

Direitos Humanos e Saúde

Human Rights and Health: Recognized Linkages, Political Controversies, and (some) Evidentiary Efforts

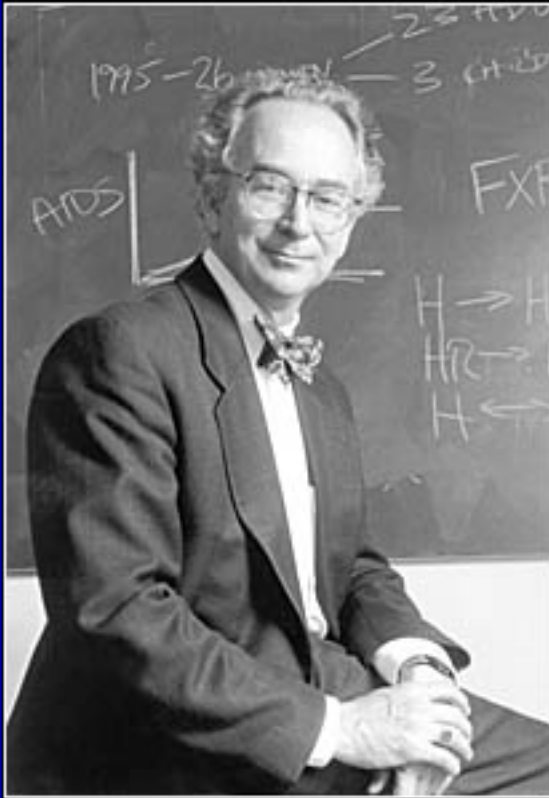
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Human Rights, International Law HIV/AIDS and Health

- History
- Concepts
- Impacts

Jonathan Mann, 1948-1998



“Action is liberating: it can teach what cannot be learned nor imagined in the abstract”.

Jonathan Mann, Health and Human Rights:
If not now, when?

Health and Human Rights, 1997:2(3):113-120

Conceptual Relationships Between Human Rights and Health

Health → Human Rights

Health ← Human Rights

Health ↔ Human Rights

The Good News

- No longer the question of why health and human rights but how?
- Massive violations in health and human rights have been averted
- Health and human rights education and training is on the rise
- Research and publications are expanding
- Health and human rights principles are increasingly applied to policies and programs

Now The Bad.....

- Assertions against human rights by some well-known public health practitioners
- The overwhelming burden of global health concerns is not going away
- Perceived limitations of the value of state and non-state compliance with human rights as they relate to public health
- Inadequate accountability for human rights by pharmaceuticals and multinationals
- Politics, politics, politics!!
- Lack of understanding/consensus of what is meant by inclusion of human rights in public health programming efforts
- Lack of evidence-base for the role that human rights play in achieving desired outcomes

What Is Meant By Human Rights

- International human rights law defines what governments can do to us, cannot do to us, and should do for us
- Human rights law is meant to be equally applicable to everyone, everywhere in the world, across all borders and across all cultures and religions
- Human rights are universal, interrelated and indivisible
- Human rights are primarily about the relationship between the individual and the state
- International human rights law consists of the obligations that governments have agreed they have in order to be effective in promoting and protecting our rights
- Governmental obligations to respect, protect and fulfill human rights

What Is Meant By Health

As an aspirational goal: *“Health is a state of complete physical, mental and social well-being and not merely the absence of disease”*

Constitution of the World Health Organization, adopted by the International Health Conference, New York, 19 June-22 July 1946

As an instrumental goal: *“Ensuring the conditions in which people can be healthy”*

Institute of Medicine, Future of Public Health, Summary and Recommendations (Washington, DC: National Academy Press, 1988 US Institute of Medicine)

Relevant International Human Rights Law

1948: Universal Declaration of Human Rights (UDHR)*

Treaties: Legally binding on nations that have ratified

1965: International Convention on the Elimination of All Forms of Racial Discrimination

1966: International Covenant on Economic, Social, and Cultural Rights

1966: International Covenant on Civil and Political Rights

1979: International Convention on the Elimination of All Forms of Discrimination Against Women

1985: Convention Against Torture

1990: Convention on the Rights of the Child

2000: Convention on the Protection of Migrant Workers and their Families

2006: Convention on the Rights of Persons with Disabilities

* The UDHR is not a legally binding document, but has served as inspiration for, and been incorporated into, all the human rights treaties that have followed

The Right to Health and Health-Related Rights

International Covenant on Economic, Social and Cultural Rights: The Right to the Highest Attainable Standard of Health, Art. 12

- Article 12 recognizes “the right of everyone to the enjoyment of the highest attainable standard of physical and mental health.”
- The steps to be taken by the States parties...to achieve the full realization of this right shall include those necessary for:
 1. The provision for the reduction of still-birth rate and of infant mortality and for the healthy development of the child;
 2. The improvement of all aspects of environmental and industrial hygiene;
 3. The prevention, treatment and control of epidemic, endemic, occupational and other diseases;
 4. The creation of conditions which would assure to all medical service and medical attention in the event of sickness.

Human Rights Relevant to Health

- The right to equality and non-discrimination
- The right to life, survival, and development
- The right to travel
- The right to bodily integrity and security of the person
- The right to an identity
- The right to privacy
- The right to health
- The right to food
- The right to housing
- The right to social security
- The right to be free from torture
- The right to association
- The right to the benefits of scientific progress
- The right to education
- The right to seek, receive and impart information

Progressive Realization

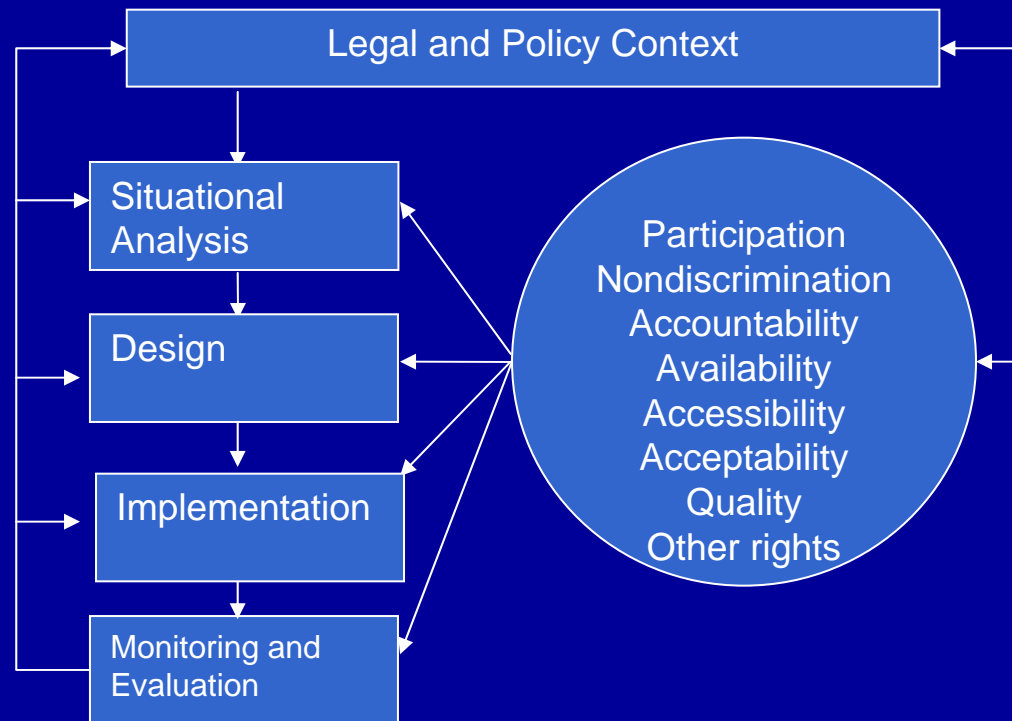
States must “take steps, individually and through international assistance and cooperation, especially economic and technical, to the maximum of its available resources, with a view to achieving progressively the full realization of the rights recognized in the [Economic, Social, and Cultural Rights] covenant by all appropriate means, including particularly the adoption of legislative measures.”

-ICESCR, Art 2 (1)

What is a rights-based approach to health?

- Attention to the legal and policy context
- Participation
- Non-discrimination
- The right to health (availability, accessibility, acceptability, and quality of services)
- Transparency and accountability

Applying a Rights-Based Approach to Health



Current Work in Human Rights and Health

- Identifying, naming and remedying violations of human rights related to health
- Advocating around health issues using human rights language
- Assessing government performance in health through application of human rights standards
- Promoting accountability at national and international levels
- Developing effective health policies and programs
- Demonstrating the value of rights based approaches to health

Categorizing Current Work in Human Rights and Health

- Advocacy
- The use of the law, including both international and national legal norms and standards
- The use of key human rights principles for designing, implementing, monitoring and evaluating HIV policies and programs (a “rights-based approach”)

Creating the Evidence Base: some evidentiary efforts

- Human rights principles commonly noted as relevant to addressing public health concerns:
 - Participation
 - Non-discrimination
 - Availability, acceptability, accessibility and quality (3AQ) of good and services
 - Accountability
 - Other recognized rights as they may be specific to the intervention

Determining how (or if) human rights are integrated into the HIV response

- Assess the extent to which human rights are integrated into HIV and AIDS policy documents
- Assess the extent to which human rights are integrated into existing HIV and AIDS programmatic efforts
- Assess the extent to which indicators currently in use are sensitive to human rights concerns
- Assess the extent to which international and national legal and policy environments are harmful or helpful for protecting human rights and for effective AIDS programs

Ultimately the goal is to provide evidence that the extent to which AIDS programs pay attention to rights has a positive impact on reported behavior, HIV prevalence and treatment outcomes

Why pay attention to human rights in the AIDS response?

Overall, UNAIDS and its partners operate from the position that human rights should be protected because:

- (a) there is a moral and legal obligation to respect, protect and fulfill rights
AND
- (b) their protection results in more effective HIV programs and more positive outcomes

Human rights in international and national responses to HIV and AIDS

- Call for non-discrimination included in the first Global Response to AIDS (1987)
- All global and many national strategy documents since have asserted the role of human rights for an effective HIV response
- WHO's 3X5 strategy referred to HIV treatment as *a human right*
- Universal Access Framework recognizes the role of human rights for successful strategic efforts, and in relation to national level targets

Setting national targets for Universal Access

- Services have to be equitable, affordable, comprehensive and sustainable
- National target setting and tracking have to be standardized based on a small set of core indicators
- Countries should focus on overcoming identified and previously reported obstacles

Source: Moving Towards Universal Access, (UNAIDS) October 2006

Principles for setting national targets include:

- Country ownership and participation
- Building on past efforts
- Review of existing data and data collection systems
- Reviewing existing indicators
- Setting targets as part of national strategic plans
- Identifying and overcoming obstacles to scale-up
- ***Human rights, gender and the greater involvement of People Living with HIV and AIDS (GIPA)***
- Quality of and equity in access to services
- Setting priorities and overcoming obstacles
- Limiting the number of targets
- Using targets to mobilize resources

Source: Moving Towards Universal Access, (UNAIDS) October 2006

Human rights, gender and the Greater Involvement of People Living with HIV and AIDS (GIPA)

- People living with HIV, women, young people and other most-at-risk populations, such as sex workers, men who have sex with men, drug users and prisoners should play a major role in setting national targets
- Targets should be considered with regard to participation, availability, affordability, accessibility and quality
- Coverage should be measured across different populations, with the aim of ensuring equitable access
- Data should be disaggregated by age and sex at a minimum, but also, where possible, marital status, location (rural/urban) and ethnic background

Source: Moving Towards Universal Access, (UNAIDS) October 2006

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Results of search for key words or their equivalent in documents reviewed

Documents reviewed	Human rights	Key words and principles								
		Rights	Stigma	Discrimination	Participation	Attention to vulnerable populations	Right to health: structures, goods and services			
							Availability	Accessibility/ access	Acceptability/ acceptable	Quality
International Documents (59)										
Global Fund	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes
PEPFAR	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	No	Yes
World Bank	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No	No
UNAIDS	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes
National HIV Strategic Plans (14)										
Botswana	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Brazil	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes
China	No	No	No	No	No	No	Yes	Yes	No	Yes
Germany	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	No	No
India	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	Yes
Indonesia	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes
Kenya	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes
Myanmar	Yes	No	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes
Nigeria	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	No	No
Papua New Guinea	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	Yes
Pakistan	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Peru	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	No	Yes
South Africa	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	Yes
Vietnam	No	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes

Source: Gruskin S, Tarantola D. 'Universal Access to HIV Prevention, Treatment and Care: Assessing the inclusion of human rights in international and national strategic plans,' *AIDS* vol. 22, suppl. 2, pp. 123-132 (2008).

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A review of HIV and AIDS programmatic efforts

- Differences exist between policy level rhetoric and programmatic realities, a false dichotomy is often made between a “public health approach” and a “rights-based approach”
- Insufficient documentation exists of what successfully integrating human rights into programming means when it does happen
- Where rights have been integrated, there has been insufficient monitoring of their impact
- Donors are requiring indicators with short time frames that focus, for example, on the numbers of people receiving treatment. Thus, human rights which emphasize not only on numbers but *who* is gaining access, *how* they are gaining access, and over *what period of time*, not just *how many* raise uncomfortable questions.

Source: Beyond the Numbers: Using Rights-Based Perspectives to Enhance Antiretroviral Treatment Scale-up, Sofia Gruskin, Laura Ferguson and Dina Bogecho AIDS 2007, 21 (suppl 5): S13:S19

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Type of indicator	Example	What is missing	How could it be improved by considering both HIV and human rights
HIV indicators used to draw conclusions about human rights	Total number of people on ART	No information on who is (and isn't) on ART. Attention to differences by sex, age, geographical location, vulnerable populations etc. is missing.	As with most HIV indicators, appropriate disaggregation could provide information that sheds light on the human rights principle of non-discrimination.
Human rights indicators used to draw conclusions about HIV	Existence of HIV policy that promotes equal access to ART for women and men	No attention to the specifics of the policy nor factors relating to its implementation.	Technical attention to HIV can highlight key components that should be included (e.g. ensuring access for women outside pregnancy-related services) and attention to factors of implementation.

Source: Gruskin S, Ahmed S, Ferguson L, HIV/AIDS Indicators for human rights: What? Why? And How? The XVII International AIDS Conference, Mexico City, Mexico, 2-8 August 2008.

Questions to Ask in Assessing if Indicators Are Sensitive to Both HIV and Human Rights

- 1. Why was this indicator designed?** Was its intended purpose to track violations, to assess programmatic performance or to capture information relevant to both HIV and human rights? Compromises relating to specificity, comparability and cost are apparent, based on the priorities that the indicator is designed to inform.
- 2. Who is using the indicator?** Who designed, constructed and funded the indicator? Each individual actor brings with them biases; explicit attention to these may help to determine the appropriate use of data generated by specific indicators.
- 3. What kind of indicator is it?** Quantitative or qualitative? Used on their own, indicators have limitations on the extent to which they capture both human rights and HIV concerns which should be taken into account.
- 4. Does the indicator provide sufficient information with regard to vulnerable populations?** What disaggregation criteria should be applied and in response to whose demand? Disaggregation of information to reflect where the needs are most acute is undisputed but sufficient attention must be given to ensuring that the realities of vulnerable populations are considered in making these determinations.
- 5. How were the data collected and how are they being used?** Were rights promoted or violated in how the data were collected? Are the data being used to foster stigma, discrimination or further violations of human rights? Attention is needed to ensure that data are not collected inappropriately (e.g. forced testing of sex workers) and that the resulting data are not inadvertently used to fuel discrimination at the community level.

Source: Gruskin S, Ahmed S, Ferguson L, HIV/AIDS Indicators for human rights: What? Why? And How? The XVII International AIDS Conference, Mexico City, Mexico, 2-8 August 2008.

Matrix for review of indicators

Example: Does your country have a policy to ensure equal access of men and women to prevention and care?

Indicator	Method of Data Collection	Level of Data Disagg.	Relevant HRs Principle	Rationale	Gaps	Alternative Available Indicators	Comments
National Commitment & Action							
Expenditures							
Policy Development and Implementation Status							
National Programmes: education, workplace policies, STI case management, blood safety, PMTCT coverage, ART coverage, and services for orphans and vulnerable children							
Knowledge and Behaviour							
Impact							

Matrix for review of indicators cont.

Example: Does your country have a policy to ensure equal access of men and women to prevention and care?

Human Rights Principle	Rationale	Comments
Right to health	Related to the provision of health services	<ul style="list-style-type: none"> • Does not provide information on <u>quality</u>
Non-discrimination	Assesses accessibility of HIV services, including breaking this down by sex, thus encompassing the element of non-discrimination	<ul style="list-style-type: none"> • Good indicator to assess <u>existence of policy</u> on equal access for men and women
Accountability	Determines <u>if a policy exists</u> for equal access to HIV/AIDS prevention and care	<ul style="list-style-type: none"> • Doesn't indicate with who accountability lies • No information on <u>implementation of policy</u> • Indicator is <u>self-reported</u>
Right to information	Determines if national policy exists to support equal access of men and women to HIV prevention and care services including information services	
Right to adequate standard of living	Determines if national policy exists to support equality between men and women and thus an adequate standard of living	

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Example laws/policies that can facilitate efforts to address HIV:

- Non-discrimination laws which specify protections for People Living with HIV and/or vulnerable sub-populations
- Policies of free access to HIV services for all

Example laws/policies that can impede efforts to address HIV:

- Laws that criminalize sex work, injecting drug use, or sex between consenting males
- Laws that require parental consent for legal minors to access HIV services

Source: Gruskin S, Ferguson L, "Ensuring an effective HIV response for vulnerable populations-assessing national legal and policy environments." The XVII International AIDS Conference, Mexico City, Mexico, 2-8 August 2008.

2001 United Nations General Assembly Special Session (UNGASS) Declaration of Commitment (DOC) on HIV/AIDS

- Prevention
- Care, support and treatment
- HIV/AIDS and human rights
- Reducing vulnerability
- Children orphaned and made vulnerable by HIV/AIDS
- Alleviating social and economic impact
- Research and development
- HIV/AIDS in conflict and disaster-affected regions
- Resources
- Follow up:
 - National level
 - Regional level
 - Global level

2001 United Nations General Assembly Special Session (UNGASS) Declaration of Commitment (DOC) on HIV/AIDS

- Emphasizes the centrality of human rights to an effective HIV response
- Countries submit reports to UNAIDS every two years on their progress towards fulfilling the DOC

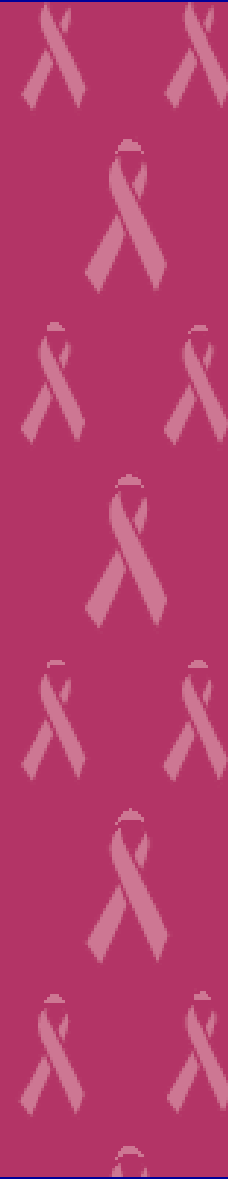
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United Nations General Assembly
Special Session on HIV/AIDS

Monitoring the Declaration of Commitment on HIV/AIDS

GUIDELINES ON CONSTRUCTION OF CORE INDICATORS

2008 Reporting

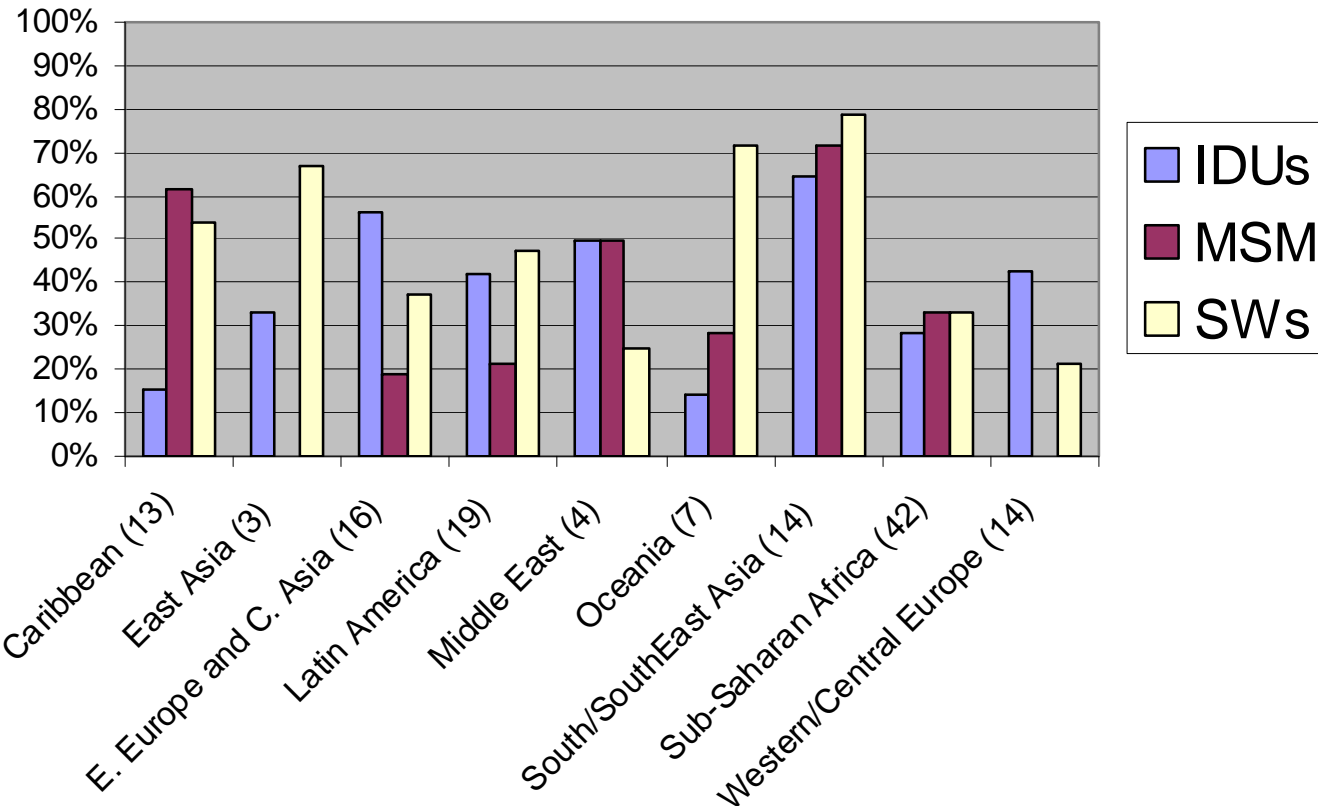


UNGASS National Composite Policy Index (NCPI)

- Part A is completed by government officials:
 - I Strategic plan
 - II Political support
 - III Prevention
 - IV Treatment, care and support
- Part B is completed by UN organizations, bilateral agencies and nongovernmental organizations:
 - I Human rights
 - II Civil society involvement
 - III Prevention
 - IV Treatment, care and support

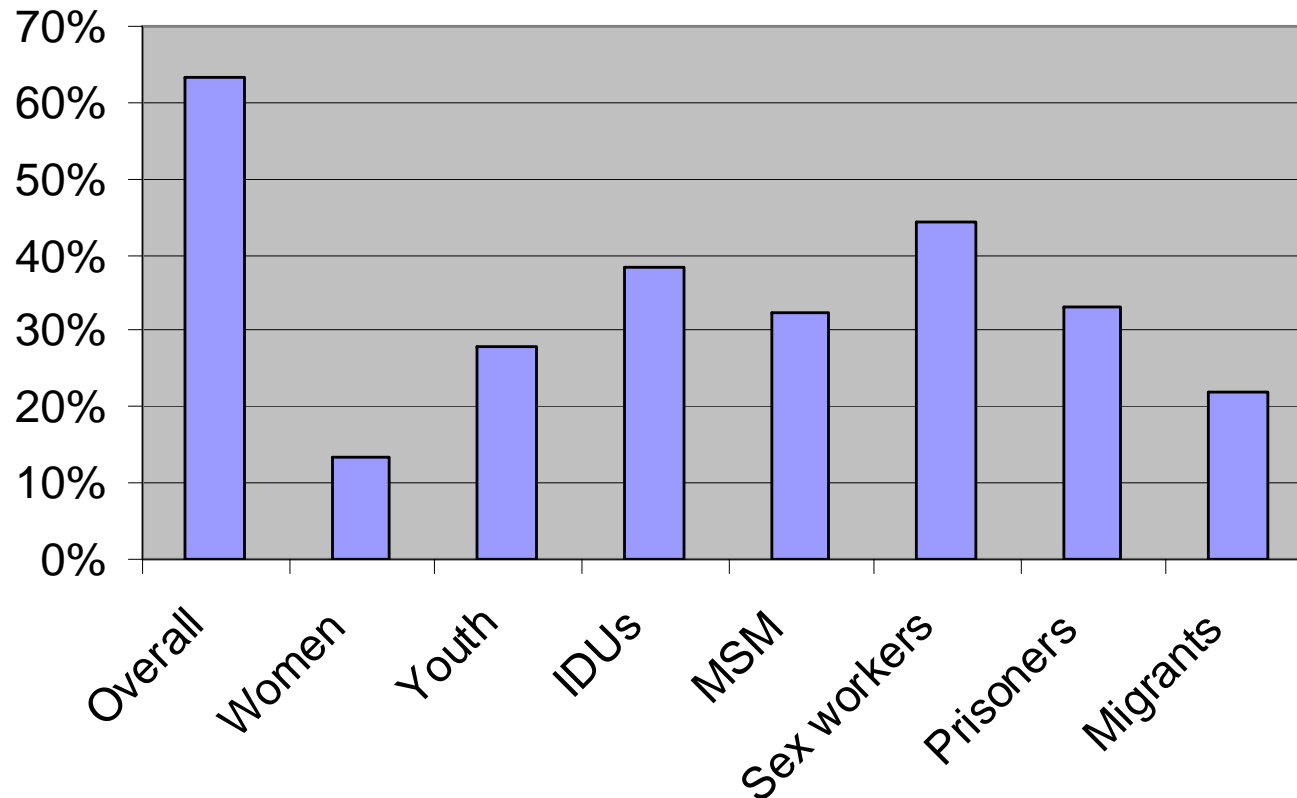
The NCPI is vetted and submitted by governments

Percentage of countries reporting laws, regulations or policies that present obstacles to effective HIV prevention, treatment, care and support for vulnerable sub-populations



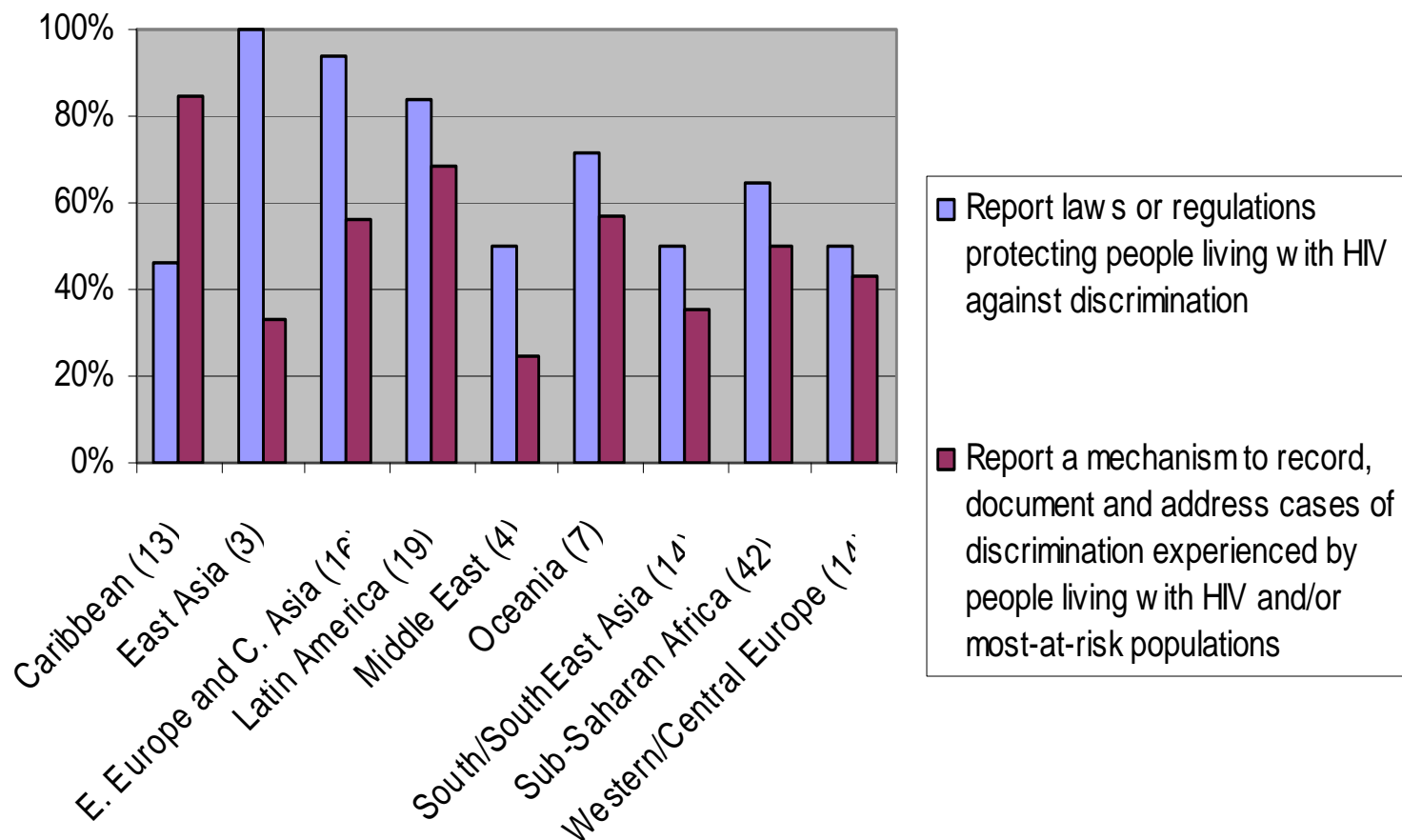
Source: Gruskin S, Ferguson L, Peersman G, Timberlake S, Rugg D, "UNGASS Results-2008: Trends in how human rights are addressed in HIV responses." The XVII International AIDS Conference, Mexico City, Mexico, 2-8 August 2008.

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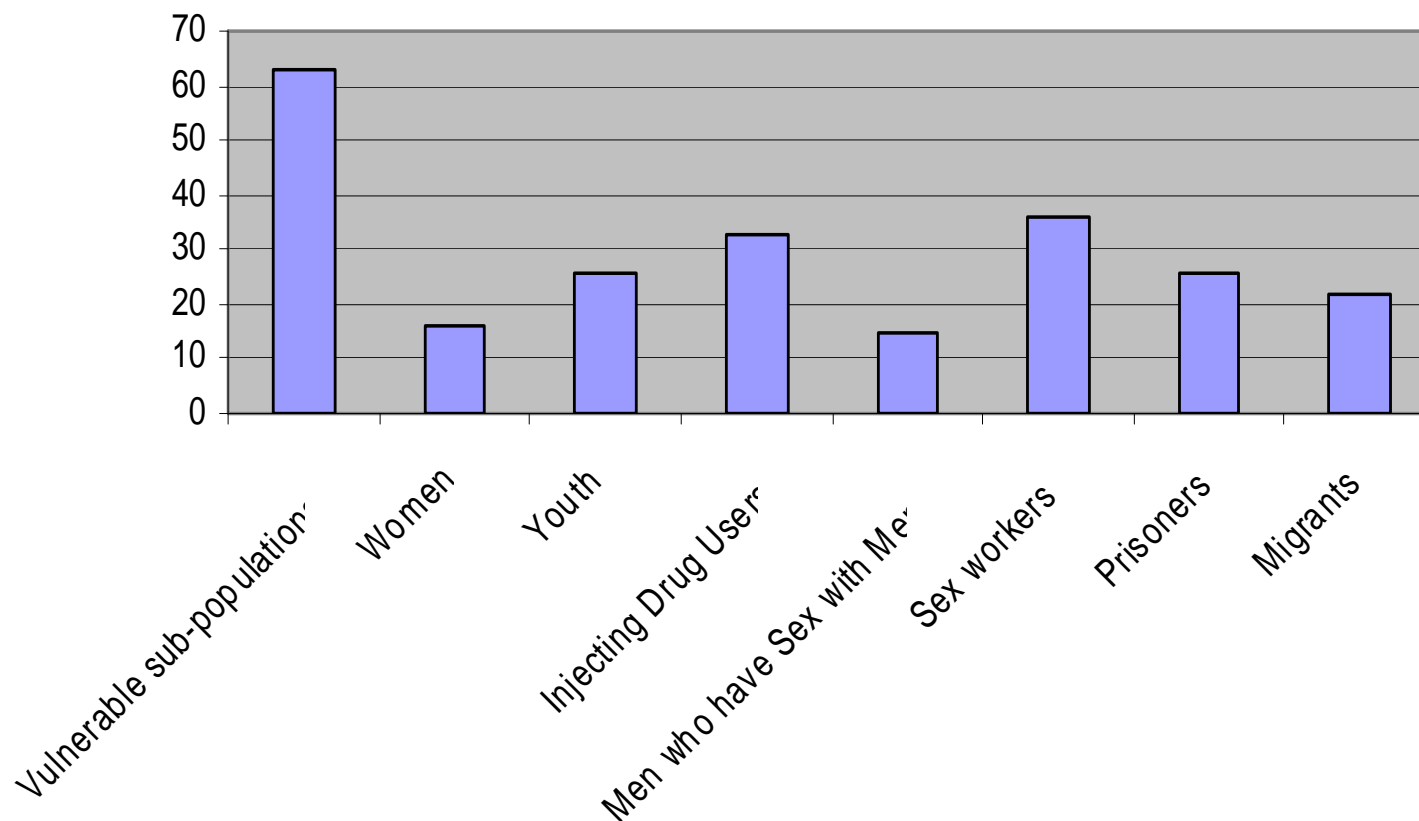
Source: Gruskin S, Ferguson L, "Ensuring an effective HIV response for vulnerable populations-assessing national legal and policy environments." The XVII International AIDS Conference, Mexico City, Mexico, 2-8 August 2008.

Percentage of countries reporting legal protections against discrimination and mechanisms for redress



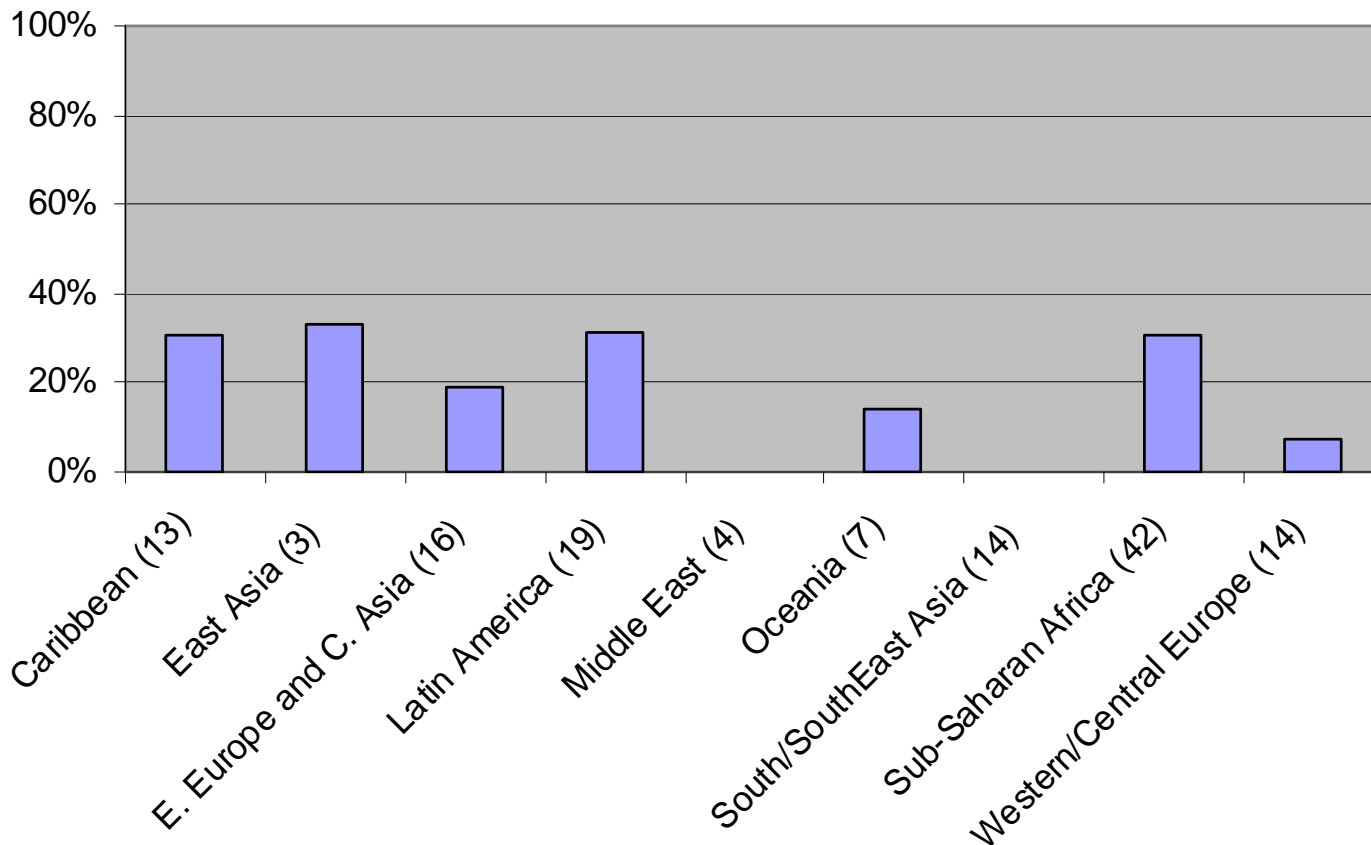
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% of countries that report having non-discrimination laws or regulations which specify protections for vulnerable sub-populations that also report having laws, regulations or policies that present obstacles to effective HIV services for these populations



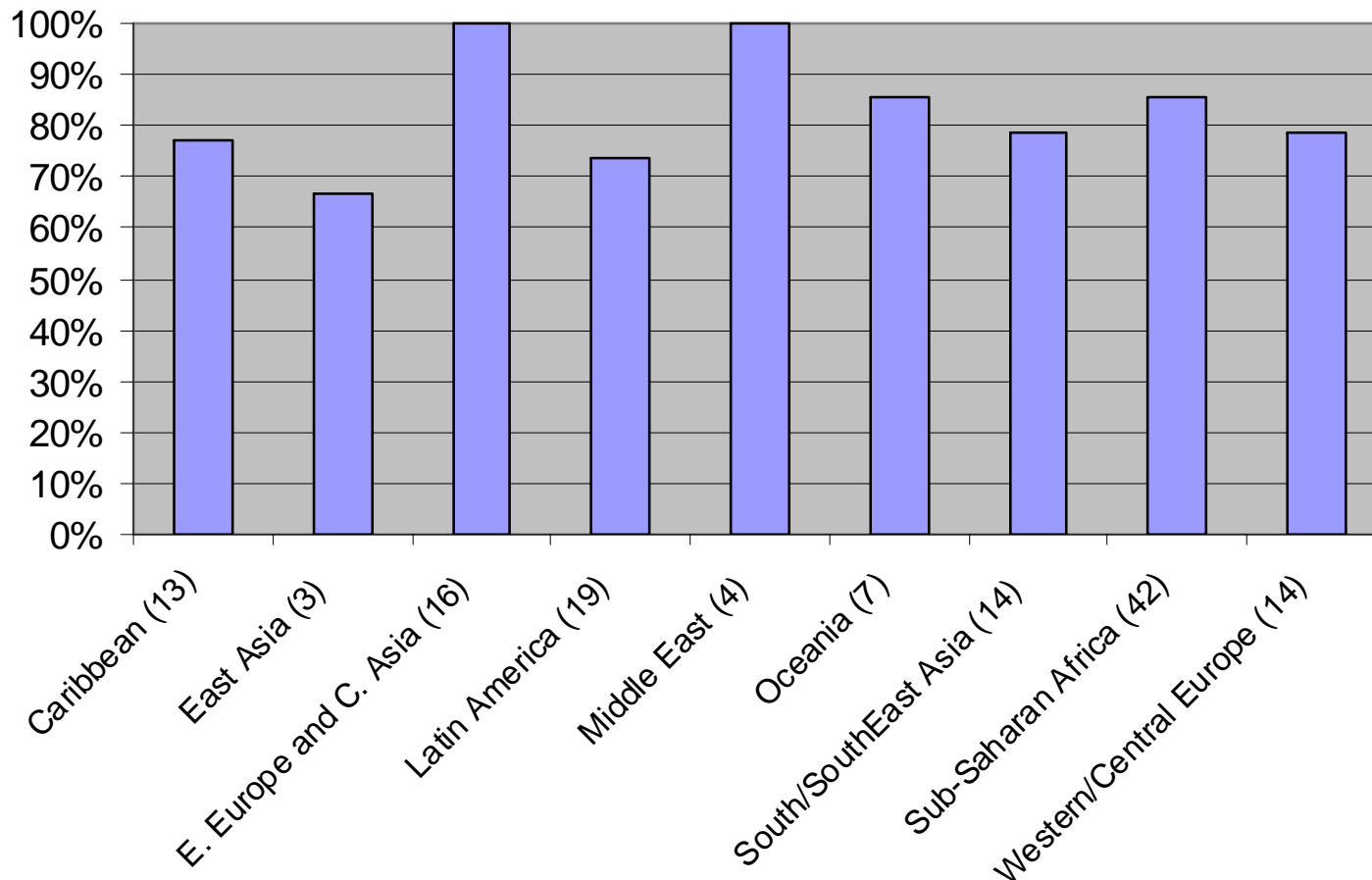
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Percentage of countries reporting the use of performance indicators to measure compliance with human rights



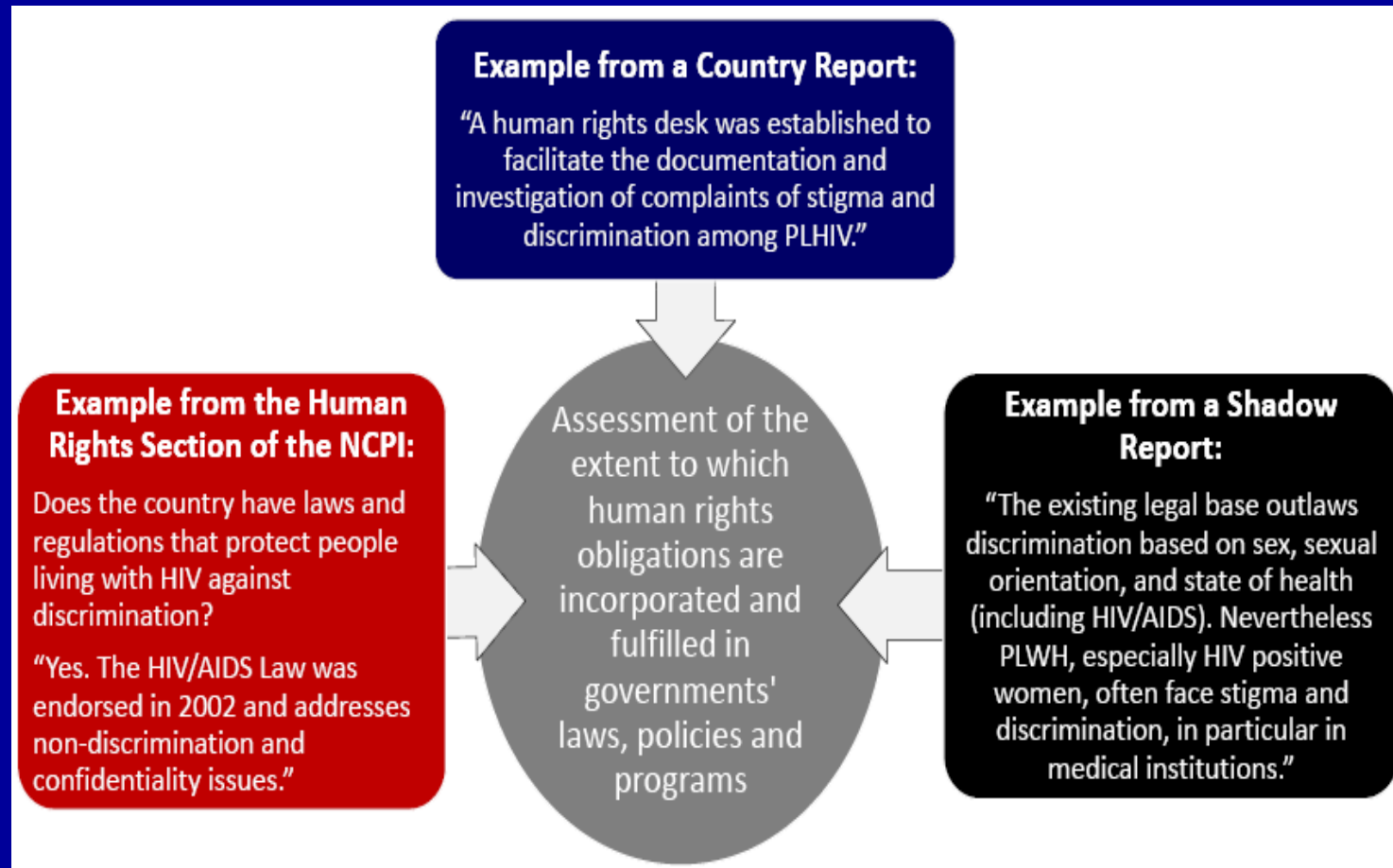
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Percentage of countries reporting a policy to ensure equal access for women and men to prevention, treatment, care and support



Source: Gruskin S, Ferguson L, Peersman G, Timberlake S, Rugg D, "UNGASS Results-2008: Trends in how human rights are addressed in HIV responses." The XVII International AIDS Conference, Mexico City, Mexico, 2-8 August 2008.

Beginning to get a complete picture



Source: Gruskin S, Ferguson L, "Human Rights in the Response to HIV: Where are human rights and why does it matter?" The XVII International AIDS Conference, Mexico City, Mexico, 2-8 August 2008.

Proposed next steps in improving the NCPI

- Add components to assess quality, content and implementation not only existence
- Add component to highlight disparities within countries
- “Officially” bring together NCPI and relevant portions of narrative and civil society reports
- Strengthen national level processes for data collection and dissemination

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Next Steps in Bringing Together Human Rights and Health

- Overcome the skepticism, denial and cynicism that seeks to undermine the power of bringing human rights and health together
- Use the tools of each to improve research, training, programming, realization of human rights, and health outcomes
- .. And have something solid to show at the occasion of the 75th anniversary of the Universal Declaration of Human Rights !!