

# Interacting with ease: Breaking the stigma of HIV by strengthening positive support and care

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- Donald T. Campbell
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- The World AIDS Foundation

# In today's presentation, we will

- Look at the effects of HIV-related stigma and social isolation on individuals and families
- Review four social-psychological principles of prejudice and intergroup relations and apply them to
  - Persons living with HIV (PLWHIV)
  - The illness HIV
- See how those principles are applied in interactive trainings given to community and institutional networks of care to promote positive caring
- Talk about adaptations to make interventions locally-relevant

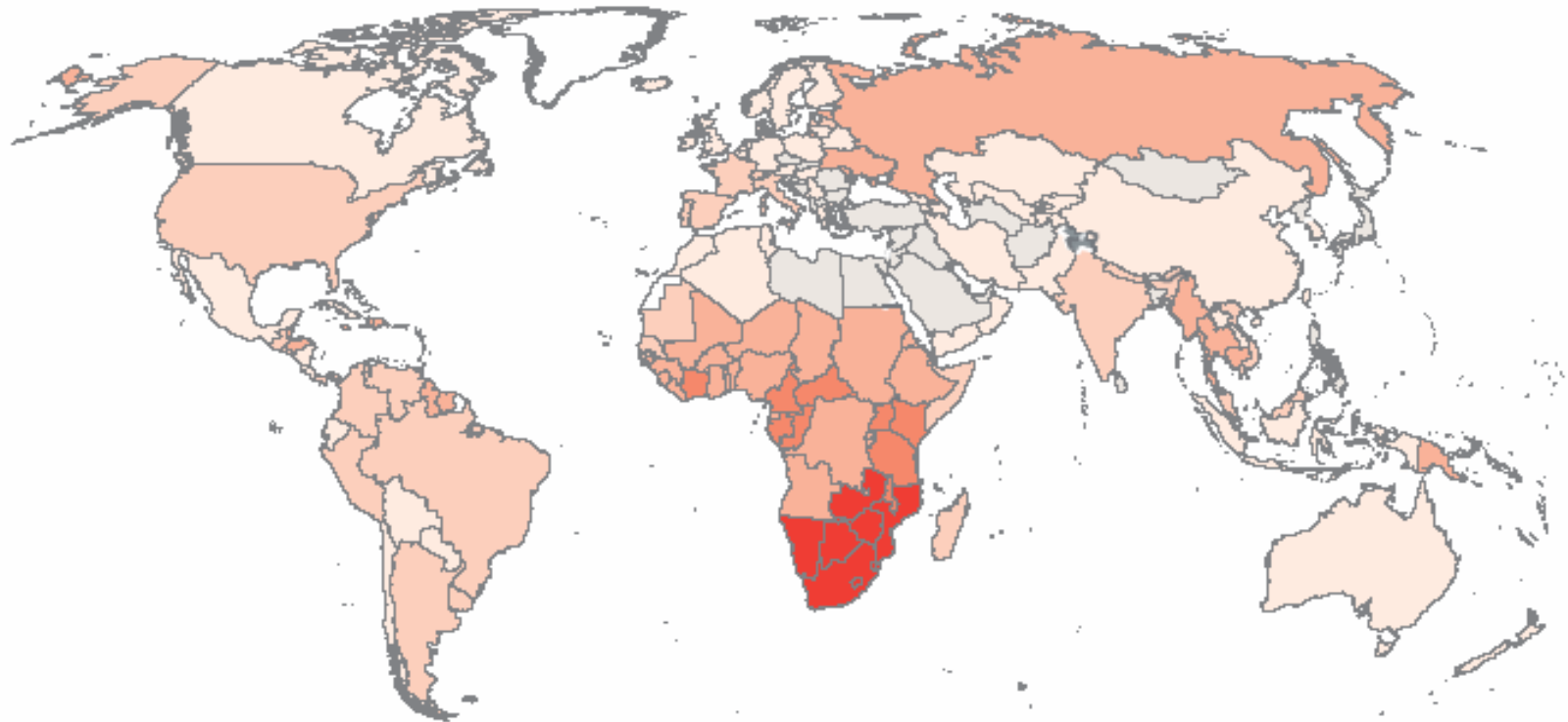
# HIV is only one of a number of emerging illnesses and existing conditions facing communities

- Our understanding of HIV is constantly emerging
- Cultures have had a short time frame in which to adapt to HIV
- Our work is enhanced if we convey practical and useful information and skills to deal with multiple local health threats
- Youth are a constantly emerging new risk group, born into a world where HIV is a threat

**FIGURE 2.4**

**A global view of HIV infection**

38.6 million people [33.4–46.0 million] living with HIV, 2005



Adult prevalence rate

■ 15.0%–34.0%

■ 1.0%–<5.0%

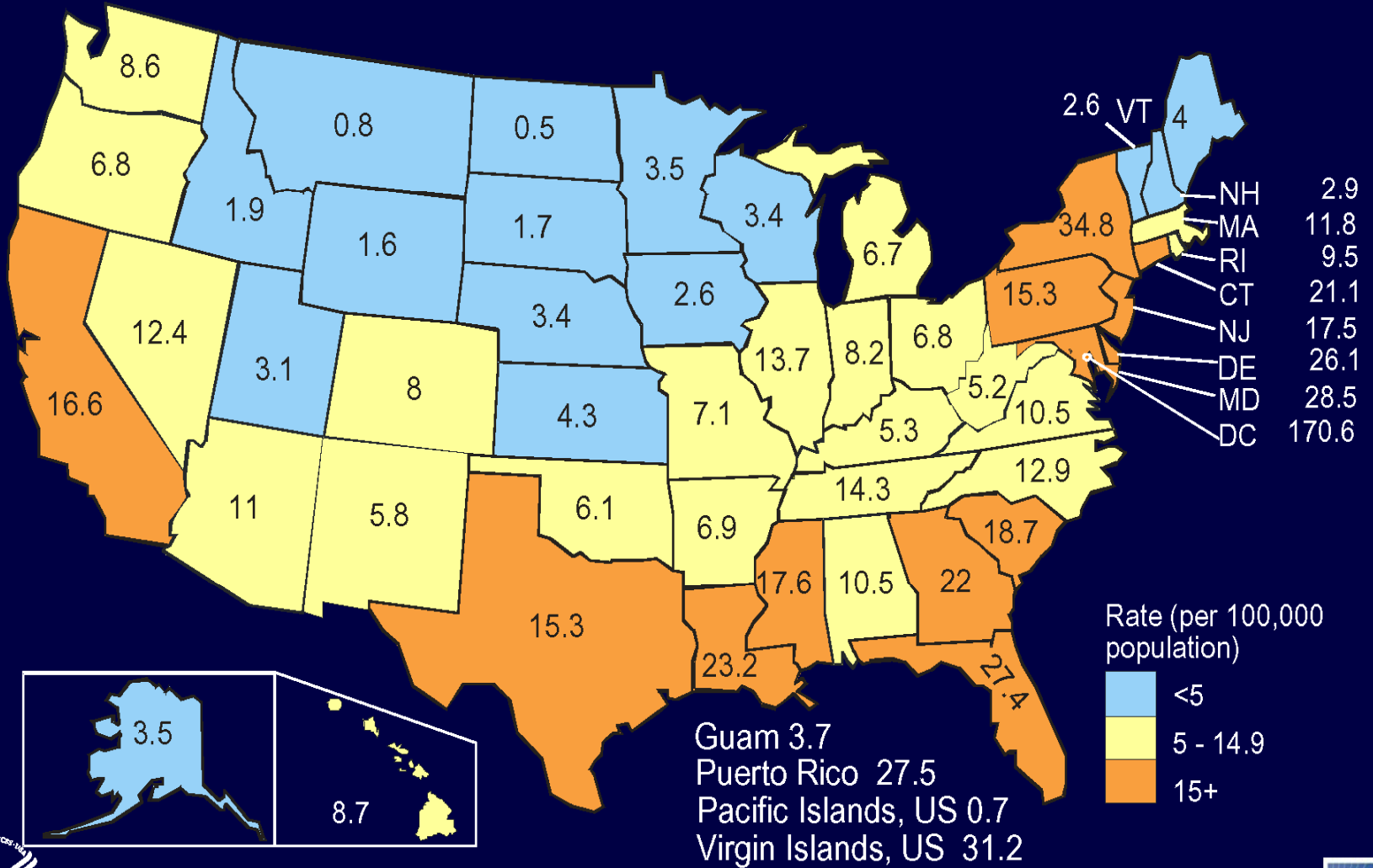
□ 0.1%–<0.5%

■ 5.0%–<15.0%

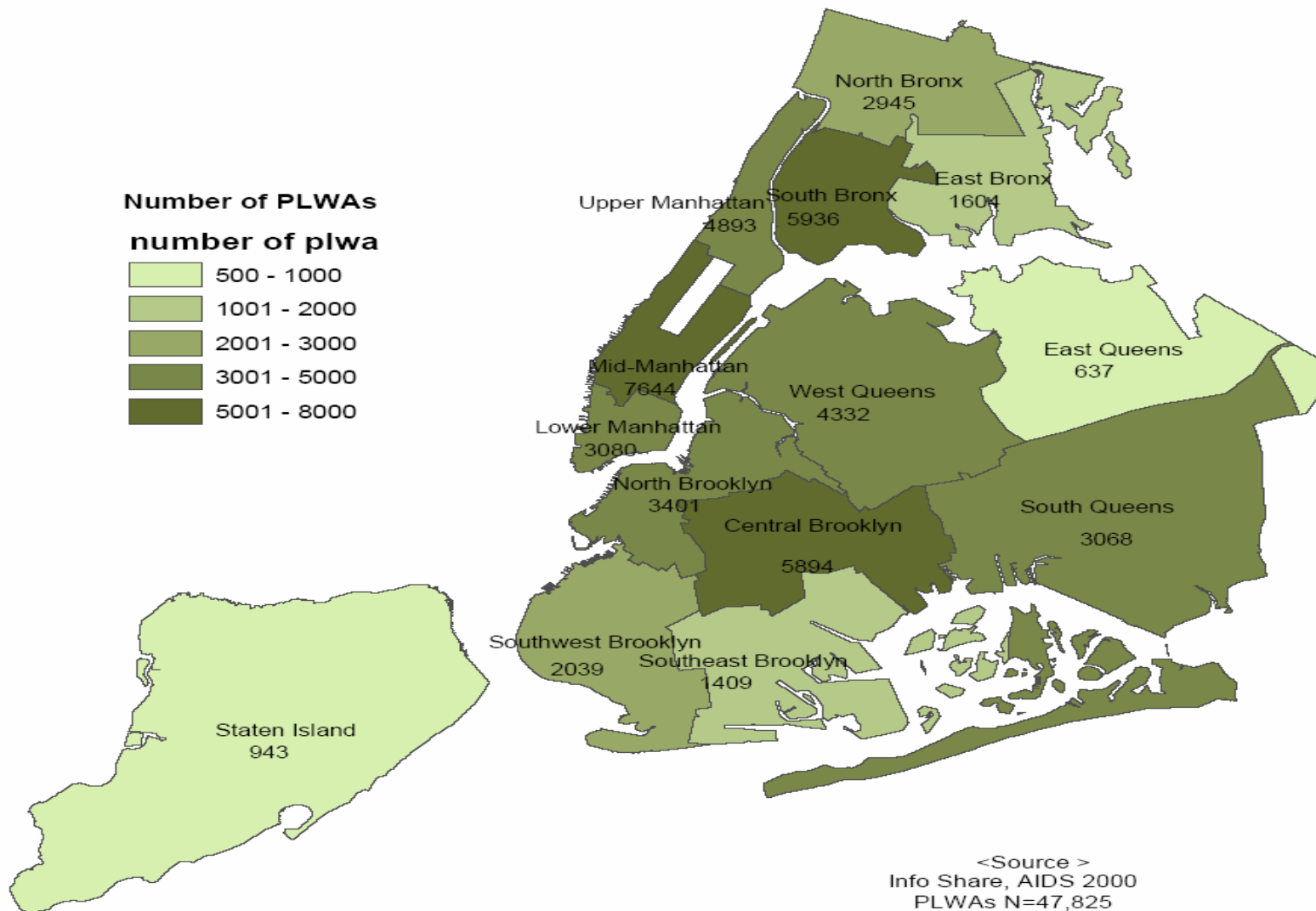
■ 0.5%–<1.0%

□ <0.1%

# AIDS Rates, Reported in 2003—United States



# Total Number of PLWAs by Sub-Borough



<Source >  
Info Share, AIDS 2000  
PLWAs N=47,825  
CHAIN Study Wave 5,6,7,8 (N=645)  
7 Homeless excluded

For people living with HIV (PLwHIV), social isolation and stigma are associated with ...

- Reduced access to care where it is available
- Increased difficulty adhering to care
- Mental health problems, including depression
- Increased difficulty dealing with the social effects of a serious illness, e.g., reduced income, continuous child care

# HIV-related social isolation and stigma also affects

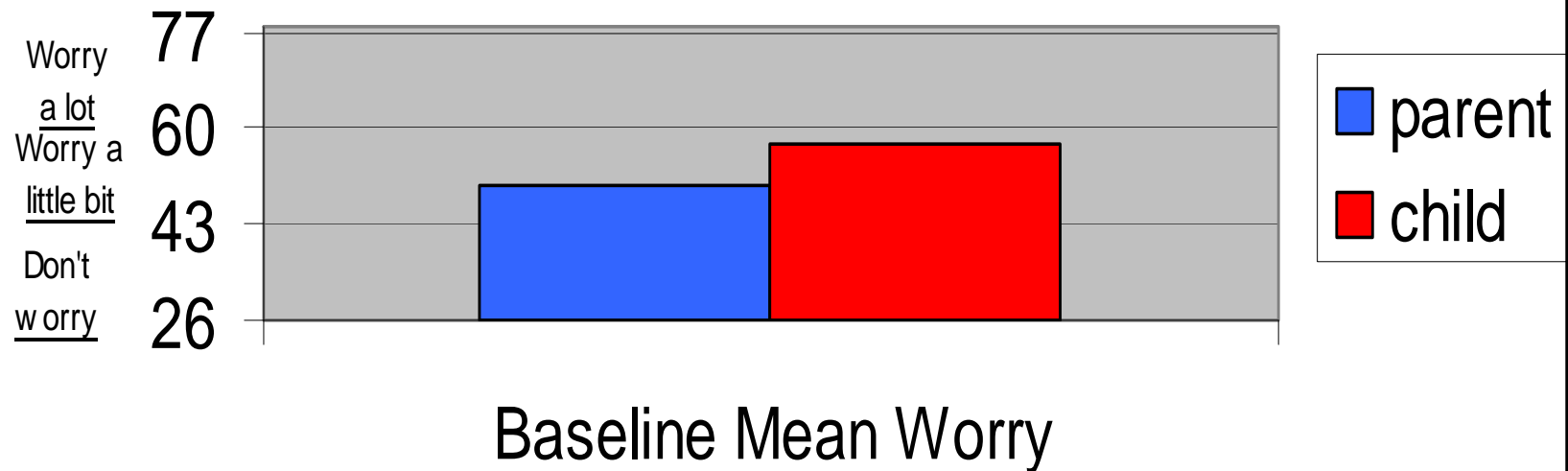
- Caregivers of PLwHIV
- Other family or social network members, including children and youth
- Communities, geographic areas, and countries highly affected by HIV
- The way we communicate about prevention, treatment and care

# Open communication is necessary to address the documented roots of HIV-related stigma

- Misperceptions about transmission
- Social awkwardness, present in many cultures, in dealing with people with a serious illness

# The effects of silence and stigma on children – High worry

## Total mean scores on a measure of unrealistic or controllable HIV-related worries



# Four social cognitive principles concerning prejudice and stigma

- Factors promoting prejudice and stigma
  - fear arises from a perception of threat combined with perceived low skill or power to control the threat
  - fear, and the avoidance that often accompanies it, is easier to maintain if the threat is seen as coming from members of a distinct outgroup

# Principles continued ...

- Factors assisting destigmatization
  - outgroup biases are more difficult to maintain if *crossed categorization* (e.g., emphasis on multiple roles and identities) occurs; when ingroup-outgroup distinctions are diminished, people can begin to experience emotions on behalf of a group with which they now identify and even on behalf of illness situations with which they now identify. We applied this principle to
    - **PLwHIV and**
    - **HIV infection—to reduce its “otherness” among diseases**
  - negative emotionality is further reduced when appropriate behavior is legitimized. Since emotionality may drive behavior, socio-emotional learning needs to take place.

# An interactive training that brings thoughts, feelings and behaviors on stage



# The community-based Parent/Preadolescent Training for HIV Prevention (PATH) curriculum was informed by social psychological principles

- Four basic modules
  - HIV knowledge
  - Child development
  - Recognizing, avoiding or negotiating risk
  - Safe and sensitive socializing with PLwHIV, a destigmatization module

# Activities in the original PATH destigmatization module

1) Communication role play	6) How people with HIV like to be treated
2) Myths and facts about infectious diseases	7) Bombardment with HIV issues—a role play game
3) Universal precautions: a practical guide	8) HIV resources: building a neighborhood map
4) Supporting someone with HIV	9) HIV and New York State Law
5) Video: HIV and my family	10) Congratulations

## A PATH exercise

Someone in this picture has HIV.  
Are they being supported in a safe and sensitive manner?



# Another scenario



**Children of trained parents said they felt significantly more comfortable performing these activities with a PLwHIV at six months post baseline**

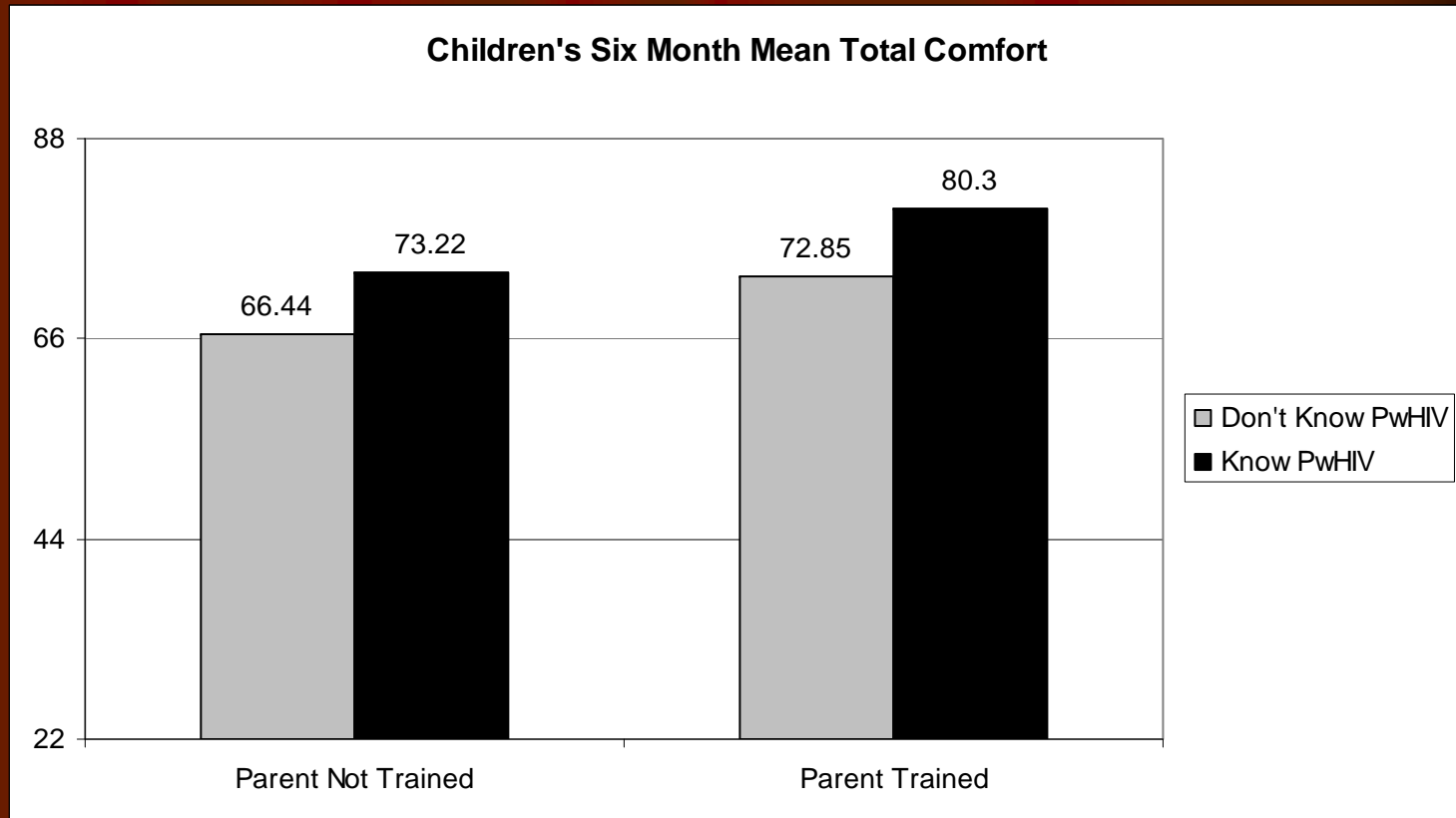
**1=very uncomfortable to 4=very comfortable**

Item	Baseline Mean	Six Month Mean	Sign Test Z	p
Shared a soda or beverage?	1.89	2.21	2.16	.031
Kissed?	2.49	2.96	3.78	<.001
Let that person cook dinner for you?	2.64	2.92	2.24	.025
Helped him/her with washing clothes?	2.92	3.37	2.86	.004

Item	Baseline Mean	Six Month Mean	Sign Test Z	p
Let him/her baby-sit you?	2.97	3.26	2.63	.009
Swam in a pool together?	3.04	3.44	2.74	.006
Had dinner together?	3.07	3.44	2.12	.034
Hugged?	3.17	3.52	2.93	.003
Played one-on-one basketball?	3.36	3.55	2.01	.045
Gone to the movies together?	3.42	3.70	2.01	.045

Item	Baseline Mean	Six Month Mean	Sign Test Z	p
Helped him/her with getting their medicine?	3.42	3.75	3.38	.001
Went with him/her to medical appointments?	3.45	3.63	2.11	.035
Listened to his/her concerns & fears?	3.52	3.74	2.09	.037
Helped him/her with running errands?	3.62	3.82	2.94	.003

# Additive effects of parent training and knowing someone with HIV



# Additional activities in stand-alone institutional trainings

- Review of mission statement for relevance to HIV-affected clients, staff, and communities
- Caring and adherence to treatment
- Surveillance maps of HIV in the world, country, state and catchment area
- HIV 101
- Primary modes of HIV transmission in your catchment area
- PATH module activities
- On-site and off-site supports for information

# Pre-training to post-training changes in rated comfort interacting with a PLwHIV for hospital staff

1=very uncomfortable to 4=very comfortable

Scale or Item	Pre-training Mean (sd)	Post-training Mean (sd)	t <sub>dep</sub>	p
Total scale: 8 items	27.5 (5.5)	29.5 (4.5)	11.89	<.001
<u>Items</u>				
Helped him/her with washing clothes	3.27 (.95)	3.65 (.67)	12.08	<.001
Hugged	3.28 (.92)	3.63 (.71)	11.92	<.001
Fed him/her	3.30 (.88)	3.62 (.69)	11.04	<.001
Had dinner together	3.45 (.81)	3.72 (.63)	9.87	<.001
Helped him/her with getting his/her medicine	3.53 (.79)	3.72 (.63)	7.25	<.001
Went with him/her to medical appointments	3.55 (.76)	3.73 (.61)	7.90	<.001
Went to the movies together	3.55 (.72)	3.74 (.60)	7.08	<.001
Prepared meals for him/her	3.61 (.71)	3.73 (.64)	5.14	<.001

# The processes of adaptation

- Understand local context
  - HIV and other health issues
  - Collaborate with the formal and informal communities of care
  - Co-design the “local” intervention while preserving underlying principles of intervention
- Test-operate-test-exit: Design, implement, test, revise; review, update, test, revise

# THE MODEL

Global HIV/AIDS Information



Research and Training Institutions



New York City



New York State



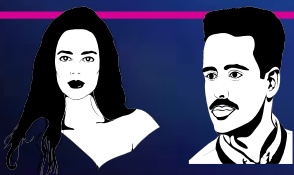
Mexico City



Miami, Mumbai  
and New Partners



Community Outreach Partners



Parents & Children



# Conclusion

- To reduce the stigma associated with HIV
  - de-stigmatize PLwHIV
  - de-stigmatize HIV
  - increase useful and practical transmission knowledge
  - increase comfort in caring interaction
  - normalize appropriate behavior
- Recognize that some trainees may become HIV "ambassadors"
  - provide support and certification, if possible

Thank you for your  
kind attention!!

