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FROM HUMAN SCIENCE TO MEDICINE

Creating a balanced framework of rights and responsibilities in HIV

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Title: Creating a balanced framework of rights and responsibilities in HIV

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Author(s): Whitaker R, Westin A, Pitt D

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Purpose

The general purpose of this consultation-document is to create interest in the formation of a participatory policy-group of scholars and community-experts in HIV to address ethical and practical issues affecting the response to the HIV pandemic. In this document, the authors present an initial position for discussion, identifying some of the primary issues that a framework of rights and responsibilities in HIV would need to address in order to ensure maximally effective clinical and public health-services. Such a framework would be used to promote better health-policy and health-services for people with HIV and it has consequences for broader policy-creation, service-commissioning, and service-provision.

Goal

The specific goal of this document is the creation of a consensus-statement supported by an international group of scholars and community-based organisations that makes requirements of clinical and public health-services to protect the rights and enable the responsibilities of people with HIV for the purposes of protecting and promoting health.

Background

The Tuke Institute's research into rights and responsibilities in HIV was prompted by concerns over the transmission of HIV and its effects on people and societies. In 2011 in the UK, statistics show a rise in the number of people contracting HIV, a new high in the incidence of new infections, coupled with persistent proportions of people with unidentified HIV-infection (over 20%) and late diagnoses (in various groups, over 40%). Renewed efforts at the criminalisation of both people with HIV and people at higher risk of HIV, along with resurgent stigmatisation and discussions of both treatment-rationing and treatment-as-prevention, prompt us to re-evaluate not only the effectiveness of interventions but also how we construe interventions, in light of the core principles of health-ethics: autonomy, beneficence, non-maleficence, and justice.

The Denver Principles (1983) was created by a group of visionary people with HIV. It proposed a rights- and responsibilities-based framework in reference to the stigmatisation and

marginalisation of people with HIV and those perceived to be at risk of HIV, and it specified the following rights of people with HIV:

1. to participate in decision-making at all levels of the response to HIV, including representation on boards of provider-organisations
2. to quality medical and social services
3. to be protected from stigmatisation and marginalisation
4. to have the experience and opinions of people with HIV respected as equally valid as other forms of knowledge
5. to privacy, confidentiality, and respect
6. to have as full and satisfying sexual and emotional lives as anyone else
7. to die and to live with dignity

It also included the following responsibilities as recommendations:

1. to support one other against discrimination
2. to participate politically and in every level of decision-making
3. to protect one's own and others' sexual health

These Principles, in tandem with those of the Universal Declaration of Human Rights, provide an excellent reference and foundation for further development in the era of anti-retroviral medication.

Rationale/Need

We want people with HIV get well and stay well long-term; we believe that this occurs through receiving the best possible treatment of both the infection and its physical, mental, and social antecedents and consequences for the person. Similarly, we want to prevent the transmission of HIV: we believe that by creating a framework for clinical and public health-interventions that address why new HIV-infections continue to occur, strategies to reduce these statistics can be developed that are more effective than those currently available.

Rights and responsibilities are integral parts of this debate, especially in how they are promoted and protected. To date, most discourses have addressed rights and for important reasons there has been little about responsibilities. We believe that enabling the mutually enhancing nature of rights and responsibilities is necessary to promote sustainable health for all people affected by

HIV, directly and indirectly. It is the same for other chronic illnesses, especially those in which behaviours play a major role.

There is a need now to develop the foundations of a constructive and balanced framework for both rights and responsibilities, so as to guide *responsible* policy-making in the future. We are aware that these issues are often used for purposes other than promoting health, which becomes an obstacle to equality and justice for all and thus to the public's good; awareness of this misuse is a key reason for laying such a foundation. The discussion of responsibility, therefore, must never be to the detriment of an integrated discussion of rights. It is our belief that there can be no protection of the rights of one group if they exclude the rights of another; it is in observing this balance in our individual, daily actions that healthy responsibilities lie, a position echoed by the Denver Principles.

Position

Rights and responsibilities are essential to health

1. The Tuke Institute defines health in accordance with the World Health Organization's definition: "**Health** is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity" (1946). It entails therefore physical, mental, and social health.
2. **Rights** are defined as the ethical or legal entitlement to some thing or action; they are considered justified claims that require the action or self-restraint of others. For humans, they are best defined in the Universal Declaration of Human Rights (1948). These rights are considered universal values and therefore *inalienable*: that is, they can not be taken away and can not be given away. They are not optional and they are due to all people.
3. Rights protect people:
 - a. from violations by others that directly harm their health
 - b. from becoming vulnerable to illness due to a lack of empowerment and resources
 - c. by empowering health-promoting actions.
4. Health-protecting and -enabling rights include the rights to food, housing, health-services, civil welfare, privacy, autonomy, education, information, participation, and freedom from discrimination.

5. **Responsibilities** are defined as having either an obligation towards, or control over, some thing, person, or action, entailing autonomy and accountability for the outcomes of such actions.
6. Responsibilities entail the power with which one is able to act — literally, it refers to the legal status of being an adult. Unlike rights, responsibilities entail an ability to know and understand the nature of those responsibilities. Also unlike rights, they can be abdicated except under legal contract.
7. Responsibilities protect people:
 - a. from engaging in actions that directly harm their health
 - b. from the infringement of their rights by others
 - c. by enabling their health with empowered autonomy in the enactment and protection of those rights for themselves and for others
8. Health-protecting and -enabling responsibilities include:
 - a. the protection of one's own and others' rights equally
 - b. informed and skilled health-protection (e.g., having health-protecting sex)
 - c. informed and skilled health-promotion (e.g., eating health-promoting food)
9. There are great and poor reasons why we do not always act responsibly towards ourselves and others; these reasons need to be considered as part of the framework. What people need in order to enact their responsibilities towards themselves and others needs to be addressed in developing strategies to reduce HIV-illness and -transmission.

Rights and responsibilities are mutually enhancing

1. No responsible discussion of responsibility can emerge without equally considering its mutuality with rights. Responsibilities must be grounded in an understanding of human rights that is built upon the intrinsic dignity of the individual — that is, both the integral respect due to them by others and their self-respect.
2. All acts entail responsibility as they reflect the power and decision to do them. This includes acts of decision not to act at all or to not act further. The act of empowerment of others, and the acts to not empower or to actively disempower, all entail accountability. In a pandemic, this is particularly true of health-services.
3. Rights and responsibilities are synergistic, not antagonistic:

- a. protecting our own rights entails empowering ourselves to enact our responsibility to others
 - b. protecting our own rights entails the responsibility of protecting others' rights
 - c. the responsibility of protecting others' rights also entails empowering them both to protect both their own rights and to enact their responsibilities to others
 - d. empowering and enabling rights and responsibilities in others requires empowering and enabling them in ourselves as well
 - e. if we are not empowered to enact our responsibilities to others, socially and professionally, we can not protect our own rights or those of others
 - f. promoting rights or responsibilities without equal reference to the other is itself irresponsible and deleterious to health
4. Historically, the recognition of rights is achieved by the self-sacrifice of people who demand not only others' responsibility to them but also recognise their responsibility to others — that is, the universality and mutuality of rights. We call Nelson Mandela to mind. Even though this mutuality is inherent, rights are still inalienable.
5. Rights and responsibilities are inextricable from empowerment and enablement towards autonomy, considered across many societies to be necessary to healthy personal maturation and adulthood. Maturity entails healthy — and therefore mutual — relationship with others, which, itself, entails rights and responsibilities.

The enablement of rights is essential to effective health-services

1. Article 25 of the Universal Declaration of Human Rights identifies medical and social services as essential to 'a standard of living adequate to health'.
 - a. 'medicine' may be best defined by what is necessary for people with ill-health to get well and stay well; this definition of 'medicine' is synonymous with 'health-services'.
 - b. this definition is different from the narrower definition of medicine used by the physicians' profession, which is more accurately called biomedicine. The continuing transmissions and co-morbidities of HIV in people with complete access to antiretroviral medication shows biomedicine to be unable to achieve adequate health-outcomes in HIV, including protecting the right to 'a standard of living adequate to health'.

2. Illness has multiple determinants involving the physical, mental, behavioural, and social aspects of a person. Likewise, the recovery from illness, the effectiveness of treatment, and any degree and speed of recovery, are partially determined by the physical, mental, behavioural, and social aspects of a person. The same is true for the prevention of further illness.
 - a. medicine that addresses these comprehensive factors is called 'biopsychosocial medicine'.
3. Research has established that:
 - a. the most health-effective services, especially for chronic disorders, are integrated and 'comprehensive' — i.e., biopsychosocial. The need for this is obvious in HIV
 - b. health-services need to address these biopsychosocial factors in order to be maximally efficient and effective in achieving health-outcomes
 - c. biopsychosocial health-services have been demonstrated to be less financially costly, making them more cost-effective as well as more health-effective
4. The right to 'a standard of living adequate to health' entails a right to a health-service that is the most effective possible in reference to its resource-setting. Without such a derivative right, the right of Article 25 is vitiated and incompletely protected. The protection of a person's right in Article 25 therefore entails a right to a health-service that is fully comprehensive and integrated.
5. Given that health-services for people with HIV are almost purely biomedical and unintegrated, and that access to many are restricted by commercial barriers, HIV-focused health-services need to better their means of protecting the rights of people with HIV.
6. Health-services also need to review how they enable patients' rights, including the rights to autonomy, participation, privacy, information, freedom from discrimination, and to enabling the protection of rights and the enactment of responsibilities.

The enablement of responsibilities is essential to effective health-services

1. To each person's degree of capacity, we are all responsible for maximising our own health and for actualising our potential to do so. This requires responding as best we reasonably can to our current health-situation and engaging actively in the recovery and maintenance of our health.

- a. “responding as best we reasonably can” requires informed understanding, motivation, and skilled behaviours in the context of individual capacity. These are key to the enactment of responsibility and should therefore be maximised competently by a health-service.
 - b. beyond asserting our rights in relation to health-services, we must also act in a way that enables these services to help create the best possible health-outcomes with us. This includes both requiring and enabling clinicians to meet their professional and personal responsibilities to us, which in turn include, but are not limited to, providers’ “duty of care” to us as patients and vulnerable people.
2. Insofar as our actions affect others’ health, we have responsibilities to others as adults living in community. Addressing HIV effectively places a call to action on all members of the community in which we live, promoting both rights and responsibilities in a healthy and mutually-enhancing way.
- a. to enact their own responsibilities, clinical and public health-services should enable this understanding of responsibility. Likewise, providers of such services must empower people competently to protect their rights and enact their responsibilities and also advocate for the resources needed by the public to do so
 - b. the communal responsibility engendered by HIV indicates that individuals cannot fully get well and stay well through models of health-services that promote dependence, passivity, and consumerism. The prime examples of such models are the physician-centred, biomedical model and profit-making health-services, both of which are pervasive
 - c. protecting rights and enabling responsibilities also entails the eradication of obstacles to such, including individual and professional incapacity, stigmatisation, discrimination, complacency, inequalities, and the provision of inadequate clinical and public health-services
3. Clinical or public-health services that do not protect rights and enable responsibilities in patients and the public can not be truly called ‘health-services’.