HIV and Human Rights

"Testing Times"

Dr Mandeep Dhaliwal

Head: Care & Impact Mitigation
International HIV/AIDS Alliance
Outline

• HIV/AIDS situation

• What are human rights?

• What is the relationship between HIV/AIDS, public health and human rights?

• Key issues : consent, confidentiality and discrimination
HIV/AIDS at the end of 2004

- 42 million people living with HIV/AIDS
- 4.9 million new infections
- 3.1 million deaths due to AIDS
- Women and girls are amongst the most affected
What are human rights?

• People have rights because they are human

• Human rights are universal and inter-related

• Human rights treat all people as equal

• These are primarily the rights of individuals but they do directly address the relationship between the State and individuals. States have a responsibility to protect, promote and fulfil rights.

• Encompass the principles of humanity

• Protection, promotion and fulfilment of human rights is not bounded by the frontiers of Nation States
"It was never the people who complained of the universality of human rights, nor did the people consider human rights as a Western or Northern imposition. It was often their leaders who did so."

Kofi Annan
UN Secretary-General
Key rights in the HIV/AIDS response

- The right to health
- The right to equality and non-discrimination
- The right to privacy
- The right to information
- The right of participation
- The right to enjoy the benefits of scientific progress
- Freedom from torture
- The right to work
- The right to education
- The right to an adequate standard of living
- The rights of the child
"The right to health does not mean the right to be healthy, nor does it mean that poor governments must put in place expensive health services for which they have no resources. But it does require governments and public authorities to put in place policies and action plans which will lead to available and accessible health care for all in the shortest possible time. To ensure that this happens is the challenge facing both the human rights community and public health professionals."

Mary Robinson
former UN High Commissioner for Human Rights
Continuum of human rights: moving from principles to practice

- International covenants
- National laws
- Principles to shape policies, services and practice
- Ideals to shape advocacy
Human Rights and Public Health

- Human rights and public health share a principal objective: to promote and protect the well-being of people
  - In human rights terms: promoting & protecting the dignity of all, with an emphasis on those most vulnerable
  - In public health terms: promoting health for all, with an emphasis on those most vulnerable/ill

- Differences between human rights and public health:
  - Human rights action focuses on the protection and promotion of rights, freedoms and dignity of individuals.
  - Public health can be defined as “what we as a society do collectively to ensure the conditions in which people can be healthy.” Public health focuses on the health needs of society - groups of people and actions affecting many people.
Human Rights, Public Health: HIV/AIDS

• Historically, as public health strategies for HIV/AIDS prevention and care were designed and implemented, health experts realised that public health programmes work better when human rights and the dignity of persons concerned are respected.

• "In order to prevent and control the spread of the HIV/AIDS epidemic, the rights of those most marginalised/vulnerable must be protected and promoted."

    Justice Michael Kirby
    High Court of Australia
    1989
### Isolationist v. Integrationist Approach

<table>
<thead>
<tr>
<th>Isolationist</th>
<th>Integrationist</th>
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<tbody>
<tr>
<td>1. Mandatory testing</td>
<td>1. Voluntary testing</td>
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<tr>
<td>2. Isolation if HIV+</td>
<td>2. No isolation but inclusion if HIV+</td>
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<td>3. Confidentiality breached</td>
<td>3. Confidentiality preserved</td>
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<tr>
<td>4. Discrimination against HIV+</td>
<td>4. No discrimination against HIV+</td>
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Consent, HIV testing & “routine testing”

- Scaling up ARV treatment could be used as justification for rights violations.

- Key ethical and human rights principles of equality, autonomy & dignity must be respected for HIV testing and counselling and treatment to be successful in the long term.
Consent, HIV testing & “routine testing”

- ‘Voluntariness’ must be at the heart of all HIV policies and programmes both to comply with human rights and ethical principles and to achieve sustained public health benefits (UNAIDS Global Reference Group on HIV/AIDS and Human Rights 2004)

- Who has the power to ‘opt out’?

- The right to refuse treatment
Confidentiality & disclosure

"The boundaries of confidentiality receive the most intense scrutiny when conflict arises with the duty to inform another person who may be exposed to the risk of transmission of HIV"

Justice Edwin Cameron
Supreme Court of Appeals, South Africa

• Duty to disclose - a prevention tool? impact on care?
  • for a duty to arise, those bearing the duty must have knowledge that their acts or omissions involve real danger to another

• Assessing significant risk ~ foresee actual harm
Confidentiality & disclosure

• Laws recognise the rights and duties of both HIV-positive and HIV-negative persons and the conflicts that may arise between them.

• Balancing rights and duties ~ difficulty in acknowledging where the boundaries of one end and the other begin.

• Supporting beneficial disclosure ~ process.
Confidentiality & disclosure

"As for me, the more I am supported to follow through with the disclosure of my status and safer sex, the more I know I’m part of the solution, not the problem. That feeling empowers me. I hope it empowers others."

Person living with HIV/AIDS
Stigma and discrimination

"I don’t think you can ever come to terms with it, with HIV. Because in yourself you can come to terms with it but society doesn’t allow you to, it’s like society is fighting you all the time from all kinds of directions."

Person living with HIV/AIDS

- Stigma and discrimination remain the biggest barriers to HIV prevention, care and treatment
Discrimination

• Discrimination and the lack of respect for human rights and dignity are understood to be root causes - and not only effects - of the HIV/AIDS pandemic.

• Those who are typically marginalised by society (e.g.: migrants, sex workers, men who have sex with men, drug users, homeless) experience HIV/AIDS related stigma and discrimination more profoundly.

• Studies show that the majority of people living with HIV/AIDS experience discrimination in the healthcare setting,
  e.g.: refusal to treat, discriminatory or sub-optimal treatment, forced testing, medical threats, negative attitudes of health workers.
Access to ARV Treatment

• Lack of access to ARV treatment is discrimination
  - the role of the pharmaceutical industry, international patent regime, super-powers

• Scaling up ARV treatment could also entrench existing inequalities
  - treatment rationing
  - treatment for health workers
  - treatment for sex workers, drug users, men who have sex with men, children, women
“Rapidly increasing numbers of people infected with HIV and people with AIDS will be accompanied by intense political, social and economic stresses. Threats to and interference with the human rights and dignity of those infected, those who are ill and those most vulnerable will increase substantially. The temptation to return to coercive public health measures will also intensify.”

Mann and Tarantola
AIDS in the World
1996