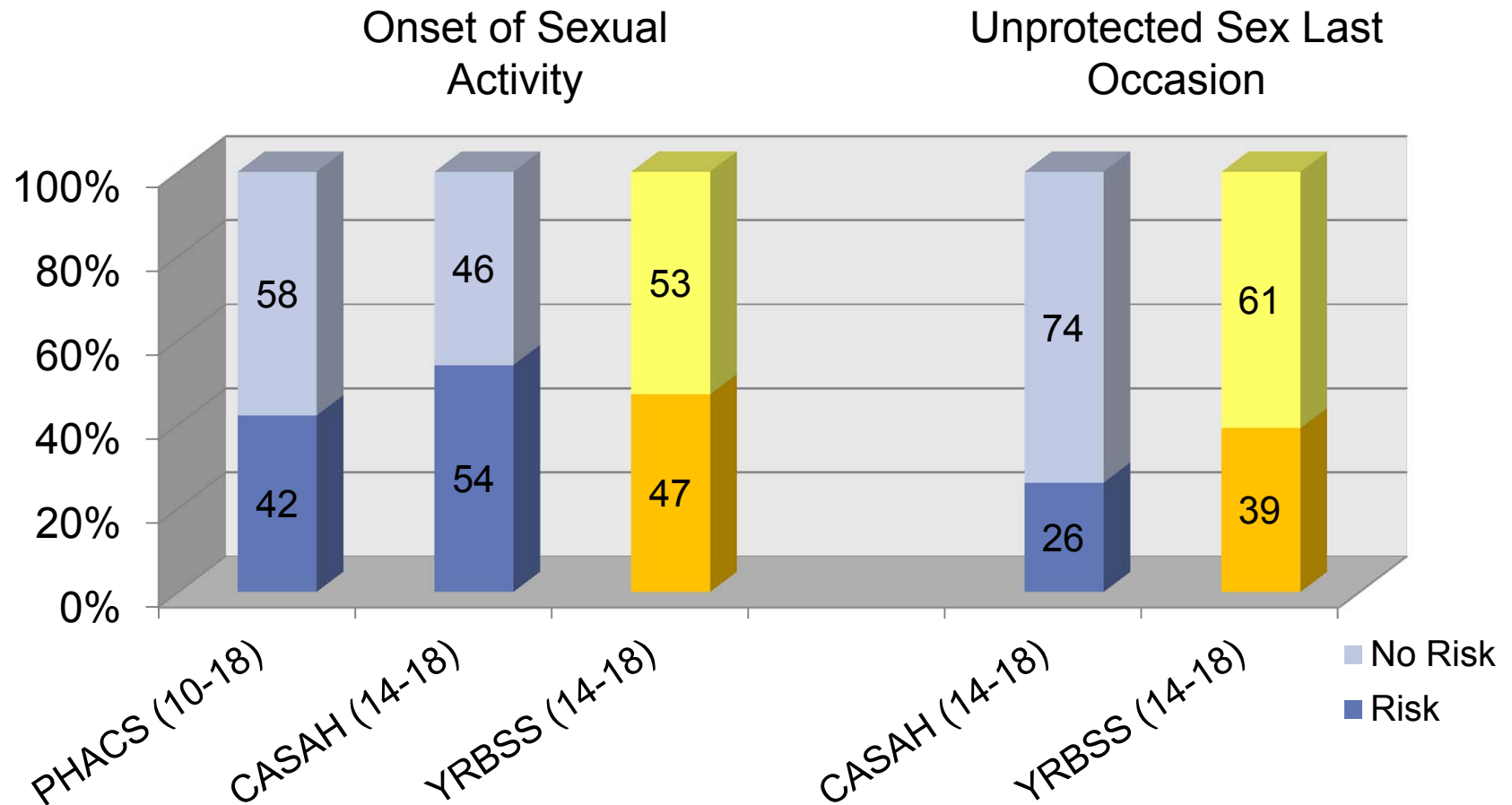
P1055 (Gadow, 2012); **CASAH** (Mellins, 2009, 2011); **General Population** (NCS-A, Kessler, 2012; n-10,148)

PHIV+ Youth: Substance Use



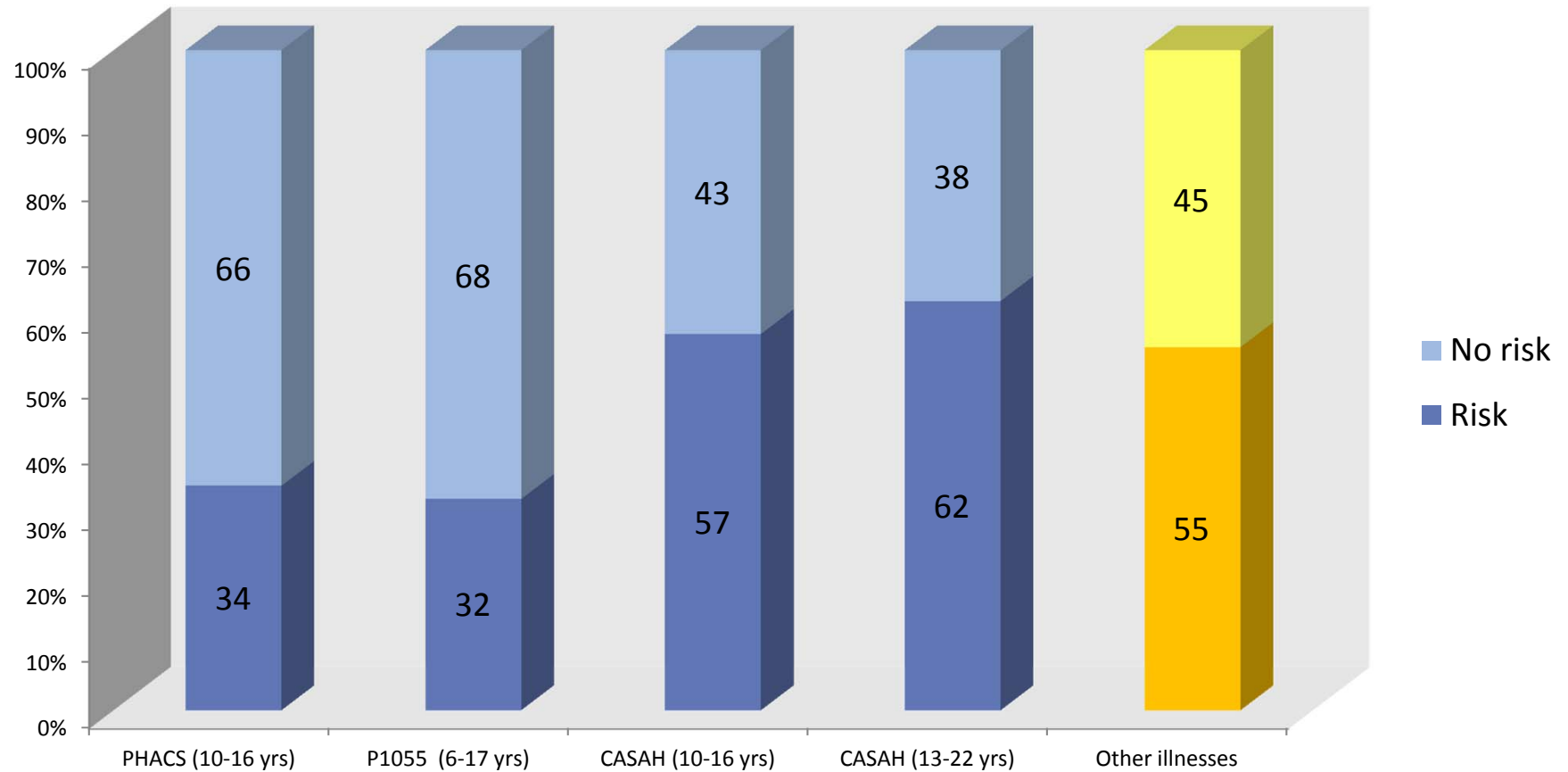
P1055 (Williams, 2010); **CASAH** (Elkington, 2009); **PHACS** (Mellins, 2011); **General Population** (2009 Youth Risk Behavior Systems Survey; **YRBSS**; n-15,425)

PHIV+ Youth: Sexual Risk



PHACS (Tassiopoulos, 2011; Mellins, 2011); **CASAH** (Bauermeister, 2009); **General Population** (2012 Youth Risk Behavior System Survey; **YRBSS**)

PHIV+ Youth: Non-Adherence in the Past Month



PHACS (Mellins, 2011; Usitalo, 2009); **CASAH** (Marhefka, 2009); **P1055** (personal communication, Kacanek, 2013); **Other illnesses** (Bender, 2000; Johnson, 2002)

International Studies Show Similar Rates

- **Difficult to present comparable data:** fewer studies, particularly on adolescents and young adults, different age ranges, diverse measures and study variables
- **Mental health problems** (Zambia; Menon, 2007; Thailand; Lee, 2011)
 - ▶ **28%- 48%**
- **Sexual Behavior** (Uganda: Birungi, 2009)
 - ▶ **33%** sexually active (15-19 yrs);
 - ▶ **53%** of whom currently did not use condoms)
- **Substance Use** (Thailand/Malaysia: Prasitsuebsai, 2012; Lee, 2009)
 - ▶ **19%- 24%** alcohol (10-18 yrs)
- **ART Non-adherence** (Togo: Polisset, 2009; Kenya: Vreeman, 2010; Rwanda: Kikuchi, 2012)
 - ▶ **50% - 58%** (0-15 yrs)
 - ▶ Only 20% of youth achieved 100% adherence by pharmacy refill data at 6 months (Nachega et al., 2009)

What is Related to Behavioral Health Outcomes in CASA? Lessons from CASA

- **Not often HIV status (few differences between groups)**
- **Better Family Functioning (communication, relationships, caregiver mental health, family support)**
 - ▶ Better mental health and better adherence
 - ▶ Delayed onset of sex/protected sex, disclosure to partners
- **Less neighborhood stress and fewer major life events**
 - ▶ Better mental health, less substance use
- **Better peer norms**
 - ▶ Less substance use and delayed onset of sex or protected sex
- **Better youth mental health**
 - ▶ Less substance use, less sexual risk behavior
 - ▶ Better adherence, more time virally suppressed

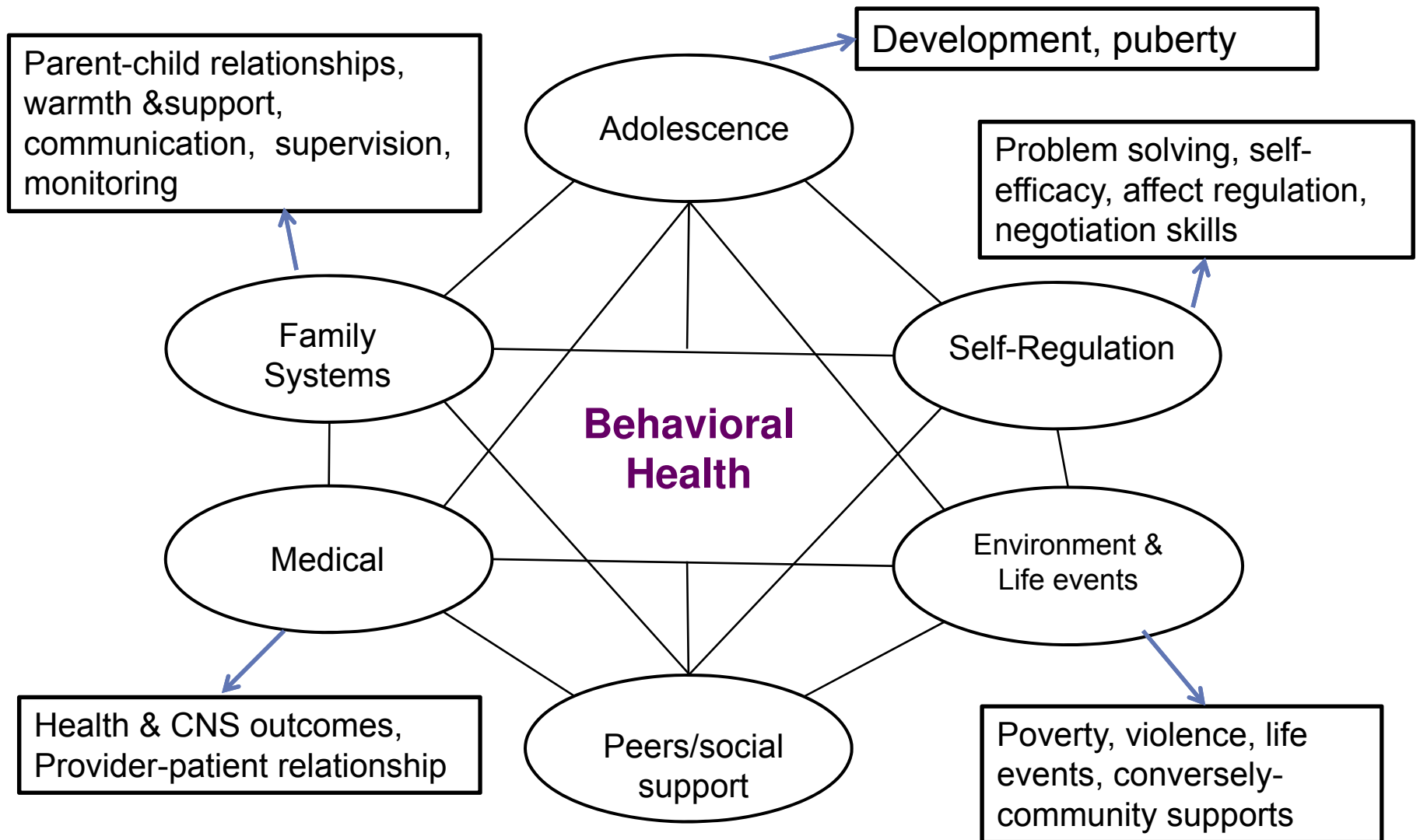
(Bauermeister, 2009, 2012; Bucek, 2016; Elkington, 2011,2014, 2015; Marhefka, 2008; Mellins, 2008, 2009, 2011,2016 ; Kang, 2012; Mutumba, 2016; Benson, 2016)

What can we do to support a safer passage through adolescence?

■ THERE IS NOT 1 MAGIC PILL



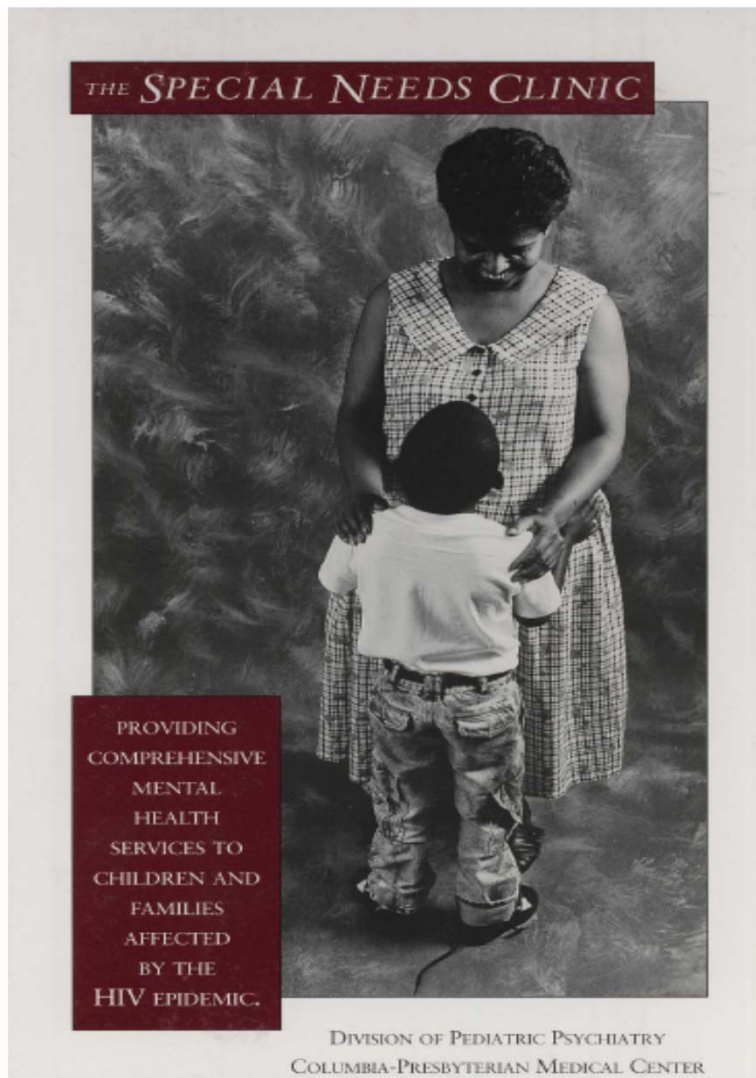
Models of Risk and Resilience



What does this mean for Interventions?

- **The National Institutes of Health (2006)** noted that effective behavioral interventions
 - ▶ Simultaneously target multiple risk factors
 - ▶ Intervene at multiple system levels
 - ▶ Integrate behavioral interventions into the environment
- Many service programs across the globe are trying to do this- but have not been evaluated
- **Very Very few Evidence-based Interventions that promote mental health and reduce other behavioral health risks**

Model of Psychosocial Services for HIV-affected Families



■ One stop shopping

- ▶ Adults & children treated in the same site
- ▶ Mental health services coordinated with medical services
- ▶ Multidisciplinary services delivered in a coordinated manner
- ▶ **VERY financial and labor intensive- but effective**



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CBT and MI

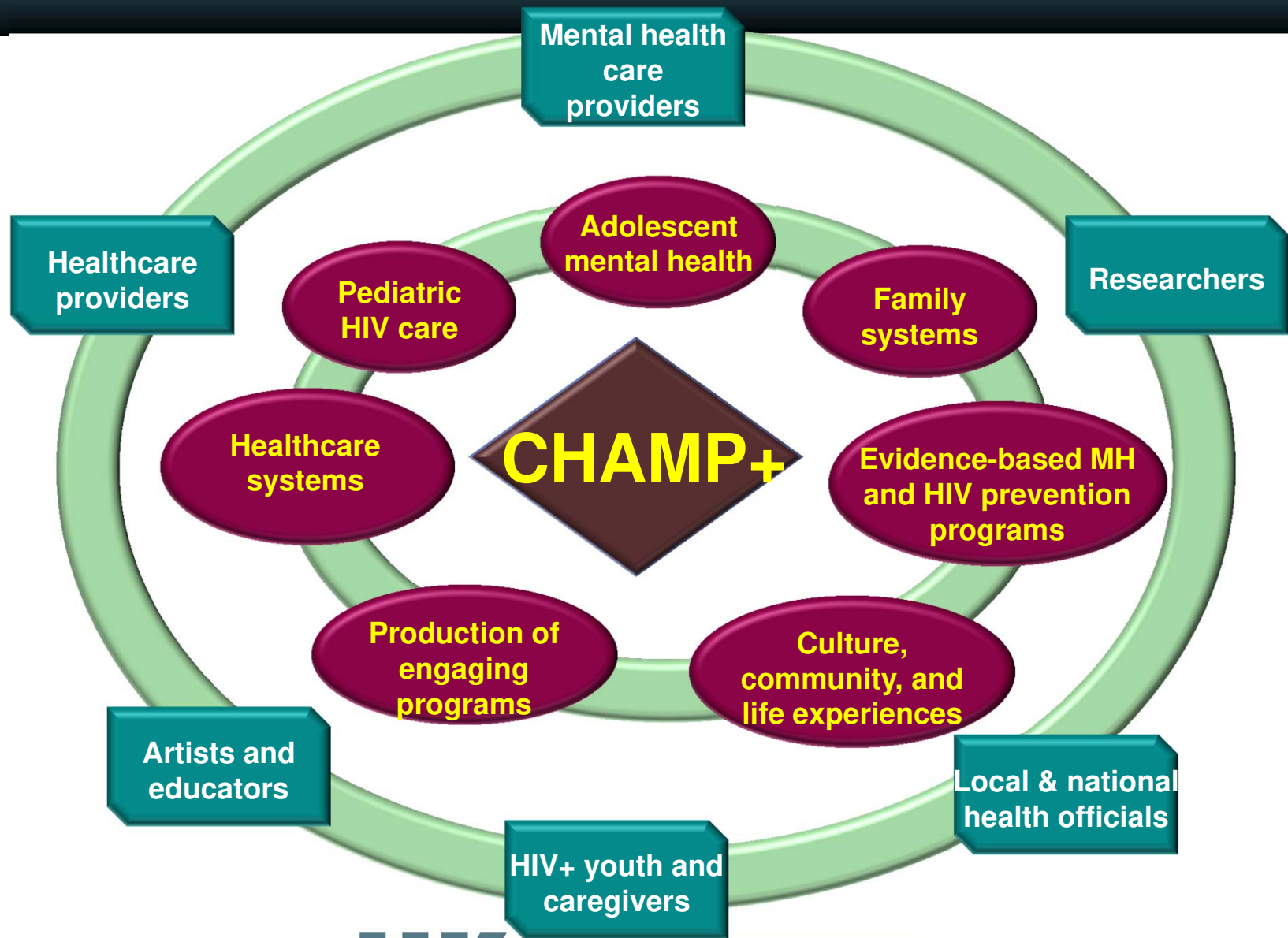
- **Cognitive Behavioral Therapy (Field 2015)**
 - ▶ Brown et al., 2016 (US): CBT + medication management for HIV+ depressed 18-24 yr olds (mostly BHIV);
 - ▶ RCT of 24- week intervention with 44 ATN participants
 - ▶ **Positive impact on Depression symptoms**
 - ▶ Senyoni et al., 2012 (Uganda): CBT with 186 PHIV+ adolescents
 - ▶ RCT of 8 week 80 minute sessions-
 - ▶ **Positive impact on anxiety only**, not depression, sex risk or alcohol use
- **Motivational Interviewing (MI): (Miller, 2002)**
 - Naar-King et al., 2009: 186 16-24 year old ATN participants; 18% PHIV+
 - RCT of 4 sessions focused on adherence and sex and substance use risk behavior; **significant impact on depression only; 50% did not complete intervention**

CHAMP:

Collaborative HIV/AIDS Mental Health and Prevention Project (NIMH: McKay, 2000; Bhana, 2010)

- **CHAMP:** Family-based mental health and HIV prevention program for uninfected pre- and early adolescents
- **Goal: promote POSITIVE YOUTH DEVELOPMENT by**
 - ▶ Strengthening the adult protective shield by improving parent-child relationships, communication and supervision skills, and family support
 - ▶ Strengthening youth skills in problem solving, coping and negotiation of risky situations
 - ▶ Promoting youth self-esteem and mental health
- **Method:** Multiple families come together for 10 sessions, led by lay staff
- **Curriculum and materials** tailored to the specific context through collaborative work with community stakeholders
- **Successful RCTs** in US, South Africa, Trinidad: improved youth skills, family variables, participation in situations of risk

Turning CHAMP → CHAMP+ Model



CHAMP+ and VUKA

(NIMH, NICHD, NINR; Victor Daitz Foundation, WALDO Foundation, Columbia University's MTCT plus/ICAP program)

- CHAMP+ (for PHIV+ youth): focus on mental health, sexual and substance use risk behavior, and **ART non-adherence**
- **Clinic-based**, multiple-family groups, facilitated by lay staff
- 10 session curriculum developed based on community work
 - 1) **loss and bereavement**, 2) **ART adherence**, 3) **youth identity**, 4) **disclosure** and coping, 5) adolescent development, 6) negotiating sexual possibility situations and peer pressure, 7) family communication, supervision, involvement, 8) **stigma** 9) social support
- Successful pilot RCTs in US, South Africa, Argentina (Bhana et al., 2010; Mellins et al., 2012; McKay et al., 2012)
- Current large-scale RCT in South Africa (VUKA) and pilot RCT in Thailand (CHAMP+Asia)

The Vuka Family



MA' MAFUTHA

BAB' VUKA

GOGO

MUZI

NONHLANHLA & NHLANHLA

SINDI



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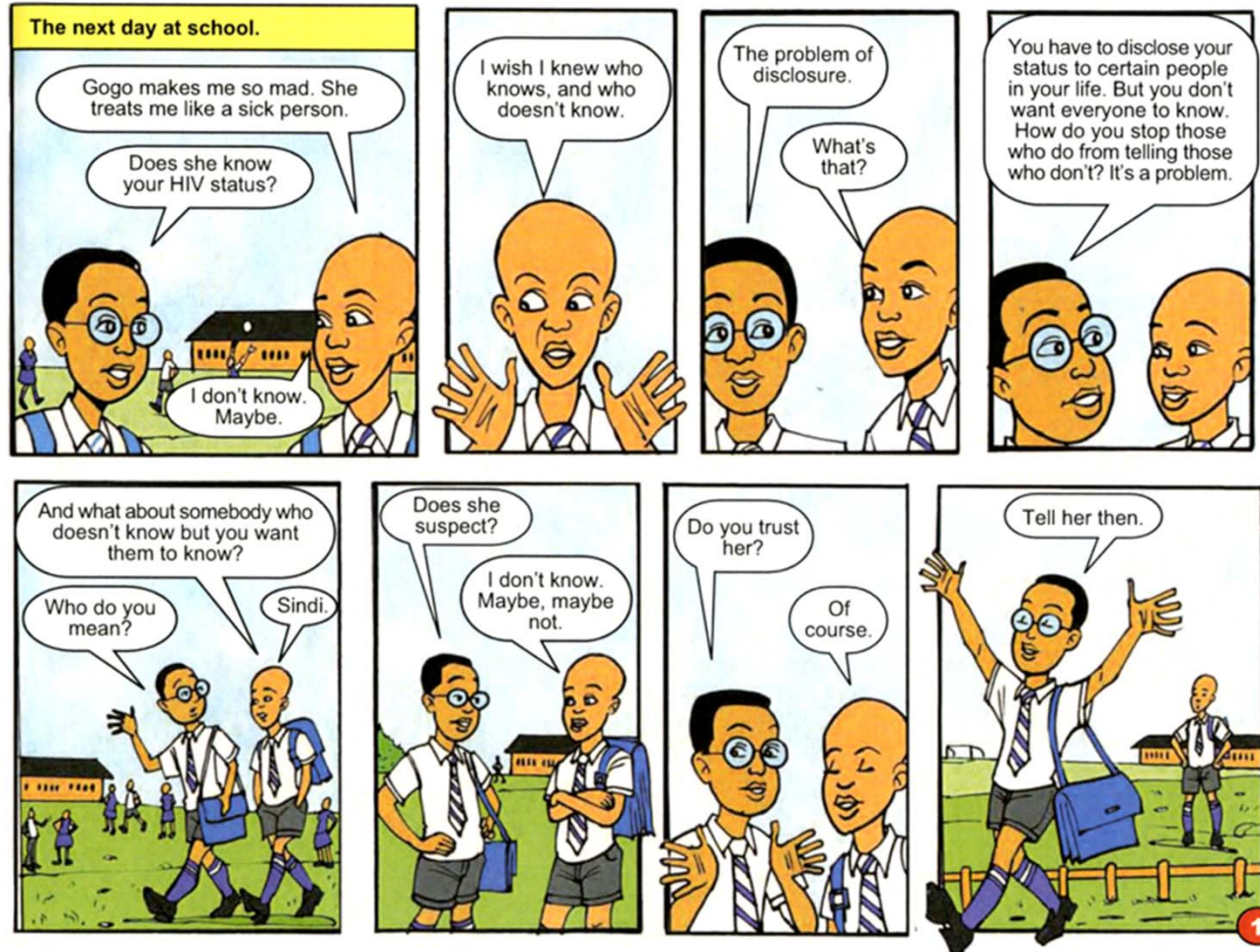
Surviving Loss and Bereavement



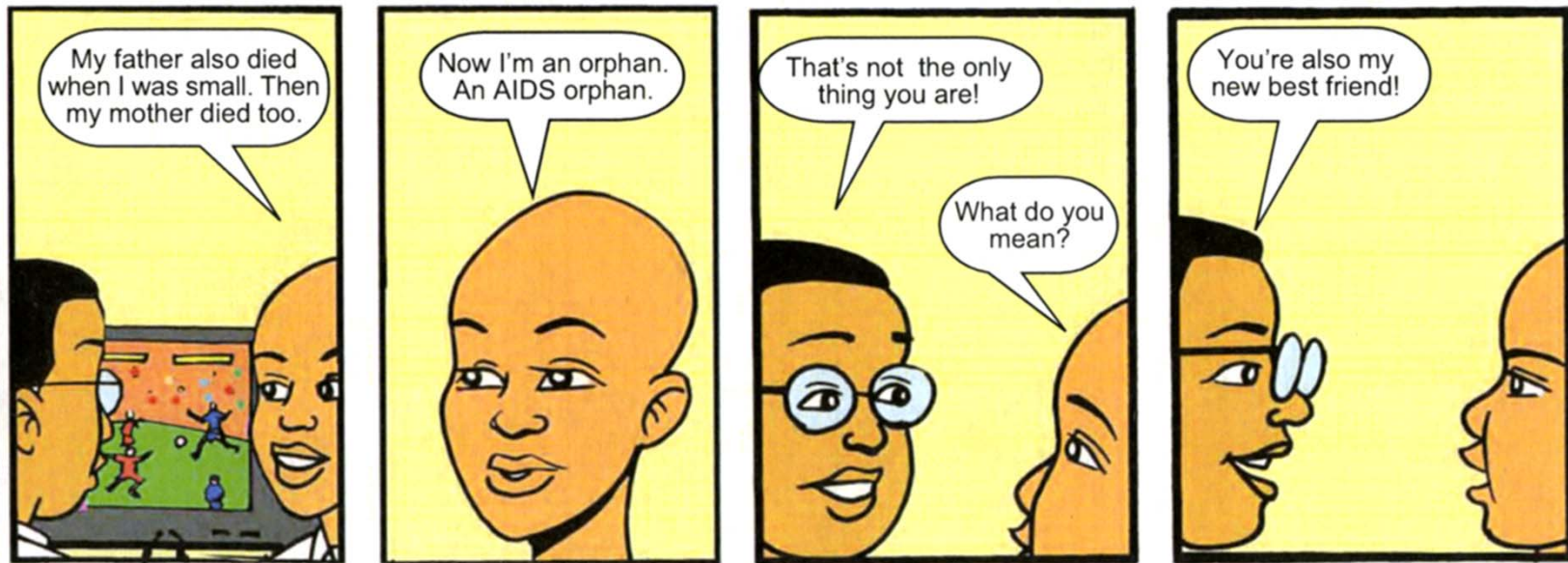
Adherence



Disclosure



Youth Identity



CHAMP+Asia pilot study: Thailand

- In 2013-2014, a needs assessment was conducted with support from TREAT Asia, SEARCH, HIV-NAT, TRCARC
- Focus groups and interviews with Thai and Indonesian adolescents and their families were conducted: identified strong need for CHAMP to address stigma, secrecy, non-adherence, mental health, generation gaps around obedience and discipline and need for help with family communication and social support
- Working with providers and patients, a culturally and contextually appropriate curriculum for Thailand was created
- Cartoons and most topics retained, but order of sessions different and story adapted for context (the Thai name is 'Walking Together' 'ก้าวไปด้วยกัน')

CHAMP+ Asia: “Walking Together”

CHAMP+ THAI

ทางสายไหม



ปีแรกๆ 15 ปี ลีพงษ์เงิน... อยู่กับแม่จูน... มีน้องชายคนหนึ่ง ชื่อพี่ชาย...
พี่ชายชื่อพี่ชาย... พี่ชายชื่อพี่ชาย... พี่ชายชื่อพี่ชาย...
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แม่จูน... พี่ชาย...
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แม่จูน... พี่ชาย...



คุณจูน... พี่ชาย...
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CHAMP+ THAI

ตัวฉันเอง



หลังจากที่... พี่ชาย...
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แม่จูน... พี่ชาย...
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แม่จูน... พี่ชาย...

Loss & Bereavement



Girlfriend and Identity



Are you okay, Tam? Try not to worry about what your mother said to you about having a girlfriend. She's just worried about you.



It's okay. I just want to be able to be myself—and do what I want to do. I'm not hurting anybody.



I understand. Maybe try talking to your mom again. She was upset before. Are you worried about dating and having HIV?



I'm not worried about that. I might have HIV, but I'm no different from everyone else.



I know these issues can be hard to talk about but your mom is trying to listen and help you. If you have any worries you can also talk with me.



CHAMP+Asia pilot study: Thailand

1. Goal: To examine the impact of CHAMP+Asia intervention on children' behavioral, health and psychosocial outcomes
2. Methods: 88 subjects from 4 Thai pediatric HIV clinics were randomized to intervention or comparison group
3. Results:
 1. CHAMP+ was well received with high attendance rates
 2. Preliminary findings: impact of CHAMP+Asia with better viral suppression in Intervention vs Control group ($p=.08$)
 3. We will examine impact on mental health and adherence
4. Challenges include: limited professional, space, and funding resources, cultural need to focus on the positive, thus, difficult for youth to address negative feelings and barriers

SUUBI+ Adherence

(NICHD; PI: Ssewamala; Co-I: Mellins, McKay)

- Unfortunately many behavioral interventions do not have long term effects.
- Adherence remains an elusive outcome and a major barrier to actualizing the full potential of medical advances.
- Beginnings of SUUBI+ Adherence- RFA and Fred Ssewamala question:
 - Is poverty a primary barrier to ART adherence for youth?
 - Can an economic empowerment intervention improve adherence?
- Economic inequalities and substantive impoverishment have been thought to influence access, but not necessarily daily adherence.

SUUBI

Economic empowerment of adolescents in Sub-Saharan Africa (PI: Ssewamala)

- **Designed for:** uninfected orphans and vulnerable children
- **Goal:** promote mental health, reduce sexual risk behavior
- **Method:** improve capacity for economic stability of child, family and community by working with local banks and families to teach youth about savings and loans, and vocational skills
- Significant impact on mental health, health, and sexual risk



1. **SEED Pilot Study** (The Friedman Family Foundation; CU; CSD); 2. **SUUBI (Hope) Project** (NIMH); 3. **SUUBI-Maka Project** (NIMH); 4. **Bridges to the Future – R01 (Uganda)** (NICHD)

SUUBI Studies: Intervention Components

Usual Care/Control:

1. School Supplies: books; uniforms, lunch
2. Counseling
3. PH messaging— “ABC” Model and “talking” compounds



Treatment Condition:

Usual Care PLUS

1. Children Saving Accounts
2. Microfinance Training/FC
3. Mentorship

SUUBI+ Adherence

(NICHD; PI: Ssewamala; Co-I: Mellins, McKay)

- In Uganda: focus groups with HIV+ youth & their caregivers
 - Poverty-related factors were the primary barriers to ART adherence: food insecurity vs need to take some medicines with food; school fees vs ART; Work vs clinic visits
- Developed SUUBI+: Goal: to improve ART treatment adherence, while reducing risk behaviors and improving mental health and economic stability
 1. Family-based asset-building and promotion of education
 2. Clinic support using VUKA HIV treatment adherence materials
- RCT with PHIV+ youth (10-16 yrs) in 32 clinics in 3 Districts
- At baseline: adherence strongly associated with economic assets.



Conclusions

■ **Risk:**

- ▶ Studies primarily from the US indicate some cognitive function and behavioral health problems that place PHIV youth at risk, although HIV is not the only reason
- ▶ Data also suggest normative sexual behavior, substance use, and non-adherence that are public health concerns in context of HIV

■ **Resilience:** Data suggest relatively high rates of resilience, and need to focus on individual, family, social and contextual predictors

■ **Only a few evidence-based interventions exist: WE NEED MORE**

■ **We need to go where the epidemic is to:**

- ▶ Conduct cross-cultural studies of cognitive and behavioral health needs- such as the Resilience study in Thailand
- ▶ Develop evidence-based interventions to promote youth health and well-being, and support families

Global Treatment Disparities

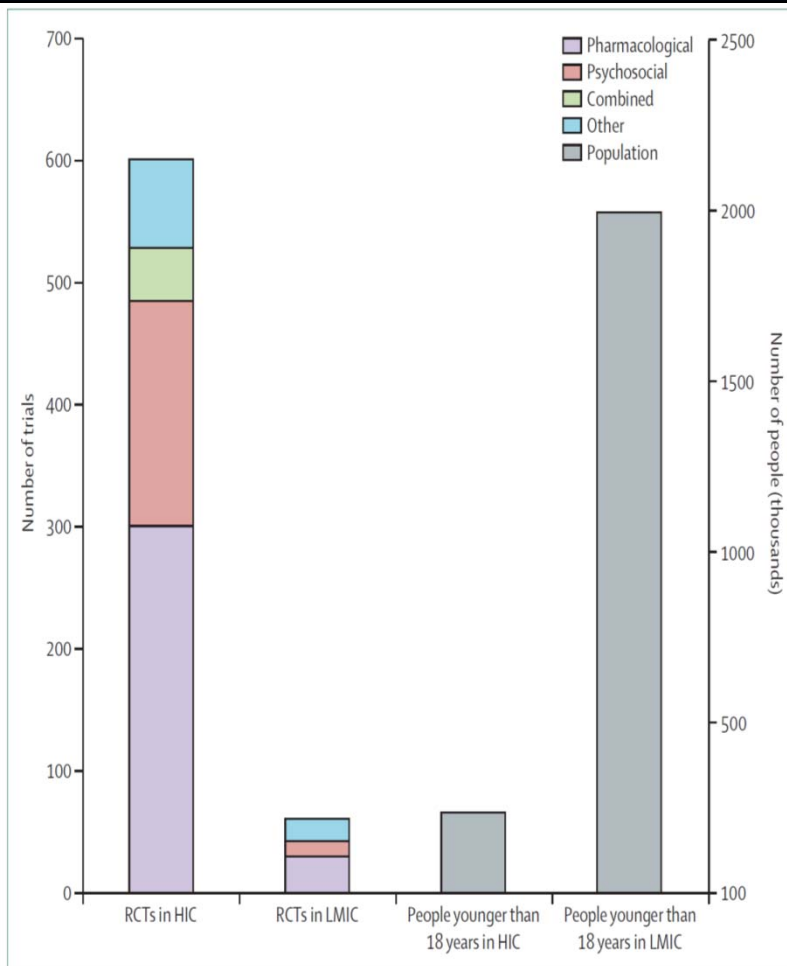


Figure 2: The 10-90% divide in research into treatment for childhood and adolescence mental health disorders
RCTs= randomised controlled trials (between 2001 and 2010). HIC=high-income countries. LMIC=low-income and middle-income countries.

- 90% of children and adolescents live in LMIC
- But only 10% of RCTs on child and adolescent mental health (MH) treatment done in LMIC
- Only 10% of children and adolescents live in HIC, but 90% of RCTs on child and adolescent MH treatment done there (Kieling et al., 2011)

CHALLENGE



PHIV+ youth such as AC, like every other young person their age, deserve a fair shot at playing the Safari of Life.

May seem like a hurdle or big wall to climb.

The question is not whether we can afford to invest in opportunities for [PHIV+ adolescents]

but how we can possibly afford not to.

***Adapted from Nicholas D. Kristoff-
1/31/2013***

NY Times Op-Ed

It Takes A Village: Collaborators

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