

# HUMAN RIGHTS, EQUITY AND HEALTH

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PROCEEDINGS FROM A MEETING OF THE HEALTH EQUITY NETWORK  
HELD AT THE LONDON SCHOOL OF ECONOMICS

Debbie Fox and Alex Scott-Samuel (Editors)



The Nuffield Trust  
FOR RESEARCH AND POLICY  
STUDIES IN HEALTH SERVICES

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March 28th 2003

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*“I believe that in time, the Human Rights Act will help bring about a culture of rights and responsibilities across the UK... the Convention rights... are going to become an anchor for our laws and policies and a sail for service delivery.”*

Jack Straw, Home Secretary (2000)



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# 1. SETTING THE CONTEXT

Debbie Fox and Alex Scott-Samuel

*Department of Public Health, University of Liverpool, March 2003*

## 1.1 International human rights

*“All human beings are born free and equal in dignity and rights. They are endowed with reason and conscience and should act towards one another in a spirit of brotherhood.”*

Article 1 UDHR

On December 10, 1948 the General Assembly of the United Nations adopted and proclaimed the Universal Declaration of Human Rights (UDHR). The Declaration conveys important values that should be upheld to create a fairer and more socially just world. It also provides a legally binding framework as to how we address the implementation of these rights in practical ways. After all it is the *implementation* that makes the difference not the rhetoric. The UDHR is now the most translated document in the world and is available in over 300 languages (WHO, 2002). So it is reasonable to assume it uses a globally agreed discourse.

It would also be reasonable to assume that the notion of human rights grew in the wake of two devastating World Wars and the establishment of the United Nations. Whilst indeed this era provided the impetus to help try to prevent such atrocities reoccurring, the idea of human rights has existed long before the establishment of the UN and can be found in many cultures. The first declaration (The Cyrus Declaration) was published in 539BC on a clay barrel known as Cyrus's inscription cylinder (Jahanian, 1997). History has assigned many other declarations to the archives. They, like the current focus on human rights and like previous attempts to agree and implement important values, have been created in opposition to the abuse of power.

## 1.2 The right to health

The World Health Organisation, the United Nations specialized agency for health, was established in 1948. WHO's objective, as set out in its Constitution, is the attainment by all peoples of the highest possible level of health. Health is defined in WHO's Constitution as "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity".

Every woman, man, youth and child has the right to the highest attainable standard of physical and mental health, without discrimination of any kind. Enjoyment of the right to health is vital to all aspects of a person's life and well-being, and is crucial to the realisation of many other fundamental human rights and freedoms.

## 1.3 The UK Human Rights Act

The Human Rights Act 1998 applies to all public authorities. It makes it unlawful for bodies like the police, government departments, NHS and local councils etc. to violate the rights contained in the European Convention on Human Rights. The Human Rights Act does not impose duties directly on private individuals or companies unless they are performing public functions. Article 2 to 12 and 14 to 18 of the European Convention on Human Rights plus Article 1 to 3 of the First Protocol to the Convention have been incorporated into UK law by the Human Rights Act.

## 1.4 The seminar

The seminar was held on March 28th 2003 at the London School of Economics. The aim was to:

- provide a general introduction to health and human rights (HHR) issues in the context of equity;
- set HHR in the UK (as well as the global) context;
- demonstrate that HHR relates to the audience's work and experience;
- raise awareness about the value of using the human rights perspective to enhance action on health inequalities.

This volume brings together papers presented at the Health Equity Network seminar and links the concepts of health, equity and human rights. The seminar was divided into three sessions, the first focused on adult rights, the second the rights of the child, and the third was an open plenary discussion. The programme and attendance list are in the appendices, with copies of the Universal Declaration of Human Rights, an abridged version of the Convention of the Rights of the Child, and a list of useful websites on human rights.

The papers in this publication are presented in the order that they were given on the day. In brief, Paula Braveman highlighted how a human rights perspective can provide a universal framework of reference for identifying inequitable conditions and how we, as health workers, could use it as a tool to enhance health equity. Jeanelle de Gruchy demonstrated the use of an HHR framework to consider not only the way in which vulnerability to

mental illness is being reduced in the UK, but also, how using the HHR tool illuminated the different ways in which the rights of people with mental health problems may be violated through health policies and professional practice. Mike Jones shared his knowledge and experience of applying a rights framework in Liverpool in a way as to empower children's participation in public decision making and persuade local policy makers to include their views, concerns and needs. Eileen O'Keefe and Martha Chinouya examined how young black migrant African Londoners affected by HIV/AIDS make sense of the language of rights, and highlighted the problems in applying an HHR framework that is culturally biased.

## Final comment

At the same time as the UDHR was being ratified, George Kennan (1948), a US strategic planner said:

*“ ... our real job in the coming period...is to maintain this position of disparity. To do so, we have to dispense with all sentimentality...we should cease thinking about human rights, the raising of living standards and democratisation.”*

(cited in Pilger, 2003:101)

Fifty-five years on, the application of rights equally, and the promotion of health equity is a continued and constant source of political struggle throughout the world. Whilst there are powerful elites who share Kennan's view, and governments that show a persistent disregard of social and economic rights (in contrast to political and civil rights), the struggle will continue.

## 1.5 Acknowledgements

On behalf of the seminar planning group, we would like to thank all the contributors to the seminar and this publication for sharing their knowledge and experiences with us, and to those who managed to make it to London (despite a train strike) and participated in the lively, stimulating debate that followed. A special thank you to Adam Oliver for his excellent organisation, time and patience in making the day go smoothly.

The seminar was sponsored by the Economic and Social Research Council (award number R451265135) and the venue was kindly provided by the London School of Economics.

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## 2. HEALTH EQUITY AND HUMAN RIGHTS: WHAT'S THE CONNECTION?¹

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### *Abstract*

While an accumulating literature addresses links between human rights and health in general, links between human rights and health equity have not previously been examined systematically. Health equity and human rights are distinct concepts, but they are closely linked operationally as well as conceptually. Both dictate striving for equal opportunity for health for groups who have suffered discrimination or marginalisation. Human rights perspectives reinforce the responsibility of health institutions not only to reduce the health-damaging effects of discrimination or marginalisation, but also to address the underlying conditions that create and perpetuate inequities in health. Human rights perspectives, norms, laws, and accountability mechanisms could enhance efforts to achieve greater health equity.

Keywords: health equity, equity, human rights

### *The purpose of this paper*

While an accumulating literature articulates connections between human rights and health in general (Gruskin and Tarantola, 2002; Mann *et al.*, 1999; Mann, 1997; WHO, 2002; Annas, 1998; O'Keefe and Scott-Samuel, 2002; Health and Human Rights), links between human rights and health equity have not been examined rigorously and work in these areas

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1. This paper is based on a longer paper by the authors, titled "Poverty, equity, health and human rights", in press at the *Bulletin of the World Health Organisation* 2003; 81(7).

has generally been separate. This paper is primarily directed to the public health community, particularly those committed to achieving greater equity in health. In it, we explore the concepts of health equity and human rights, their points of convergence and divergence, and operational implications and opportunities for effective action by health institutions.

### *Health equity*

Equity is an ethical concept (Whitehead, 1992) grounded in the principle of distributive justice. Equity in health reflects a concern to reduce unequal opportunities to be healthy associated with membership in less privileged social groups such as the poor, disenfranchised racial/ethnic or religious groups, women, rural residents, and others. In operational terms, pursuing equity in health means eliminating health disparities that are systematically associated with underlying social disadvantage or marginalisation (Braveman and Gruskin, 2003). An equity framework systematically focuses attention on socially disadvantaged, marginalised, or disenfranchised groups within and between countries (Braveman, 1996).

Practical experience suggests that eliminating systematic health disparities between more and less advantaged social groups will generally require addressing their fundamental causes as well as cushioning their health-damaging effects (Whitehead, 1988; Acheson, 1998). Furthermore, a commitment to equalising opportunities to be healthy inherently requires addressing the determinants as well as manifestations of health disparities (Braveman and Gruskin, 2003). However, in practice, it can be difficult to convince a resource-constrained health sector of these responsibilities.

### *Health and human rights*

As used here, *human rights* refers to internationally recognised norms applying equally to people everywhere in the world. International human rights law is a set of legal standards to which governments have agreed with the purpose of promoting and protecting these rights. International human rights treaties not only prohibit direct violations of rights but also hold governments responsible for progressively ensuring conditions enabling individuals to realise their rights as fully as possible. Every country is now party to at least one treaty addressing health-related rights, and is therefore responsible for reporting periodically to an international monitoring body on its compliance (Tomasevski, 1995; United Nations, 1996b).

The *right to health*, i.e., the right to the highest attainable standard of health (Constitution of the WHO, 1946; ICESCR, 1976; United Nations, 1993) makes governments responsible for prevention, treatment and control of disease, and the creation of conditions to ensure access to health facilities, goods and services (Kirby 1999; Leary 1994). Because all human rights, economic, social, cultural, civil and political, are considered interdependent and indivisible (United Nations, 1998), governments are accountable for progressively addressing conditions that may impede the realisation of the *right to health*, as well as related rights to education, information, privacy, decent living and working conditions,

participation, and freedom from discrimination (Eide, 1995). Systematic attention to this range of rights by the health sector can provide a coherent framework to address conditions that may limit people's ability to achieve optimal health (Gruskin and Tarantola, 2002).

### *Health equity and human rights: the links*

The links between the concepts of health equity and human rights are many and profound. Both dictate striving for equal opportunity for health for groups who have historically suffered discrimination or social marginalisation. Achieving equal opportunity for health entails not only buffering the health-damaging effects of poverty and marginalisation; it requires reducing disparities between populations in the underlying conditions - e.g., education, living standards, and environmental exposures - necessary to be healthy. Thus, both human rights and equity perspectives require that health institutions seek to address poverty/disadvantage and health not only by providing health care to improve the health of the disadvantaged but also by helping to alter the conditions that create, exacerbate, and perpetuate poverty, deprivation, and marginalisation. Governments are accountable as signatories of human rights treaties to set targets and show good-faith towards progressive achievement of full realisation of all rights.

Poverty is not *in and of itself* a violation of human rights; however, government action or inaction leading to poverty and/or government failure to adequately address the conditions that create, exacerbate, and perpetuate poverty and marginalisation often reflect or are closely connected with violations or denials of human rights (WHO, 1978). For example, lack of access to education, in particular primary education, is increasingly recognised both as the denial of a right in and of itself and as inextricably connected with both poverty and ill-health. Education fosters empowerment and participation in informed decisions about health-related behaviours (Backlund, 1999), and is therefore key to breaking the poverty-ill health cycle.

Both equity and human rights principles require that health institutions systematically consider how the design or implementation of policies and programs may directly or indirectly affect social marginalisation, disadvantage, vulnerability, or discrimination. For example, improving the geographic and financial accessibility of preventive health services may not alleviate disparities in their use, without active outreach and support for the groups most likely to be under-utilizers despite equal or greater need (Hart, 1971; Aday and Anderson, 1981). Equity and human rights principles require identifying and addressing the obstacles - such as language, cultural beliefs, racism, gender discrimination, and homophobia - that keep disadvantaged groups from receiving the full benefits of health initiatives (Gruskin and Tarantola, 2001). While many policies and programs to reduce poverty/improve the health of the poor routinely consider and address these concerns, unfortunately, many do not (Feinstein and Piccioto, 2000). Explicit adoption of equity and human rights approaches can help bring systematic attention to social disadvantage, vulnerability, and discrimination in health policies and programs.

A human rights perspective can provide a universal frame of reference for identifying inequitable conditions; whether a given disparity constitutes an inequity may be a matter of

dispute. For example, human rights norms assert rights to living standards which are a prerequisite for optimal health; and they prohibit discrimination on the basis of sex, racial or ethnic group, national origin, religion, or disability. Particularly where certain groups (e.g., women, disenfranchised racial/ethnic groups) are systematically excluded from decision-making, human rights standards can play a crucial role in agenda-setting by strengthening consensus about the existence of inequities in health and the need to reduce them.

Furthermore, a human rights perspective removes actions to address health equity from the voluntary realms of charity, ethics, and solidarity to the domain of law. Furthermore, the internationally recognized human rights mechanisms for legal accountability could be used by the health sector to provide processes and forums for engagement, and to suggest concrete approaches to reduce poverty and health inequity. International human rights instruments provide not only a framework but also a legal obligation for policies toward achieving equal opportunity to be healthy.

Just as equity and human rights frameworks can strengthen work focused on poverty or marginalization, efforts to reduce poverty and social exclusion are essential aspects of fulfilling commitments to equity and human rights. Throughout most of the world, absolute material poverty and its associated disadvantages play a central role in creating, exacerbating, and/or perpetuating ill health (Wong *et al.*, 2002). There is wide consensus on the causal role of absolute deprivation in ill health (World Bank, 2001; United Nations, 1996a and 1997; McKeown and Lowe, 1966; Mosley and Chen, 1984), but controversy about the effects of relative deprivation in the absence of absolute poverty (Wilkinson, 1996 and 1997; Kawachi, 1997; Deaton, 1999; Lynch and Kaplan, 1997). Both equity and human rights perspectives can highlight wealthier countries' responsibility to address the causes and consequences of poverty within and beyond their borders (Gruskin and Tarantola, 2002).

### *Operational implications*

These conceptual links have operational implications. Based on the concepts above, we recommend five major areas in which health institutions could productively focus in order to achieve greater health equity and realisation of human rights.

**1) Institutionalise the systematic and routine application of equity and human rights perspectives to all health sector actions.** While most public health efforts are intended to benefit whole populations, and sometimes particularly the disadvantaged, experience has shown that a strategic approach is necessary to overcome the tendency for the poor or marginalised to benefit too little from even the best-intentioned efforts (Hart, 1971; Braveman and Tarimo, 1994). Work on equity, and human rights must be integrated as an ongoing priority, not an afterthought, across health institutions' programs; this requires simple, practical tools that personnel perceive as helpful in their ongoing work, and training and ongoing support. Findings from ongoing monitoring of health inequalities should routinely be discussed within a framework of equity principles and human rights norms.

**2) Strengthen and extend public health functions, apart from health care, that address the basic conditions necessary for health and for escaping poverty.** The health sector could make a major contribution to addressing equity and human rights by strengthening and extending those crucial public health functions, apart from healthcare services, that address the basic conditions needed to achieve health and escape poverty. Such functions entail setting and enforcing standards for water and sanitation; food and drug safety; tobacco control; and working, housing, transport, and environmental conditions; they benefit society as a whole but particularly the disadvantaged.

The health sector itself has little or no direct control over most of the underlying conditions required for health; thus, traditional public health functions should be expanded through collaboration with other sectors to develop strategic plans addressing those conditions in light of both equity and human rights concerns. Reflecting human rights norms (United Nations, 2000), such conditions include an adequate food supply; education permitting full economic, social, and political participation; housing and neighbourhood environments that promote health; and dignified, safe employment. Such efforts require collaboration with a range of sectors that have not traditionally been health-sector partners, e.g., sectors addressing economic, social, political, educational, environmental and general development activities.

**3) Implement equitable financing of healthcare.** Equitable financing means that those with the least resources pay the least, in absolute terms and as a proportion of their total resources. It means that lack of personal resources does not restrict an individual's receipt of services recommended based on prevailing norms and scientific knowledge. Equitable financing would increase access to healthcare, which - if healthcare services are effective - should improve people's health and thus their ability to earn a living. Equitable financing of healthcare also could more directly reduce poverty by protecting those who are most vulnerable from impoverishment resulting from health-care expenses. Equitable financing is likely to be sustainable only with risk-pooling (Davies and Carrin, 2001); implementing this strategy requires building public consensus around commitments to equity and human rights.

**4) Ensure that healthcare services effectively address the major causes of preventable ill health and associated impoverishment among the poor and disadvantaged.** Health institutions must ensure that services effectively address the major causes of preventable ill health - and associated impoverishment - among the disadvantaged. This requires systematic and sustained efforts to build infrastructure, overcome the complex barriers to receiving healthcare that often accompany poverty and social disadvantage, and achieve comprehensive and high-quality universal services. Access and quality are inseparable; perceived low quality is a widespread barrier to use of available services by the disadvantaged (Haddad *et al.*, 1998).

Resource constraints have at times been cited as a rationale for focusing on a limited number of conditions (such as malaria, tuberculosis, HIV/AIDS, and maternal morbidity/mortality) that disproportionately affect the poor. However, a human rights commitment to "progressive realisation" of all rights requires this narrowed focus to be

temporary. Targets must be set within a long-range plan to progressively ensure more comprehensive, high-quality services for the entire population (Gruskin and Loff, 2002).

**(5) Monitor and address the health equity and human rights implications of development policies in all sectors that affect health.** The health sector must strengthen its capacity for active, ongoing monitoring and become an effective advocate to address the potential implications of development policies for health equity and human rights. This must be done at international, national, and local levels, in both public and private sectors, and with respect to policies in all sectors affecting health, not only the health sector. The fact that most societies have far less tolerance for social disparities in *health* than in *wealth* or other social privileges (G Dahlgren, personal communication, 1996) provides the health sector with a powerful tool for mobilising public opinion.

Routine assessment of potential health implications for different social groups should become standard practice in the design, implementation, and evaluation of all development policies. Both equity and human rights principles require that routinely-collected data on health and on health care and other health determinants be monitored not only in the aggregate but also within more and less socially advantaged groups. The relevant data should be disaggregated by factors such as wealth, gender, and race/ethnicity, that reflect social disadvantage (Braveman, 1996; Braveman, 1998; Joint UNAIDS 1997); otherwise, it will be difficult to hold any sector accountable for the differential impact of policies on vulnerable groups.

### *Final remarks*

Based on the considerations discussed in this paper, we have concluded that health equity and human rights are closely linked, conceptually and operationally. Each construct can provide unique, valuable and concrete guidance for actions of national and international organisations focused on health and development. Health workers should be aware that human rights perspectives, norms, laws, and accountability mechanisms are highly relevant tools that could enhance efforts to address health equity. The authors hope that discussions based on this document will lead to greater awareness of opportunities to strengthen work addressing equity and human rights, globally and within countries.

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### 3. HUMAN RIGHTS, EQUITY AND MENTAL HEALTH

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A front-page media story of the New Year (2003) was the unfolding narrative of the police search for, and arrest of, a man following the discovery of women's body parts in a rubbish bag. Soon thereafter, a broadsheet headline proclaimed 'Secure unit freed "body bags" suspect' (Bright and Revill, 2003). The article rehearses common themes currently framing the presentation of cases such as this: the irrational violence of mentally ill people; the 'failure' of care in the community; and the belief that psychiatric good practice (preferably back in closed institutions) could and should prevent such events:

- The man had been 'released into the community ... from a secure mental hospital ... as he was not considered a risk to the public'.
- He was 'seen by staff there ... only days before [the] human remains were found'.
- The Trust had 'launched an internal inquiry into why Anthony Hardy was released ...' but added that 'no-one had been suspended'.

The 1992 killing of Jonathan Zito by Christopher Clunis, a man diagnosed with paranoid schizophrenia, was the first of such high-profile cases, marking 'a watershed in the history of mental health care in Britain' (Laurance, 2002). Following this event the focus shifted from improving the care of patients in the community to 'risk avoidance' and 'public safety', building up to the current controversial draft legislation that foregrounds these aspects and allows for further restriction of the rights of people diagnosed with mental illness.

This increased restriction of the human rights of people with mental illness is not only discriminatory and unacceptable, but will lead to a deterioration in many people's health. In this paper I use a health and human rights framework to explore the issues raised by the current debate about mental health services and legislation in the UK.

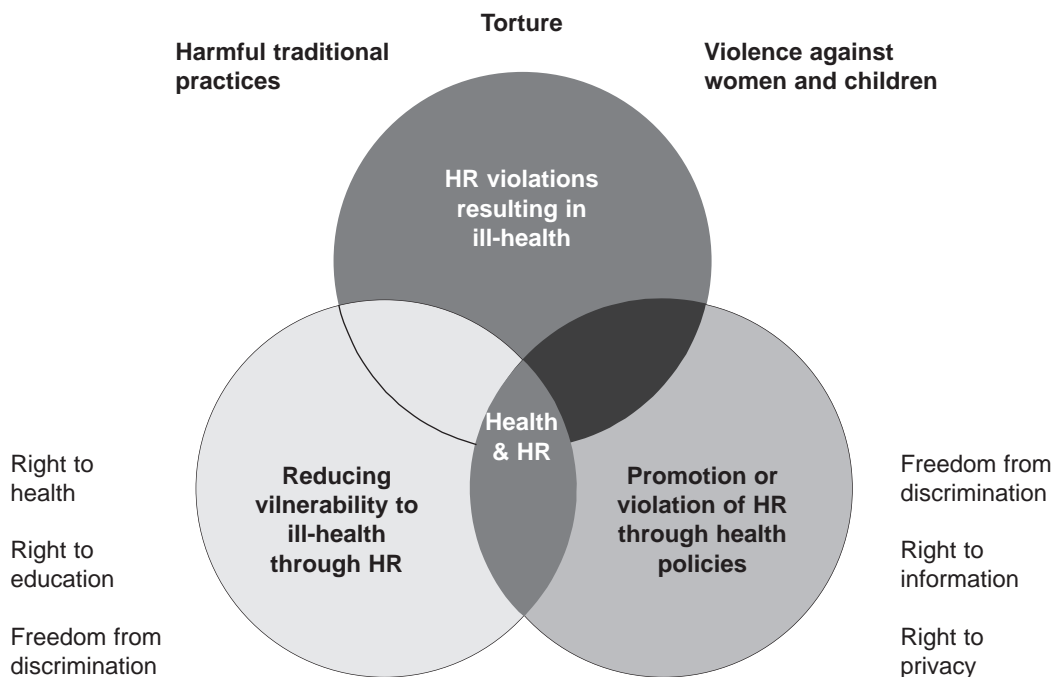
### *Approaches to health inequity*

The main approach to health inequity – avoidable health inequalities that are unfair and unjust (Whitehead 1992) – in the UK is the focus on socio-economic status and its correlation to health. There is a clearly documented gradient from lower socio-economic status groups with the poorest health to higher groups having the best health. Whilst this is a key focus in public health, it should not be the only approach, as it cannot explain all health inequity.

There is a danger that by focusing largely on socio-economic disadvantage, other determinants such as ethnicity, gender and sexual orientation that may result in health inequity directly, or compound the experience of material disadvantage, are marginalised (Mann *et al.*, 1999; Laughlin, 2002).

Mann and colleagues present a health and human rights framework as a complementary approach for analysing and addressing health inequity (Mann *et al.*, 1999). This approach highlights three interconnected relationships between health and human rights (Figure 1):

- a. Violations or lack of attention to human rights can have serious health consequences.
- b. Vulnerability and the impact of ill health can be reduced by taking steps to respect, protect and fulfil human rights.
- c. Health policies and programmes can promote or violate human rights in design or implementation.



**Figure 1.** Examples of the links between health and human rights (World Health Organisation, 2002:13)

The goal of linking health and human rights is to contribute to advancing human well-being beyond what could be achieved through an isolated health- or human rights-based approach. Using this framework of health and human rights linkages to analyse the current approach taken by the UK government to people with severe mental illness reveals the inherent contradictions with the approach and leads us to consider more effective alternatives.

#### *Analysing Mental Health legislation and service provision in the UK within a health and human rights framework*

##### **i. Violations of, or lack of attention to, human rights can have serious health consequences.**

There are an estimated 600,000 people in England with severe enduring mental illness (Department of Health, 1999). Socio-economic disadvantage and discrimination (e.g. racial, gender) may increase the risk of severe mental illness. Severe mental illness carries with it considerable stigma (Phelan *et al.*, 2000), and people with mental disability experience discrimination in many aspects of their lives, affecting their access to employment, adequate housing, education, and so forth. This often results in poor socio-economic circumstances and exposure to health-damaging environments: for example, people with severe mental illness living in the community are more than twice as likely to be victims of violence than the general public (*Guardian* staff reporter, 2003).

The United Nations *Resolution on the Protection of Persons with Mental Illness and the Improvement of Mental Health Care* (United Nations, 1991) states that facilities for people with mental illness should receive ‘the same level of resources as any other health facility’. However, mental health services in the UK have a low status and receive fewer resources for need than many other services. Discrimination affects the rights of particular groups to mental healthcare, with serious health consequences, for example young African-Caribbean men with psychotic illness, or young Asian women at increased risk of suicide (Henderson *et al.*, 1998, Department of Health, 1999).

Individually and in synergistic combination, discrimination, including in access to health services, results in health inequity.

##### **ii. Vulnerability and the impact of ill health can be reduced by taking steps to respect, protect and fulfil human rights.**

There is an acknowledgement in the United Kingdom of the need to promote mental health for all and to tackle the stigma, discrimination and social exclusion associated with mental health problems. This is set as the first standard of the National Service Framework (NSF) for Mental Health. The NSF notes the important role of legislation in tackling discrimination, for example, the Disability Discrimination Act (1996) which places a duty upon employers to take steps to prevent disabled persons, including those with mental impairment, from being placed at a disadvantage.

But it is the Human Rights Act (1998) which provides an immediate and highly visible recognition of the importance of human rights in the UK. Articles of particular relevance to mental health care are:

- Article 2: Right to life;
- Article 3: Prohibition of inhuman and degrading treatment;
- Article 5: Right to liberty and security;  
5(1) No one shall be deprived of his liberty save ... (e) the lawful detention ... of persons of unsound mind ...  
5(2) Everyone who is arrested shall be informed promptly, in a language which he understands, of the reasons for his arrest ...  
5(4) Everyone who is deprived of his liberty ... shall be entitled to take proceedings by which the lawfulness of his detention shall be decided speedily by a court and his release ordered if the detention is not lawful;
- Article 8: Right to respect for private and family life;
- Article 14: The right not to suffer discrimination in the enjoyment of rights under the Convention.

There is evident potential for tension within the complex need to balance the rights of individual patients and the protection of the public; yet the emphasis of the Act is on the immediate protection of the rights of individual citizens, or patients.

In terms of the development of mental health services, government policy recognises the importance of involving service users, with the policy document *The Journey to Recovery – The Government’s vision for mental health care* stating that ‘the people who use mental health services ... [be] involved, as equal partners and at every level, to ensure the new services make sense’ (Department of Health, 2001). This reflects the philosophy of the overarching NHS Plan, which aims to deliver ‘a health service designed around the patient’ (Department of Health, 2000).

These developments are important steps towards protecting and fulfilling the rights of people with severe mental illness, and in so doing improving their health and reducing health inequity.

### **iii. Health policies and programmes can promote or violate human rights in design or implementation.**

It is the third consideration that causes most concern. A society’s laws apply equally to all citizens, but there are exceptions, most notably when a person is considered to have mental health problems. Mental health legislation allows compulsory detention and treatment of an individual against his or her will – this inequality means that people with mental health problems do not enjoy the same rights as other citizens.

The power given to psychiatry to compulsorily detain and treat is unique in medicine. Cognizant of this power, it is salient to remember that psychiatry has been responsible for gross violations of people’s rights, such as active participation in the mass murder of people

with mental disability during Nazi Germany, the silencing of Soviet political dissidents, and the violation of gays' and lesbians' rights through their pathologisation and 'treatment' (Lewin and Meyer, 2002). In the UK, there have been allegations of institutional discrimination and the abuse of patients' rights in mental health services (Reid-Galloway, 2002; Golding and Stewart, 2002). It is vital to acknowledge this contemporary history in order to learn lessons about the use of psychiatry for social and political control so that these forms of abuses are not repeated.

Current mental health policy in the UK presents a contradictory message about mental illness. As discussed above, there are important moves to counter stigma and discrimination against people with mental illness and to make services responsive to users' needs. However, at the same time, recent developments suggest that the government seems set on undermining these initiatives and violating patients' rights through its presentation of the risks people with mental illness present to public safety and its approach to dealing with this perceived risk through an increasingly coercive mental health system and proposed legislation.

Laurance reports that Paul Boateng, then the Junior Health Minister, said in reference to the failure of some mentally ill people to take their medication, '*we will not tolerate a culture of non-compliance*' (Laurance, 2002).

- The policy document *Modernising mental health services: safe, sound and supportive reflects this approach to patients' rights* (Department of Health, 1998). It explicitly foregrounds the aim of 'safety', stating that 'public protection will remain our first priority at all times'.
- The draft Mental Health Bill (Department of Health, 2002) prioritises the rights of the public to safety over the individual rights of people with mental health problems and increases the responsibility of individual mental health professionals in balancing these rights.

And there is concern that the mental health system is becoming more coercive. The number of people detained under the Mental Health Act has risen by half in a decade (Wall *et al.*, 1999). The view of the Chair of the Mental Health Commission is that 'a high proportion of these patients would not need to be detained if satisfactory health and social care were available in the community' (Laurance, 2002).

Yet there is no good evidence that care in the community has led to people with mental disorder contributing a greater proportion of societal violence. In the UK, the contribution of mental disorder to homicide statistics 'seems to be falling rather than increasing'. 'Ten times as many people die at the hands of so-called "normal" people, most as a result of domestic disputes, as are killed by people with mental problems' (Walsh and Fahy, 2002).

Restrictive laws, without sufficient data (epidemiological or otherwise) to support their approach, raise most human rights concerns. The restriction of certain rights should always be a last resort and should comply with the Siracusa principles,<sup>2</sup> which arguably the draft legislation does not do. In addressing violence in society, focusing solely on the danger presented by people with severe mental illness, and legislating to curb their rights, is 'discriminatory and morally unjustifiable' (World Health Organisation, 2002).

It is also key that risk assessment is an inexact science. Applying general principles about risk to individuals presents a wide margin of error<sup>3</sup> and the rights of many individuals need to be restricted in order to render society a bit more safe (Holloway and Szmukler, 1999).

The motive for using mental health policy to detain those who haven't been convicted of an offence has been questioned. The impetus for the government is most likely the political pressure caused by coverage of rare, high-profile cases – Christopher Clunis, Michael Stone and now Anthony Hardy – against a background of widespread negative media coverage of mental health (*The Lancet*, 1998).

In George Szmukler's view, *'the ascription of mental disorder is being applied to a group of apparently risky individuals as a means of securing their preventive detention under a veneer of ersatz "healthcare"'* (Szmukler, 2001). The government is simply trying to re-define those they feel present a risk as *'persons of unsound mind'* so that Human Rights protection can be circumvented (Eastman, 1999). In so doing, the *'government has shifted its responsibility ... to individual psychiatrists and other health professionals'* (Leung, 2002).

The analysis raises four related issues. Firstly, the focus on the behaviour of individual patients works to detract attention from the under-resourcing of mental health services generally and community care in particular. We do not have appropriate, comprehensive, adequately resourced community care in England. The Audit Commission in 1986 reported that insufficient resources had been put into community care (Stewart, 2003). Since then, successive reports have noted that most services operate at crisis level, especially in London (Goldberg, 1997, Bardsley *et al*, 1998).

Secondly, what is missing from the debate is analysis of the racial and gendered nature of policy decisions and service developments. The focus on those with serious mental disorders who commit offences, with practitioners prioritising those who present the greatest theoretical risk *to others*, raises concern about the increased potential for continued institutional racism. Research studies and anecdotal evidence suggest that black patients, especially African Caribbean people, are perceived as being violent and are therefore given stronger medication, for longer periods of time, than white patients; they are also less likely to remain in contact with services; they are more likely than white patients to be transferred from prisons into psychiatry. Are black patients at further increased risk of compulsory detention?

And with the development of services targeting a predominantly male population, is the quiet 'non-dangerous' female psychiatric population partly left behind (Kohen, 2000)? Services that are blinkered to race or gender will not meet the mental health needs of people with mental illness in the UK.

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2. The Siracusa principles are:

- The restriction is provided for and carried out in accordance with the law;
  - The restriction is in the interest of a legitimate objective of general interest;
  - The restriction is strictly necessary in a democratic society to achieve the objective;
  - There are no less intrusive and restrictive means available to reach the same objective;
- The restriction is not drafted or imposed arbitrarily, i.e. in an unreasonable or otherwise discriminatory manner. (World Health Organisation, 2002).

3. The false-positive rate for prediction of violence is suggested to be double the true-positive rate.

Thirdly, the potential for psychiatry to be used by the state for abusive practices of social control was highlighted above. State use of psychiatry to further its aims has been documented in the UK. It was recently reported that psychiatrists at Broadmoor accused the Home Secretary, David Blunkett, of '*unprecedented political interference*' after he told them to admit a man with psychiatric problems who had been detained under the Anti-Terrorism, Crime and Security Act (*Guardian* staff reporter, 2003). This raises major concerns about the role of psychiatrists working within a state health service, in a situation of 'dual loyalties', with simultaneous obligations, express or implied, to the patient and to the state. How much 'lack of tolerance for non-compliance' should they have? Those who fail to use the powers could be held accountable for any adverse consequences to the public (implicit in the media coverage that someone should have been suspended in the 'body bags' case discussed in the introduction) while compulsory detention of the patient for certain undesirable 'social problems' and those considered *potentially* dangerous might infringe upon the patient's human rights and be professionally unethical. Whilst the current 'blame culture' operates, professionals may well go for the latter as the 'low-risk' (to them) option (Quirk *et al.*, 2003). Clearly concerned about the implications of the Bill, the Royal College of Psychiatrists responded to the draft Bill by reiterating that the only rationale for psychiatric intervention is for the benefit of patients' health and that public protection is secondary (Mental Health Law Sub-Committee, 2001).

Lastly, the concern should be that patients, aware of the increased intrusions on their lives, may become further alienated from services and actively avoid contact. This in turn may lead to an increase in their distress, negative impact on their health, and may increase risk to themselves and others.

What is encouraging is that the draft Bill has encountered considerable resistance from a broad range of professional, user and advocacy organisations that have come together as the Mental Health Alliance, through their united concern about the extended legal power to detain (Warner, 2002). The Alliance has used a human rights discourse to argue that this Bill has the increased potential to violate human rights, as well as the potential to damage the health of people with mental health problems. The Alliance Charter for Consensual Treatment states that: '*Public protection will be enhanced by encouraging people to speak openly about mental health, improving the quality of community services and breaking the false link between violence and mental health*'.

#### *Conclusion*

The increased restriction of the human rights of people with severe mental illness is not only discriminatory and unacceptable, but will lead to a deterioration in many people's health. The rights of people with mental health problems must be respected and protected to address health inequity, in particular the right to good quality, non-discriminatory health services.

I have used a health and human rights framework to analyse the current approach taken by the UK government to people with severe mental illness. It provides a systematic way to consider the ways in which vulnerability to mental illness is being reduced, but also the different ways



in which the rights of people with mental health problems may be violated, including through health policies and professional practice. It compels us to think critically and respond actively to situations that increase the likelihood of human rights abuses and inequity.

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## 4. CHILDREN'S RIGHTS AND HEALTH INEQUALITY

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Over the past two decades the 'children's rights movement' in the UK has grown significantly in size and influence. This growth has been fuelled by international developments - notably the United Nations Convention on the Rights of the Child (UNCRC) - and the work of non-governmental organisations (NGOs) and academics, particularly in the disciplines of sociology and law. The report submitted by the Children's Rights Alliance for England to the United Nations Monitoring Committee on the Rights of the Child was signed by no fewer than 75 NGOs. Such organisations have contributed to an explosion of work aimed at empowering children's involvement in public decision making at a local and national level. Government has placed a strong emphasis on a rights approach to children as active participants in the development and delivery of services. It has formed the Children and Young People's Unit to provide a strategic coherence across all departments and set itself the ambitious target of eliminating child poverty by 2020. This period has also seen the emergence of a new 'sociology of childhood', which has argued for the re-construction of children as social actors having agency, in opposition to perceptions of them as the passive recipients of services. Despite some qualifications, these, and other developments, have led Michael Freeman (1997) to state that:

*'The children's rights movement has achieved much, not least a convention which nearly every country in the world has accepted. A generation ago who would have thought this possible?'*

Despite such achievements, there are questions about such a growth in the children's rights movement taking place alongside increasing inequality in the UK - and an apparently contradictory policy agenda, which at times displays very dissonant views about children and childhood. Michael Freeman also stated that:

*'A child's life is not necessarily improved by giving him or her more rights.'* (Freeman, 1997)

An objective of the HEN seminar was to raise awareness about the value of using a human rights perspective to enhance action on health inequalities. My aim is to try and look at this growth in 'children's rights' in such a context, in particular for those children living in the poorer, working class, areas of England. For the purpose of this presentation I have adopted a broad definition of health put forward by the World Health Organisation.

*'A state of complete physical, mental and social well-being and not merely the absence of disease or infirmity.'*

In relation to the World Health Organisation's definition of health it has been argued that all of the articles of the United Nations Convention on the Rights of the Child are relevant:

*'The convention is so coherent that most articles reinforce and expand one another and so can be related, for example, to health ... child's physical and mental integrity and well being,'*  
(Alderson, 2002).

The UK became a signatory to UNCRC on the 19th April 1990 and the then Prime Minister, Margaret Thatcher, stated that it would give (Lyon, not dated):

*'A high priority to the rights of children in all areas of legislative, judicial and administrative activity and policy making.'*

An elected UN Committee monitors state compliance with the convention and governments have to submit a national report. The UK's second report was submitted in September 1999. In the section of this report entitled 'Basic Health and Welfare' it was stated (Department of Health, 1999).

*'Health is a constant theme of Government policy, which is concerned with taking determined action to deal with the social and economic influences that undermine health.'*

The UN Committee published its response to the UK report in October 2002 and welcomed the progress made in a number of areas, but it also raised a number of concerns in relation to inequality and poverty (United Nations, 2002):

- *'While welcoming the reduction of infant mortality rates and the new focus on children in the planning of the NHS, the Committee remains concerned at persisting inequalities in health and access to health services across the State party linked to socio-economic status and ethnicity.'*
- *'The Committee is extremely concerned at the high proportion of children living in poverty... which limits their enjoyment of many rights under the convention and leads to higher incidence among those children of mortality, accidents, teenage pregnancy, poor housing and homelessness, malnutrition, educational failures or suicide. The Committee welcomes the... commitment to end child poverty and the initiative taken in this regard, but notes the lack of an effective and co-ordinated poverty eradication strategy...'*

An additional problem is that children are not able to pursue their rights, because in general they aren't aware of them. They only have them by proxy - adults and agencies more often than not apply children's rights for them. Studies have shown that children have very little knowledge of the UNCRC (Alderson, 1999).

The last quarter of the twentieth century saw a world-wide increase in inequality (Beck and Beck-Gernsheim, 2002) which has been echoed by increasing levels of poverty and inequality in the UK and the effect of inequality is disproportionately greater for children (Novack, 2002; Bradshaw, 2000). In his introduction to Bringing Britain Together (Social Exclusion Unit, 1998), the Prime Minister stated:

*‘Over the last two decades the gap between the “worst estates” and the rest of the country has grown. It has left us with a situation that no civilised society should tolerate. It is simply not acceptable that so many children go to school hungry, or not at all, that so many teenagers grow up with no real prospect of a job...It shames us as a nation, it wastes lives and we all have to pay the costs of dependency and social division.’*

At the beginning of 2002 over £7b had been expended to meet the government's commitment to eradicate child poverty by 2020 - cutting it by a quarter by 2005 and halving it by 2010. The Government's Opportunity For All - Fourth Annual Report 2002 provided the following statistics:

- 3.9m children remain under the 60% median income line
- 2.5m children live below the 50% median income line
- 0.5m fewer children living in relative poverty
- 1.4m fewer children living in absolute poverty

This is a significant achievement in reducing the number of children living in relative and absolute poverty, but inequality has continued to grow. In an article in the Guardian newspaper, the social commentator Polly Toynbee stated (Toynbee, 2003):

*‘As a direct result of Labour's tax and benefits regime, the bottom fifth of society has gained an extra 15% while the top 10% has been taxed an extra 3%. So why aren't hats being tossed in the air ... This is the big picture: Britain is now more unequal than it was under either Thatcher or Major. Trying to pull the poorest up over a moving line while the rich soar away is like running up a down escalator...this is the most unequal country in the EU, with the most poor children ... The country grew 30% richer in the last 10 years.’*

Whilst not discounting the effects of absolute poverty the Acheson Report (1998) placed great significance on the effects of inequality:

*‘The economic and social benefits of greater equality seem to go hand in hand. The quality of the social environment is worst where financial deprivation is greatest, such as the inner cities. Recent research suggests that, in addition to the ill effects due to absolute poverty, societies in which there is a wide gap between the rich and the poor suffer additional social problems, for instance, through high rates of violent crime and truancy.’*

The Government produces indicators of deprivation for England based on 8414 electoral wards (DETR, 2000). Liverpool contains 33 wards and of these 27 rank in the 20% most disadvantaged - In the Rank of Child Poverty Index, 9 are in the most 100 disadvantaged and 8 in the most 50 disadvantaged. In the Rank of Health Domain, 13 wards feature in the 100 most disadvantaged - with Everton ranking first (most disadvantaged) out of 8,414. By

comparison, in the Rank of Employment Domain, 13 also rank in the 100 most disadvantaged - with Everton again ranking first in England. Poverty and affluence go together in Liverpool and Merseyside. For example on the Wirral (a local authority on the other side of the River Mersey from Liverpool) the wards of Bidston and Heswall are ranked at opposite ends of the child poverty indicator. Bidston being ranked 1st and Heswall 7844. A study undertaken in 1996 by the Department of the Environment Transport and the Regions on public expenditure (DETR, 1996) calculated per capita expenditure on children aged 0-15 living in the Granby ward of Liverpool at £1,059, but in the least deprived ward this was £1,416. The study stated:

*'... when you allow for the underlying age structure of the population ... instead of a gentle upward slope of spending with deprivation, the pattern in two important cases, children and young people, now looks more banana shaped, with highest expenditure in the most affluent wards. The suggested reason for this is that while deprivation drives some elements of spending in nonlinear ways, other elements of expenditure (particularly education over 16) are more demand led.'*

It has been announced that 60% of 'poor children' do not live in the most 20% disadvantaged wards. But it should not come as any surprise that in an increasingly unequal society, inequality is in fact 'evenly' distributed and not just confined to certain geographic areas of the UK. What is interesting in the results of the DETR study is that public expenditure on children and young people was higher in affluent wards and lower in poor ones.

In Liverpool, considerable 'rights' work has taken place over the past ten years. This has been aimed at empowering children's participation in public decision-making and persuading local policy makers to include their views, concerns and needs. The academic, voluntary and public sectors combined to develop the Liverpool Bureau for Children and Young People as a strategic mechanism for promoting their participation in their City (Feasibility Study, 2000). There has been a marked increase in the commitment to including children and promoting their rights. Moreover, children have clearly demonstrated their capacity and competency across a range of issues - and the ability to make moral, social and political judgements. They perhaps don't contextualise their comments in relation to big concepts such as rights, inequality and health, but they have a keen understanding of 'fairness', which is grounded in their everyday experiences of the social and economic world they inhabit. Even young children have shown an extensive knowledge of the issues confronting their neighbourhoods and communities, and the effects on their lives, which show a remarkable resonance with those at the centre of current policy making.

Priority Search Survey – Liverpool 8 (Toxteth) 1996 –

Top 10 issues for children aged 7-11

- Stop selling and taking drugs
- Stop guns and knives being sold and used
- Stop strangers picking up children

- Give homeless people somewhere to live
- Take care of animals
- Stop people being robbed
- Better police on the streets
- Look after old people better
- Stop racism
- More for the disabled

*'Children should pester the Government. We don't want our estate where we live to be like Bosnia or Columbia, because if our estate becomes like these other countries there will be no peace in the world where I live ... We want robbers and drug addicts to be in a special home and to have special care because locking people up just makes them worse. Not all drug addicts are bad. Drug addicts are sick people.'*

*'I think that drugs should not be sold because the children get affected by it as well. It causes arguments, riots and a lot of violence. This shows that people don't respect themselves or the people that care for them. This makes the community dull and sad. I think that the community should be alive and bright, with people able to stop on the street and talk to one another. I think this would affect the children and the community around them in a better way.'*

*'In our community we have good neighbours who help each other when people are sick. Good neighbours can teach people how to be good. Safe feelings are good for you' ... 'Our neighbours are our friends and they are good to us. I like to stop on the streets and talk to people.'*

Priority Search - Wirral Children's Fund Consultation 2002 top 10 issues

- More money for parents to help children
- More police, security cameras and security people
- Stop speeding motor bikes and cars on roads and pavements
- Parks that are safe and clean for children
- Stop vicious dogs running around
- Somewhere for teenagers to keep them off the streets
- Stop bullies outside school
- Stop bullies in school
- An adult to talk to

The 'problem' with the views of children described above is that they are at the heart of major policy issues, which successive governments have struggled to deal with over many years. Over several decades there has been wave upon wave of initiatives and programmes designed to address the decline of urban neighbourhoods and other communities. In their responses, and in their own words, children are charting the social effects of long-term structural decline. Such 'rights' work undertaken with children in Liverpool may have

succeeded in identifying the concerns of children, but of itself it can't redress such problems. Yet, there has been hope that major initiatives introduced by the present Government would bring resources to the issues raised by children. The Government's Children and Young People's Unit oversees the delivery of major programmes, such as the Children's Fund, which in delivery have shown a noticeable shift towards a representation of children as in danger and dangerous (Prout, not dated). Helen Seaford (2001) describes what she terms the following 'caricature' of policy attitudes to children:

*'The child moves through Whitehall growing and shrinking like Alice: in the Department of Health she is a small potential victim, at the Treasury and Department of Education a growing but silent unit of investment, but at the Home Office a huge and threatening job.'*

Government has placed great emphasis on intervening directly and significantly in the lives of children it deems at risk, vulnerable and potential or actual perpetrators of crime, anti-social behaviour and pre-crime activity. The White Paper, Respect and Responsibility - Taking a Stand against Anti-Social Behaviour (Home Office, 2003) states:

*'Healthy communities are built on strong families. These are communities where people know their neighbours and can call on them in good times and bad. These are neighbourhoods that are safe, where parents take responsibility for their children's well being and behaviour...Parents have to set limits; they have to ensure their children understand the difference between right and wrong. Without this children feel free to do as they wish and can, in some cases, make life a misery.'*

The White paper sets out a whole range of measures and initiatives to address anti-social behaviour by children and young people. Children and young people are not portrayed as active contributors to their communities - as moral agents - rather they are a blank slate, with the potential to become either 'little devils' or 'little angels'. In addition, it is becoming clear that a welfare state approach is becoming replaced by, or operating alongside, the criminal justice system. In a survey contained in a report issued by the Audit Commission, young people were second only to dog dirt (Audit Commission, 1999). A 'rights' approach in Liverpool has played an important role in promoting children's views and capacities, but it has to work alongside a policy and welfare approach, which seeks to address structural problems, which affect the lives and futures of children living in the most disadvantaged communities.

For 30 years I have worked with children and in all this time I have yet to meet a child who, in my judgement, if given the choice would pick a bad childhood in preference to a good one; or a future of poverty, unemployment, imprisonment or early death. If we can unite around the idea of giving all children the opportunity to realise a good childhood, it is my belief that the future will take care of itself. From work in Liverpool it is clear that children want adults to recognise their rights and to take responsibility for addressing the issues they face.

The question is whether or not it is possible to find a way of balancing these tensions or, as the sociologist Beck argues (2002), are we on the verge of a period of change as profound as that of the Reformation? That of a post modern age of individualisation - with children



as the shock troops of this new age - and what are the role of rights in this? Will such an age result in greater levels of inequality - indeed is increasing inequality perfectly consistent with increasing individual rights? As a counter to this it could be argued that in terms of children's rights we are only at the beginning of a long term process, one which bears comparison to the feminist and anti-racist movements - that endurance and persistence will eventually reap the reward of greater equity for children.

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## **5. YOUNG AFRICAN LONDONERS AFFECTED BY HIV: MAKING SENSE OF RIGHTS**

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### *Introduction*

This paper examines how young black migrant African Londoners affected by HIV/AIDS make sense of the language of rights. The paper is based on a survey and interviews with African adults infected with HIV and interviews with their HIV affected children (Chinouya 2002a). Results show tensions for children between having rights and having respect for adults, family and community. Children varied widely about wanting 'rights'. However, many said that they did want HIV related information and decision-making capacity, accorded by rights artefacts. Although a majority of the parents believe that children should be informed about how HIV affects them, few of the children had had their information rights upheld.

### *Human rights and HIV in Europe*

Human rights issues related to children affected by HIV need to be addressed. New diagnoses of heterosexually acquired HIV in western Europe show significant increases (Nicoll and Hamers, 2002). Almost two thirds of new infections between 1997-2000 were to migrants from high prevalence countries, most notably sub-Saharan Africa. Approximately 7,000 African adults and just over 600 children resident in the United Kingdom (UK) are known to be living with HIV.

The Office of the UN High Commissioner for Human Rights and the Joint UN Programme on HIV/AIDS have issued international guidelines on human rights (OHCHR and UNAIDS,

1996). The guidelines indicate entitlements conferred by the Convention on the Rights of the Child (1989), in the context of the HIV/AIDS epidemic:

*Children have ‘... many of the rights that protect adults (e.g. non-discrimination...liberty and security, privacy, asylum, expression, association and assembly, education and health) ...’ (para 94).*

*‘The freedom to seek, receive and impart information and ideas of all kinds and the right to education provide children with the right to give and receive all HIV-related information needed to avoid infection and to cope with their status, if infected. The right ...to abolition of traditional practices which are prejudicial to the health of children...the rights...to be actors in their own development and to express opinions and have them taken into account in making decisions about their lives should empower children ...’ (para 95).*

Some commentators believe that the Convention on the Rights of the Child is eurocentric, universalising distinctively western conceptions of childhood (Pupavac,1998). Pupavac argues that childhood ‘remains a luxury that is unrealisable for the population in developing countries’. This correctly signals social and economic obstacles faced by children in exercising rights enshrined in the Convention. This applies as well in the UK. We think it is more constructive to hold governments to account for their obligations to ensure that children’s social and economic rights are secured.

### *The African Charter on Human and People’s Rights*

Human rights artefacts constructed by African countries are distinctive in emphasising *duties* and treating *social and economic rights as foundational*. The African Charter on Human and People’s Rights (ACHPR, 1981) treats ‘*freedom, equality, justice, and dignity [as] essential objectives*’, contrasting with the primacy of ‘*liberty*’ in western rights discourse. The ACHPR places human rights in the context of ‘*tradition and the values of African civilisation*’. Article 18 identifies the family as the ‘*natural unit and basis of society*’ but it does not treat the family and/or tradition as unchanging. Acknowledging the importance of addressing problems faced by children, it asserts that the state shall ‘... *ensure the protection of the rights of the child as stipulated in international declarations and conventions*’ (para 3). Article 29 specifies duties ‘*to work for the cohesion and respect of the family; to respect parents at all times, to maintain them in case of need*’ (para.1). This presents resources and challenges for the recognition and exercise of children’s rights. One of those challenges is children’s entitlement to information and decision-making about their health. Mutua (2002) argues that pre-colonial African societies had practices and norms which are ‘*human rights ideals*’ but that ‘*speech and dissent rights of non-adults or minors were ... severely restricted*’.

The construction of declarations and covenants expressing rights, to which states commit themselves, derive from long-standing but changing traditions. This applies to rights instruments constructed in western societies which highlight individuals and their entitlements and initially gave precedence to men of property (O’Keefe and Scott-Samuel, 2002). In the West, rights have been, and continue to be, accorded to women only through vigorous struggle. The application of rights discourse to children is a recent innovation.

However, this move continues to be contested by some sections of the population in the UK, e.g., in relation to corporal punishment administered by adults and sex education in schools. In light of the emergent nature of rights, and their continued contestation in western countries, it is not surprising that migrants affected by HIV bring their own meanings to children's rights. These meanings must be taken into account in constructing effective strategies for promoting the health of African children affected by HIV in the industrialised countries.

As in the West, rights artefacts constructed by African societies are steeped in tradition, but subject to change, not least through social movements in Africa (de Waal *et al.*, 2002). Likewise, African communities in the UK are using traditional resources to promote health and well-being (Chinouya, 2002a, 2002b, 2002c, 2003). These resources are grounded in notions of *Ubuntu-Hunhu*: duty, respect for one another and social solidarity (Tutu, 1999). Many children, living in the cities of US and Europe, are members of diaspora communities. They are reconstructing childhood using cultural resources from both source and recipient countries. It would be easier for them to do this in the UK if the Convention on the Rights of the Child were implemented adequately.

The UK has been found wanting by the UN Committee charged with monitoring compliance with the Convention in two successive reports (Committee on the Rights of the Child, 2002; O'Keefe, 1996; O'Keefe and Hogg 2000). The most recent report was concerned about the '*wide-ranging reservation on immigration and citizenship*' (para 6). Reviewing the government's actions on child poverty, it asserts, '*the Convention is not implemented to the maximum extent of available resources*' (para 10). It calls attention to the lack of a '*rights-based approach*' to legislation, policy and action plans, particularly for groups of children whose vulnerability requires '*special attention*'. These groups include '*poor households ... minority groups ... asylum seekers*' (para. 15). Regarding the right to non-discrimination, the Committee notes that these groups suffer from '*unequal enjoyment of economic, social and cultural rights*' (para 22). It '*remains concerned at persisting inequalities in health and access to health services ... linked to socio-economical status and ethnicity*' (para 39), subsequently leading to the children's poor health outcomes. The Committee welcomed the government's commitment to end child poverty, but noted a lack of an effective and coordinated poverty-eradication strategy. The implementation failures regarding the economic and social rights accorded by the Convention make it more difficult for African London children affected by HIV to access the information and decision-making rights which would help them to promote their health.

### *Making sense of rights: Telling African children about HIV*

Research carried out for a PhD explored disclosure of HIV status between parent(s) and child(ren) amongst African Londoners (Chinouya, 2002a). This involved surveys of HIV-positive parents, interviews with some of these and focus group discussions with affected teenaged children, some of whom did not know their parents' or their own HIV status. Participants were Black migrant Africans resident in 14 London boroughs, just over half of whom had lived in the UK 6-10 years, others for less. They had high levels of formal education and high unemployment. Of the 119 children, 51 were non-resident,

## 5. Young African Londoners affected by HIV: Making sense of rights

accommodated by kin in Africa. Although two thirds of parents thought children should be told of their own HIV status, 10 out of the 11 HIV positive co-resident children had not been told of their own status by their parents. Parents had reasons for not telling: children could not keep secrets; children would be subjected to discrimination; HIV was shameful, construed as due to “sleeping around”; family interests might be compromised, notably on issues surrounding unresolved immigration status which might be jeopardised by such disclosure. Importantly, a positive HIV diagnosis was not a high priority against a background of economic deprivation. “From parental accounts, children were experiencing poor health without an awareness of the underlying cause of their illness” (Chinouya, 2002a).

In discussions with young people, common themes emerged. (N.B. Children’s names have been changed to protect confidentiality. “MC” refers to Martha Chinouya.) They were engaged in high levels of responsibility and extensive caring duties, providing material and emotional support to their parent(s) living with AIDS and siblings. Their commitment to duty is clear:

Ngoni: *I still feel guilty (silence) leaving her on her own, not being around in case she needs me ... By going to school I would feel guilty. Cause I wasn't sure how she was coping at home and I would call every time I could to find out if she was fine.*

MC: *You called from school?*

Ngoni: (silence) *Yes, I call from school... I stayed away from school because I wanted to care and look after her (217) (Chinouya, 2002a).*

Their caring responsibilities involved (re)negotiating gender and generational norms, giving parents the space to recover whilst free from childcare and family responsibilities. They expressed low levels of autonomy. This is how some children put it when asked about parents:

Girl 7: *Not speaking to your parents when they are telling you ... (interjecting: if you speak back that's not respect).*

Girl 4: *Whether they are right or wrong you just have to sit quietly and listen.*

Girl 2: *Don't look into their eyes when they speak to you (interjection: if you look into their eyes that's lack of respect. All the girls speaking at the same time ... British kids have no respect ... 194)*

Concepts of children’s rights to information and to be heard were largely unknown:

MC: *... children have rights.*

Girls: *Who said that?*

MC: *The Children Act...*

Girls: *We have never heard of it.*

Girl: *What Act?*

Girl: *Martha said it's the children one.*

Girl: *Never heard of it! (216).*

Rights were often construed as threatening family solidarity, in particular, respect for those older than they. Non-subscription to 'rights' language was perceived as part of 'normal childhood':

MC: *Do you think you have a right to be heard in this house?*

Ngoni: *No. I don't at all. I just see myself as a normal child.*

MC: *What is a normal child?*

Ngoni: *One with respect for their parents. I do not believe in these rights. When those people hear about their rights they answer back to their parents and lose respect (217).*

It would be a mistake to believe that children spoke with one voice. Some children welcomed the notion that they have rights. But in no case, in this study, did any child think that this was straightforward:

Tapu: *They have rights and it's very good. Though sometimes it's very bad ... In most cases parents should talk to their children and ask them how they feel. But if you tell someone to clean and it's a child and she shouts at you it's very bad. Children should respect adults. They should talk to an adult knowing that I am talking to an adult (217).*

Nevertheless, children wanted information, their voices to be heard and to be consulted about matters that affected their lives. This did not prompt them to use the language of "rights".

### *Conclusion*

We take the view that children's rights to be heard and take part in decisions are essential principles. This is very important in the context of HIV infection in migrant African communities in the UK. However, these principles present tensions and contradictions for children and young people and their parents who are constructing their identities in social and economic circumstances which threaten their well-being. Some young African Londoners do not think of themselves as having 'rights'. Being an individual with rights was seen as threatening to an already beleaguered family. Autonomy was viewed as disrespectful and rendered the language of rights foreign. At the same time children favoured the principles articulated in 'rights' language.

Traditional cultural factors present barriers to the recognition of rights when rights are wrapped in individualistic language. These barriers are reinforced by social and economic barriers, including poverty, discrimination and worries about immigration status. Economic and social worries are so pressing that HIV-related issues are given a low priority in affected people's lives. Some young African Londoners affected by HIV take on 'adult' responsibilities, not least because they are imbued with a strong sense of duty to their parents and siblings which they associate with being *African*. From their standpoints it is 'normal' for anyone to be responsible for others. Paradoxically, these children creatively transgress traditional age, gender and generational norms necessary to carry out what they

see as their traditional caring duties. At the same time they do not want this creative manoeuvring to threaten respect for elders. They do, however, want information about their own as well as their family members' health and to be key players in family well-being.

These children's cultural heritage provides resources which would make it possible for rights to make sense to them. This can be supported if their rights as individuals to information and decision-making about their health are presented very clearly by professionals (e.g. teachers, health and social care workers) as bound up with economic and social rights for them and their families which in turn are grounded in the duties that all of us have to one another. Western societies may have much to learn about the centrality of social solidarity to the promotion and exercise of the civil and political rights to which their dominant elites give precedence.

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## **6. APPENDICES**

### **6.1 Human Rights Act 1998**

#### *Schedule 1: Rights and Freedoms*

##### **Article 2: Right to Life**

1. Everyone's right to life shall be protected by law. No one shall be deprived of his life intentionally save in the execution of a sentence of a court following his conviction of a crime for which this penalty is provided by law.
2. Deprivation of life shall not be regarded as inflicted in contravention of this Article when it results from the use of force which is no more than absolutely necessary:
  - (a) in defence of any person from unlawful violence;
  - (b) in order to effect a lawful arrest or to prevent the escape of a person lawfully detained;
  - (c) in action lawfully taken for the purpose of quelling a riot or insurrection.

##### **Article 3: Prohibition of Torture**

No one shall be subjected to torture or to inhuman or degrading treatment or punishment.

##### **Article 4: Prohibition of Slavery and Forced Labour**

1. No one shall be held in slavery or servitude.
2. No one shall be required to perform forced or compulsory labour.
3. For the purpose of this Article the term 'forced or compulsory labour' shall not include:
  - (a) any work required to be done in the ordinary course of detention imposed according

to the provisions of Article 5 of this Convention or during conditional release from such detention;

- (b) any service of a military character or, in case of conscientious objectors in countries where they are recognised, service exacted instead of compulsory military service;
- (c) any service exacted in case of an emergency or calamity threatening the life or well-being of the community;
- (d) any work or service which forms part of normal civic obligations.

**Article 5: Right to Liberty and Security**

1. Everyone has the right to liberty and security of person. No one shall be deprived of his liberty save in the following cases and in accordance with a procedure prescribed by law:
  - (a) the lawful detention of a person after conviction by a competent court;
  - (b) the lawful arrest or detention of a person for non-compliance with the lawful order of a court or in order to secure the fulfilment of any obligation prescribed by law;
  - (c) the lawful arrest or detention of a person effected for the purpose of bringing him before the competent legal authority on reasonable suspicion of having committed an offence or when it is reasonably considered necessary to prevent his committing an offence or fleeing after having done so;
  - (d) the detention of a minor by lawful order for the purpose of educational supervision or his lawful detention for the purpose of bringing him before the competent legal authority;
  - (e) the lawful detention of persons for the prevention of the spreading of infectious diseases, of persons of unsound mind, alcoholics or drug addicts or vagrants;
  - (f) the lawful arrest or detention of a person to prevent his effecting an unauthorised entry into the country or of a person against whom action is being taken with a view to deportation or extradition.
2. Everyone who is arrested shall be informed promptly, in a language which he understands, of the reasons for his arrest and of any charge against him.
3. Everyone arrested or detained in accordance with the provisions of paragraph 1(c) of this Article shall be brought promptly before a judge or other officer authorised by law to exercise judicial power and shall be entitled to trial within a reasonable time or to release pending trial. Release may be conditioned by guarantees to appear for trial.
4. Everyone who is deprived of his liberty by arrest or detention shall be entitled to take proceedings by which the lawfulness of his detention shall be decided speedily by a court and his release ordered if the detention is not lawful.
5. Everyone who has been the victim of arrest or detention in contravention of the provisions of this Article shall have an enforceable right to compensation.

**Article 6: Right to a Fair Trial**

1. In the determination of his civil rights and obligations or of any criminal charge against him, everyone is entitled to a fair and public hearing within a reasonable time by an independent and impartial tribunal established by law. Judgment shall be pronounced publicly but the press and public may be excluded from all or part of the trial in the interest of morals, public order or national security in a democratic society, where the interests of juveniles or the protection of the private life of the parties so require, or to the extent strictly necessary in the opinion of the court in special circumstances where publicity would prejudice the interests of justice.
2. Everyone charged with a criminal offence shall be presumed innocent until proved guilty according to law.
3. Everyone charged with a criminal offence has the following minimum rights:
  - (a) to be informed promptly, in a language which he understands and in detail, of the nature and cause of the accusation against him;
  - (b) to have adequate time and facilities for the preparation of his defence;
  - (c) to defend himself in person or through legal assistance of his own choosing or, if he has not sufficient means to pay for legal assistance, to be given it free when the interests of justice so require;
  - (d) to examine or have examined witnesses against him and to obtain the attendance and examination of witnesses on his behalf under the same conditions as witnesses against him;
  - (e) to have the free assistance of an interpreter if he cannot understand or speak the language used in court.

**Article 7: No Punishment Without Law**

1. No one shall be held guilty of any criminal offence on account of any act or omission which did not constitute a criminal offence under national or international law at the time when it was committed. Nor shall a heavier penalty be imposed than the one that was applicable at the time the criminal offence was committed.
2. This Article shall not prejudice the trial and punishment of any person for any act or omission which, at the time when it was committed, was criminal according to the general principles of law recognised by civilised nations.

**Article 8: Right to Respect for Private and Family Life**

1. Everyone has the right to respect for his private and family life, his home and his correspondence.
2. There shall be no interference by a public authority with the exercise of this right except such as is in accordance with the law and is necessary in a democratic society in the interests of national security, public safety or the economic well-being of the country, for

the prevention of disorder or crime, for the protection of health or morals, or for the protection of the rights and freedoms of others.

**Article 9: Freedom of Thought, Conscience and Religion**

1. Everyone has the right to freedom of thought, conscience and religion; this right includes freedom to change his religion or belief and freedom, either alone or in community with others and in public or private, to manifest his religion or belief, in worship, teaching, practice and observance.
2. Freedom to manifest one's religion or beliefs shall be subject only to such limitations as are prescribed by law and are necessary in a democratic society in the interests of public safety, for the protection of public order, health or morals, or for the protection of the rights and freedoms of others.

**Article 10: Freedom of Expression**

1. Everyone has the right to freedom of expression. This right shall include freedom to hold opinions and to receive and impart information and ideas without interference by public authority and regardless of frontiers. This Article shall not prevent States from requiring the licensing of broadcasting, television or cinema enterprises.
2. The exercise of these freedoms, since it carries with it duties and responsibilities, may be subject to such formalities, conditions, restrictions or penalties as are prescribed by law and are necessary in a democratic society, in the interests of national security, territorial integrity or public safety, for the prevention of disorder or crime, for the protection of health or morals, for the protection of the reputation or rights of others, for preventing the disclosure of information received in confidence, or for maintaining the authority and impartiality of the judiciary.

**Article 11: Freedom of Assembly and Association**

1. Everyone has the right to freedom of peaceful assembly and to freedom of association with others, including the right to form and to join trade unions for the protection of his interests.
2. No restrictions shall be placed on the exercise of these rights other than such as are prescribed by law and are necessary in a democratic society in the interests of national security or public safety, for the prevention of disorder or crime, for the protection of health or morals or for the protection of the rights and freedoms of others. This Article shall not prevent the imposition of lawful restrictions on the exercise of these rights by members of the armed forces, of the police or of the administration of the State.

**Article 12: Right to Marry**

Men and women of marriageable age have the right to marry and to found a family, according to the national laws governing the exercise of this right.

**Article 14: Prohibition of Discrimination**

The enjoyment of the rights and freedoms set forth in this Convention shall be secured without discrimination on any ground such as sex, race, colour, language, religion, political or other opinion, national or social origin, association with a national minority, property, birth or other status.

**Article 16: Restrictions on Political Activity of Aliens**

Nothing in Articles 10, 11 and 14 shall be regarded as preventing the High Contracting Parties from imposing restrictions on the political activity of aliens.

**Article 17: Prohibition of Abuse of Rights**

Nothing in this Convention may be interpreted as implying for any State, group or person any right to engage in any activity or perform any act aimed at the destruction of any of the rights and freedoms set forth herein or at their limitation to a greater extent than is provided for in the Convention.

**Article 18: Limitations on Use of Restrictions on Rights**

The restrictions permitted under this Convention to the said rights and freedoms shall not be applied for any purpose other than those for which they have been prescribed.

Source: The Lord Chancellors Department for Human Rights  
<http://www.humanrights.gov.uk/>

*Absolute rights*

Absolute rights are not limited and they cannot be infringed no matter how necessary it might seem to be to do so. These include Article 2, Article 3, Article 4(1) and Article 7.

*Limited rights*

In such articles the right is set out at the beginning and then there are specific limitations in the article itself. These include Articles 4(2), 5, 6 and 12.

**Qualified rights**

Generally in such articles the right is set out at the start and then is qualified. Any infringement needs to promote a specific legitimate aim - in the interests of national security, public safety etc. The infringement must be properly regulated by the law and must be necessary in a democratic society. This latter concept means the interference with the right must be a proportionate response to the legitimate aim. If the aim can be achieved by a less intrusive method then that method must be used instead. These include Article 8, 9, 10, 11, 14 and Protocol 1, Article 1.

Source: YourRights.org. *The Liberty guide to Human rights* <http://www.yourrights.org.uk/>

## 6.2 Summary of the Rights of the Child

*A summary of the main points of the UN Convention produced by UNICEF as “Know your Rights! Children’s Rights in Plain English”.*

Courtesy of Mike Jones

### **Article 1**

Everyone under 18 years of age has all the rights in this convention.

### **Article 2**

You have these rights, whoever you are, whoever your parents are, whatever colour you are, whatever sex or religion you are, whatever language you speak, whether you have a disability, or if you are rich or poor.

### **Article 3**

Whenever an adult has anything to do with you, he or she should do what is best for you.

### **Article 6**

Everyone should recognise that you have the right to live.

### **Article 7**

You have the right to have a name, and when you are born your name, your parents’ names and the date should be written down. You have the right to a nationality, and the right to know and be cared for by your parents.

### **Article 9**

You should not be separated from your parents unless it is for your own good. For instance, your parents may be hurting you or not taking care of you. Also, if your parents decide to live apart, you will have to live with one or the other of them, but you have the right to contact both parents easily.

### **Article 10**

If you and your parents are living in separate countries, you have the right to get back together and live in the same place.

### **Article 11**

You should not be kidnapped, and, if you are, the government should try their hardest to get you back.

### **Article 12**

Whenever adults make a decision that will affect you in any way, you have the right to give your opinion, and the adults have to take that seriously.

**Article 13**

You have the right to find out things and say what you think through speaking, writing, making art etc, unless it breaks the rights of others.

**Article 14**

You have the right to think what you like and be whatever religion you want to be. Your parents should help you learn what is right and wrong.

**Article 15**

You have the right to meet, make friends with and make clubs with other people, unless it breaks the rights of others.

**Article 16**

You have the right to a private life. For instance, you can keep a diary that other people are not allowed to see.

**Article 17**

You have the right to collect information from radios, newspapers, television, books etc, from all around the world. Adults should make sure that you get information you can understand.

**Article 18**

Both of your parents should be involved in bringing you up and they should do what is best for you.

**Article 19**

No one should hurt you in any way. Adults should make sure that you are protected from abuse, violence and neglect. Even your parents have no right to hurt you.

**Article 20**

If you do not have any parents, or if it is not safe for you to live with your parents, you have the right to special protection and help.

**Article 21**

If you have to be adopted, adults should make sure that everything is arranged in the way that is best for you.

**Article 22**

If you are a refugee (meaning you have to leave your own country because it is not safe for you to live there), you have the right to special protection and help.



**Article 23**

If you are disabled, either mentally or physically, you have the right to special care and education to help you grow up in the same way as other children.

**Article 24**

You have a right to good health. This means that you should have professional care and medicines when you are sick. Adults should try their hardest to make sure that children do not get sick in the first place by feeding and taking good care of them.

**Article 27**

You have the right to a good enough “standard of living”. This means that parents have the responsibility to make sure you have food, clothes, a place to live, etc. If parents cannot afford this, the government should help.

**Article 28**

You have a right to education. You must have primary education, and it must be free. You should also be able to go to secondary school.

**Article 29**

The purpose of your education is to develop your personality, talents and mental and physical abilities to the fullest. Education should also prepare you to live responsibly and peacefully, in a free society, understanding the rights of other people, and respecting the environment.

**Article 30**

If you come from a minority group, you have the right to enjoy your own culture, practise your own religion and use your own language.

**Article 32**

You have the right to be protected from working in places or conditions that are likely to damage your health or get in the way of your education. If somebody is making money out of your work, you should be paid fairly.

**Article 33**

You have the right to be protected from illegal drugs and from the business of making and selling drugs.

**Article 34**

You have the right to be protected from sexual abuse. This means that nobody can do anything to your body that you do not want them to do, such as touching you or taking pictures of you or making you say things that you don't want to say.

**Article 35**

No one is allowed to kidnap or sell you.

**Article 37**

Even if you do something wrong, no one is allowed to punish you in a way that humiliates you or hurts you badly. You should never be put in prison except as a last resort, and, if you are put in prison, you have the right to special care and regular visits with your family.

**Article 38**

You have a right to protection in times of war. If you are under fifteen, you should never have to be in an army or take part in a battle.

**Article 39**

If you have been hurt or neglected in any way, for instance in a war, you have the right to special care and treatment.

**Article 40**

You have the right to defend yourself if you have been accused of committing a crime. The police and the lawyers and judges in court should treat you with respect and make sure you understand everything that is going on.

**Article 42**

All adults and all children should know about this Convention. You have a right to learn about your rights and adults should learn about them too.

## 6.3 Seminar programme

### ***UK HEALTH EQUITY NETWORK***

#### **Human rights, equity and health**

*Planning group:* Debbie Fox, Jeanelle de Gruchy, Eileen O’Keefe and Alex Scott-Samuel (convenor)

*Date:* March 28th 2003

*Venue:* Room D202, Clement House, London School of Economics

#### **Seminar objectives**

- to provide a general introduction to health and human rights (HHR) issues in the context of equity
- to set HHR in the UK (as well as the global) context
- to demonstrate that HHR relates to the audience’s work and experience
- to raise awareness about the value of using the human rights perspective to enhance action on health inequalities

#### **Programme**

*Chair:* Alex Scott-Samuel (University of Liverpool)

10.30 Introduction

Alex Scott-Samuel (University of Liverpool)

10.40 Human rights, health and equity

Paula Braveman (University of California at San Francisco)

11.30 Mental health rights and public safety

Jeanelle de Gruchy (London School of Hygiene and Tropical Medicine)

12.20 LUNCH

*Chair:* Debbie Fox (University of Liverpool)

1.30 Children’s rights and health inequality

Mike Jones (The Children’s Society)

2.20 African Londoners, HIV and human rights

Martha Chinouya (Ubuntu-Hunhu) and Eileen O’Keefe (London Metropolitan University)

3.10 Panel discussion

All speakers

4.00 CLOSE

## 6.4 Attendance List

### *HEN Seminar*

March 28th, 2003

### **Human Rights, Equity and Health**

*LSE, Clement House, Room D202*

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## 6.5 Useful websites

The Lord Chancellor's Department for Human Rights

*<http://www.humanrights.gov.uk/>*

Department of Health

*<http://www.doh.gov.uk/humanrights/>*

YourRights.org. the Liberty guide to Human rights

*<http://www.yourrights.org.uk/>*