



# The Equal Rights Review

*Promoting equality as a fundamental human right  
and a basic principle of social justice*

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- Special: The meaning of health equality
- Disability equality in Europe, South Africa and the UK
- Gender-based discriminatory ill-treatment in Moldova
- The "floating" Uyghurs in China
- Testimony from Bedouin women from Israel



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## A Right to Health Equality: What Does This Mean, Exactly?

If equality is understood as a fundamental human right and a basic principle of social justice (this is how it is described in the ERT mission statement), what does it mean in respect to health? How is health equality thinkable? In this issue of *The Equal Rights Review*, ERT searches for answers to this question.

In a double interview published inside this issue, two remarkable experts in health rights (Paul Hunt) and health policy (Norman Daniels) give us a taste of the legal, moral and political complexities surrounding this question. To the extent that the issue of health equality does not fall within any “discipline”, it has become a professional field in its own right that has attracted researchers and practitioners coming from many different angles: health policy experts, medics, philosophers, lawyers, economists, political scientists, etc. Reframed in the terms of human rights law, the question is what kind of an enforceable right to equality related to health is conferred to persons by the laws – as they are, or as they should be.

At minimum, a right to health equality includes a right to non-discrimination in relation to health. This can be understood in two senses: that health status is a protected **ground** of discrimination, or that discrimination on a protected ground (which can also be, incidentally, health status) is prohibited in the **area** of health. In the first sense, one’s

health condition should not be – as a general rule – a ground of discrimination in areas such as employment. For example, in *Hoffman v S. A. Airways* (2000) the South African Constitutional Court found that an airline, by maintaining a policy not to employ HIV-positive persons, was guilty of unfair discrimination on grounds of HIV/AIDS status. In the second sense, a person should not be discriminated against on a protected ground such as race, gender, or religion, in the area of health. For example, a hospital which ignores a call to send an ambulance to an ethnic minority neighbourhood, while it normally sends ambulances to other areas of the city for the same emergencies, would be guilty of race discrimination in the area of health. A service providing treatment for HIV/AIDS which is not as accessible to homosexuals as it is to heterosexuals *prima facie* discriminates on grounds of sexual orientation in the area of health.

But some difficult questions arise in relation to both types of discrimination. Regarding health status (as well as the related category of disability) as a protected ground, surely employers, service providers and others can’t be required to treat persons with different health conditions identically in all cases. A job may require an employee to have a health status that rules out certain conditions, be they of a sensory, physical or mental health nature. Still, there are rules to be

followed to ensure that different treatment which is unavoidable is not discriminatory. In recent years disability equality law, as shown in Jarlath Clifford's article in this issue, has developed progressive approaches to answering this type of questions, and has introduced the critical concept of reasonable accommodation as part of the right to equality.

Many moral and political puzzles exist also in respect of the right to non-discrimination in the area of health, including in the narrower area of healthcare – the services offering diagnostic, preventive, therapeutic or rehabilitative interventions. It may seem easy and unproblematic to ensure that such services do not discriminate on grounds of race, gender or religion, but problematic it is, as a closer look would reveal. For example, should the accommodating of religious needs in hospitals (special diet, religious or spiritual counsel, or expensive drugs, e.g. the genetically engineered version of Factor VII which is effective in causing rapid blood clotting and is required by a Jehovah's Witness awaiting serious surgery) be paid for out of public funds or should it be the responsibility of those concerned? It is even more challenging to determine what would amount to discrimination in healthcare on the grounds of disability or age, or indeed on the ground of health status! As early as 1984, Aaron and Schwartz showed that in the National Health Service (NHS) in Britain, there was no formal rationing rule about dialysis but an informal "understanding" that patients over 65 would not be given dialysis, and patients over 55 whose kidney failure was related to heart disease and diabetes would be ineligible. Was the NHS in this case discriminating on the ground of age? To take a more extreme case, is a person in a permanent vegetative state, or a person in stage 4 of Alzheimer, who is at risk of a fatal arrhythmia, equally entitled to

an ICD (implantable cardiac defibrillator) at a cost of \$40,000 as any other patient with the same risk? Or would the denial of ICD be discrimination on ground of disability?

From the unitary human rights perspective on equality, as expressed, *inter alia*, in the 2008 Declaration of Principles on Equality, the right to health equality is "bigger" than the right to non-discrimination on the ground or in the area of health. It includes an entitlement to such healthcare which enables the person to participate on an equal basis with others in economic, social, cultural, civil and political life, as required by Principle 1 of the Declaration of Principles on Equality. It also implies a duty of the authorities to develop a healthcare system aimed at realising this right. If health is not (just) a tradable commodity but a matter of rights and a public sector duty, it appears that equality in health is best promoted through a publicly funded health care system, as recommended by the WHO Commission on Social Determinants of Health. And while it may be futile to try to translate general principles on equality into more specific health policies and practices, the latter should be consistent with general principles on equality.

Among the central issues of healthcare equality, in particular related to equal access to healthcare, is the process of setting priorities in the distribution of healthcare resources, also known as healthcare "rationing". The term is controversial partly as a result of the continuing denial by many stakeholders that rationing exists. It is easy to deny the existence of rationing as in the most part it is invisible: there is no public scrutiny and those who make rationing decisions are rarely, if ever, accountable for the health consequences for individuals as well as segments of the population. As in a democratic society publicity is a precondition of justice, invisible

rationing is presumptively unjust. Rationing, while invisible, can be explicit (formulated in medical protocol) or implicit, as the shared “understanding” in the NHS mentioned above. But if we want to make rationing visible in the public eye, the critical question of course is who should be the decision-maker creating rationing protocols: the market, the politicians, administrative bodies, physicians’ committees, courts, the public? An example of rationing by court is the case *Soobramoney v Minister of Health (Kwazulu-Natal)*<sup>1</sup>, in which a diabetic who suffered from ischemic heart disease and cerebro-vascular disease and had an irreversible kidney failure was denied admission to the dialysis program of a state hospital because, due to scarce resources, the hospital had adopted a rationing policy that made him ineligible for dialysis. The Constitutional Court upheld the policy, but at the same time noted that the responsibility for making the difficult decisions of fixing the health budget and deciding upon the priorities that needed to be met lay with political bodies and the medical authorities and that the Court would be slow to interfere with such decisions if they were rational and taken in good faith. From the point of view of general principles on equality, the most attractive approach seems to be to entrust the rationing process to the public, through forms of democratic deliberation, as advocated by Daniels in a number of his books and in this issue – although this approach in turn carries serious risks, both in practical terms and through inherent limitations.

A further question of healthcare equality is what are the legitimate criteria on which rationing decisions should be based? Should the principle be to prioritise those who are the worst off – the most seriously ill? Or should the principle be to maximise the total benefits of healthcare expenditures, where cost-effectiveness would be measured in in-

dicators such as QALYs (quality-adjusted life years)? This last criterion may seem reasonable but would lead to many blatantly unjust or absurd results. It has been shown, for example, what kind of problems could occur if kidneys were distributed for transplantation most “efficiently”: as Veatch points out, the best way to get as much aggregate good as possible from the available kidneys is to distribute them only to Caucasian males as they do better (in terms of survival of the organ graft) due to some complicated tissue compatibility factors.<sup>2</sup> Most people would agree that this outcome of the cost-efficiency principle would be unfair. It is then interesting to ask whether it would be similarly unfair if a certain beneficial drug were offered only to categories of persons whose genetic predisposition is such that they have a three times higher chance to benefit from it. Would this not be discrimination on the ground of genetic predisposition? This is not a hypothetical example: in modern medicine, e.g. in cancer research, genetic predisposition to positively react to certain treatments is increasingly important.

There are many other questions regarding rationing: Should age matter? Should irresponsible behaviours and lifestyles that have resulted in illness be penalised? What to do with the so called “bottomless pits” – patients who have interrelated conditions likely to require a disproportionately higher number of costly interventions over long periods of time? How does the current (implicit or explicit) rationing work in our society at present? Is it just? And given the tremendous importance and inescapability of healthcare rationing for equality, the most striking question is why there is so little public discussion about it.

Another area of health equality that is of concern in this issue of *ERR* is related to the

social determinants of health, in recognition of the causal links between socio-economic status and health status. Studying the social determinants of health is an exercise in the indivisibility and inter-connectedness of human rights. As health depends on the enjoyment of many human rights, a person does not have an equal opportunity to be or remain healthy if he was born in an impoverished community, became a victim of violence, suffered harassment in school, or was treated unfairly when looking for a job. The lifetime risk of maternal death is one in eight in Afghanistan; it is one in 17,400 in Sweden. In the USA, 886,202 deaths would have been averted between 1991 and 2000 if mortality rates between whites and African Americans were equalised. This contrasts to 176,633 lives saved by medical advances in the same period. The prevalence of long-term disabilities among European men aged 80+ years is 58.8% among the lower educated versus 40.2% among the higher educated.<sup>3</sup> Furthermore, the relation between socioeconomic status and health is graded. In an example of what has been termed the “social gradient in health”, people in the second highest quintile

have higher mortality in their offspring than those in the highest quintile.<sup>4</sup> It has sometimes been asserted that life is a value of the highest order, an end in itself, and that it is therefore “priceless”. But in practice, as noted by Leonard Fleck, “the lives that are priceless are the lives of paytients [sic] – individuals who are very well insured, permitting them access to many very expensive, marginally beneficial medical interventions”.<sup>5</sup> How health insurance works in a given society is one of the best ways of revealing its structure of inequalities.

This issue of *ERR* is inspired by all of the above and similar questions. While there is a wealth of literature in political theory, health care policy, economics, social medicine and medical law addressing the central issues of relevance to health equality, an equality and human rights law approach is underdeveloped. But a rights-based holistic perspective should be integrated in the theoretical and practical search for health equality. Equal before the law, people should in some important sense of the word be equal before the doctor.

Dimitrina Petrova

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<sup>1</sup> Case CCT 32/97, decided on 27 November 1997.

<sup>2</sup> Veatch, R. M., *Patient, Heal Thyself: How the New Medicine Puts the Patient in Charge*, OUP, 2009, p. 55.

<sup>3</sup> Commission on Social Determinants of Health Final Report, *Closing the Gap in a Generation: Health Equity through Action on the Social Determinants of Health*, World Health Organisation 2008, p. 30.

<sup>4</sup> *Ibid.*, p. 31.

<sup>5</sup> Fleck, L. M., *Just Caring: Health Care Rationing and Democratic Deliberation*, OUP, 2009, p. viii.

# ARTICLES

*"Whether the Convention on the Rights of Persons with Disabilities will be able to fulfil its promise will depend on how national authorities grapple with complex issues such as legal capacity during implementation. In any case, the energy and vision that this Convention has imparted on the struggle for equality for persons with disabilities should not be underestimated."*

*Jarlath Clifford*



# The UN Disability Convention and its Impact on European Equality Law

Jarlath Clifford<sup>1</sup>

## Introduction

On 23 December 2010, the European Union (EU) ratified the United Nations Convention on the Rights of Persons with Disabilities (CRPD). It is the first time in its history that the EU has become a party to an international human rights treaty.<sup>2</sup> The CRPD was ratified just weeks after the European Commission published the European Disability Strategy 2010-2020 which sets out a detailed programme of action to empower people with disabilities so that they can enjoy their rights, and benefit fully from participating in society and in the European economy.<sup>3</sup>

Ratification means that the EU is now bound to ensure that the rights of persons with disabilities are respected, protected and fulfilled. It also mirrors the obligations of the 16 member states of the European Union that have ratified the CRPD and the remaining 11 that have signed it.<sup>4</sup> Since 2000, the EU has taken on an important role in setting down minimum standards with respect to disability discrimination law within member states. Alongside this, the European Court of Human Rights (ECtHR) has very recently handed down decisions which have broadened the scope of protection for persons with disabilities within the Council of Europe's borders. Yet, there are many issues relating to disability discrimination which are under-developed in comparison to other grounds of discrimination. This article, therefore, aims to examine some of the recent developments in relation to disability discrimination law

in Europe and explore the potential of the CRPD to improve equality outcomes for persons with disabilities.

Although some progress has been made to introduce legal safeguards to overcome discrimination against disabled people, part one of this article indicates that discrimination and intolerance are still widespread. Part two looks at the CRPD and highlights some of the key provisions for overcoming disabled persons' inequality. Finally, part three discusses the recent developments in European (both the EU and the Council of Europe) law and policy, and appraises the (potential) influence of the CRPD on regional mechanisms.

## 1. Discrimination and Intolerance against Persons with Disabilities in Europe

In the EU, one in six people - around 80 million - has a disability that ranges from mild to severe.<sup>5</sup> According to the Council of Europe Commissioner for Human Rights, this figure within the Council of Europe member states is between 10 and 15 percent of the population, i.e. between 80 and 120 million people.<sup>6</sup> The wide range of impairments that fall within the term "disability" make the definition far broader than that applying to any other vulnerable group. Persons with disabilities include persons with physical, mental,<sup>7</sup> intellectual<sup>8</sup> and sensory impairments. It is noteworthy that protection from discrimination

on grounds of disability is also often extended to persons living with medical conditions such as HIV/AIDS or diabetes on the basis of the discrimination which such persons are likely to experience following their diagnosis.<sup>9</sup>

While many disabled people may experience similar discriminatory treatment, the causes of disadvantage differ and depend on their individual impairment. For example, issues affecting the equality outcomes for a person who has schizophrenia may differ entirely to the issues that affect the equality outcomes for persons living with HIV/AIDS or those who have lost a limb or a sensory function. In light of this, the human rights definition of persons with disabilities contained in Article 1 of the CRPD offers a holistic approach to defining disability. Article 1 provides that:

“Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.”

The definition in Article 1 moves away from the historically dominant medical model of disability and towards the social model understanding of disability. In this understanding, “disabled people experience disability as a social restriction, whether those restrictions occur as a consequence of inaccessibly built environments, questionable notions of intelligence and social competence, the inability of the general population to use sign language, the lack of reading material in Braille or hostile public attitudes to people with non-visual disabilities”.<sup>10</sup>

A definition which is based on the individual experience is more capable of accurately framing discussions which are relevant to

disabled people, identifying hidden sources of discrimination and improving our understanding of human rights.<sup>11</sup> As a result of defining disability in a way that takes into consideration the impairment of the individual *and* the barriers that hinder their social participation (for example, environmental, built or human barriers), Article 1 of CRPD entitles a broad range of people who are vulnerable to discrimination on grounds of disability to protection.

Disability discrimination is a historical legacy which is ingrained in the fabric of all societies.<sup>12</sup> In Europe, this legacy is reflected in the continued acceptance of many practices that acutely discriminate against persons with disabilities. Persons with disabilities are often assumed to be incapable of undertaking productive work, attending schools on a level playing field with children without disabilities, or make active contributions to their communities, and often discussions on developing equalising measures for persons with disabilities are underpinned by such assumptions. According to the International Labour Organisation, in Europe, a person with a disability aged between 16 and 64 has a 66% chance of finding a job; this rate falls to 47% for a moderately disabled person and 25% for a person with a severe disability.<sup>13</sup> Further, inequality is not restricted to sectors such as employment. The European Union Fundamental Rights Agency has recently concluded that in 17 out of 27 EU member states, persons with mental health problems and persons with intellectual disabilities are excluded from political participation or are only permitted limited political participation.<sup>14</sup>

Another significant problem is the failure of persons without disabilities to consult or involve persons with disabilities in making decisions that have far-reaching consequences

for the latter. Since 2008, Thomas Hammarberg, the Council of Europe's Commissioner for Human Rights, has voiced concerns about the treatment of persons with disabilities on three separate occasions.<sup>15</sup> In 2009, he identified the need for greater action:

“During missions to Council of Europe member states I have had to conclude that persons with intellectual disabilities are still stigmatised and marginalised; that they are rarely consulted or even listened to; that a great number of them continue to be kept in old-style, inhuman institutions; and that moves to provide housing and other services in community-based settings have met obstacles and been delayed.”<sup>16</sup>

Yet symptoms of disability discrimination such as stigma, stereotyping and prejudice are still common and corrosive influences which marginalise persons with disabilities. These symptoms stifle clear and constructive thought about how processes and procedures could be made more accessible and inclusive for disabled people. For example, in many European countries disabled persons are marginalised from political and legal decision-making processes because of the historical perception that they do not have the capacity to be involved and actively participate.<sup>17</sup>

Of deeper concern is the stigma and prejudice which is frequently formalised in policy, resulting in egregious human rights violations against persons with disabilities in some countries. In the recent past, the European Committee on Social Rights has condemned the practice of segregating children with intellectual disabilities in educational institutions in France<sup>18</sup> and Bulgaria.<sup>19</sup> There has also been widespread media attention in the United Kingdom in respect to violent attacks on persons with learning disabili-

ties. In one widely reported case, a 64 year old man suffering from mental and learning difficulties died of a heart attack after being harassed and verbally abused by two youths in Manchester.<sup>20</sup> This case is not an isolated event. Instead, it represents a trend which demonstrates that intolerance toward disabled persons is growing and becoming more visible. One reason for this trend may be that violence against persons with disabilities is ignored, underestimated or misunderstood. The latest hate crimes report by the Organisation for Security and Cooperation in Europe (OSCE), which states that only nine European countries reported to the OSCE that they recorded any data on crimes against persons with disabilities, suggests that underreporting is a significant barrier too.<sup>21</sup> Consequently, the contention that ignorance or misunderstanding of the issue is a dominant factor which causes widespread discrimination must be matched with the fact that there is also a lack of effective monitoring and reporting of attacks.

## **2. The Unique Challenge of Disability and the UN Convention on the Rights of Persons with Disabilities**

The CRPD was adopted in 2006 and entered into force in 2008. Its purpose is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities.<sup>22</sup> It was the most rapidly negotiated human rights treaty to date<sup>23</sup> and, since its adoption, it has received impressive support globally.<sup>24</sup> Disabled people and disability organisations were key participants in influencing and drafting the CRPD.<sup>25</sup> This influence is visible not merely through the broad range of substantive rights the CRPD guarantees, including both civil and political rights<sup>26</sup> and socio-economic rights,<sup>27</sup> but also through the procedures it puts in place for mechanisms such

as monitoring.<sup>28</sup> Taking into consideration the scope of discrimination against persons with disabilities, we should highlight some of the CRPD's key provisions that will be important for combating disability discrimination throughout Europe.

### **2.1 Consultation and Involvement**

As discussed above, ignorance and misperceptions about the capabilities of persons with disabilities have propagated their exclusion from many areas of life in European societies. Lacking effective avenues of consultation or involvement, persons with disabilities are often denied the opportunity of participating in public decision-making processes and shaping key policy issues. The CRPD requires consultation and involvement through Article 4(3):

“In the development and implementation of legislation and policies to implement the present Convention, and in other decision-making processes concerning issues relating to persons with disabilities, States Parties shall closely consult with and actively involve persons with disabilities, including children with disabilities, through their representative organisations.”

Article 4(3) of the CRPD provides that meaningful consultation with and involvement of people with disabilities needs to be the starting point to developing legislation and policy to implement the Convention. Such consultation and involvement are crucial for creating laws and policies relating to disability issues. Indeed, even in respect to laws or policies that do not relate to disability issues, consultation mechanisms should aim to capture and reflect disabled peoples' views. Without effective consultation and involvement, persons with disabilities will inevitably be burdened with laws and procedures that do not

account for their individual experiences and that reproduce the paternalistic approach that has sustained historic disadvantage. For many law and policy makers, the principle of consultation and inclusion raises concerns about communication and sensitivity (not to mention funding); however, unless serious consultation and involvement procedures are ingrained into law and policy development processes, either through the direct participation of persons with disabilities or indirectly through representative organisations, effective equality will never be achieved.

### **2.2 Reasonable Accommodation**

Article 5(3) of the CRPD requires State Parties to take all appropriate steps to ensure that reasonable accommodation is provided for persons with disabilities in order to promote equality and eliminate discrimination. The CRPD also specifically requires that State Parties provide reasonable accommodation in respect to the right to liberty and security of the person,<sup>29</sup> the right to education<sup>30</sup> and the right to work and employment.<sup>31</sup> Reasonable accommodation is defined in Article 2 of the CRPD as follows:

“‘Reasonable accommodation’ means necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms.”

This definition is similar to but stronger and more far-reaching than the definition contained in Article 5 of the Council Directive 2000/78/EC of 27 November 2000, which, within the context of employment and occupation, requires that:

“[E]mployers shall take appropriate measures, where needed in a particular case, to enable a person with a disability to have access to, participate in, or advance in employment, or to undergo training, unless such measures would impose a disproportionate burden on the employer”.<sup>32</sup>

Although many states within the EU will have in place provisions to provide reasonable accommodation in employment and occupation, Article 5(3) of the CRPD creates a stronger and broader requirement. States Parties must take all appropriate reasonable accommodation steps to promote equality in the enjoyment and exercise by persons with disabilities of all human rights. In order to comply with the CRPD, States Parties bound by the Council Directive will now have to expand their legal provisions relating to reasonable accommodation for people with disabilities to cover areas outside employment and occupation.<sup>33</sup>

### 2.3 Legal Capacity

Article 12 is one of the most difficult but interesting and innovative aspects of the CRPD. Article 12 provides that:

“1. States Parties reaffirm that persons with disabilities have the right to recognition everywhere as persons before the law.

2. States Parties shall recognise that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life.

3. States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.

4. States Parties shall ensure that all measures that relate to the exercise of legal capacity provide for appropriate and effective safeguards to prevent abuse in accordance with international human rights law. Such safeguards shall ensure that measures relating to the exercise of legal capacity respect the rights, will and preferences of the person, are free of conflict of interest and undue influence, are proportional and tailored to the person's circumstances, apply for the shortest time possible and are subject to regular review by a competent, independent and impartial authority or judicial body. The safeguards shall be proportional to the degree to which such measures affect the person's rights and interests.”

Article 12 of the CRPD has a great potential to create positive change. The fact that many states continue to deny or restrict the legal capacity of persons with intellectual difficulties through court action is very problematic.<sup>34</sup> It has led to the restriction of basic rights without justification or review. For example, as the European Union Fundamental Rights Agency has reported, the majority of European Union Member States link the right to political participation to the legal capacity of the individual.<sup>35</sup> In view of the impact that the restriction of legal capacity can have on a person's exercise of their human rights, two questions are of central importance to understanding the scope of Article 12:

(1) Does Article 12 require States Parties to grant all persons with disabilities the legal capacity to act even where they are considered to lack capacity?

(2) If so, would this increase the risk of some persons with disabilities being vulnerable to people who would take advantage of their lack of capacity?

Paragraphs 3 and 4 of Article 12 provide guidance on these questions. Article 12(3) requires that states must put in place appropriate measures which support persons with disabilities in exercising their legal capacity; thus it is plain that Article 12 applies to all persons with disabilities regardless of the form of disability.<sup>36</sup> In cases of severe mental or intellectual impairment, appropriate measures may include electing a personal representative to support the person in taking decisions and exercising their legal capacity. Further, Article 12(4) provides that in such cases safeguards must be put in place to prevent abuse occurring within the exercise of legal capacity. So Article 12 requires State Parties to engage with the legal capacity issue positively by leaning toward supportive inclusion rather than automatic exclusion. As Gerard Quinn has commented:

“[I]ncapacity is not really a black and white issue, it is very much an individualised process. The first thing that a political authority should look to do is to put in the supports to enable individuals to make decisions, rather than take away this opportunity and do the easier thing of letting another person make the decision for them.”<sup>37</sup>

Therefore, Article 12 confronts the perception that persons with incapacity should not have a right to take decisions that may have a substantial effect on their lives. This, according to Gabor Gambos:

“[G]oes against a 2000 year old deep-rooted prejudice-based paradigm which says that there are people who are so disabled in their cognitive decision-making functions that they cannot exercise their autonomy, or their right to make their own choices, and that this right should be delegated to another person who will make decisions on their behalf.”<sup>38</sup>

The right to recognition everywhere as persons before the law required by Article 12(1) challenges the historical legacy of pervasive stereotyping, prejudice and stigma which has caused discrimination against disabled people. What is more, acting in combination with other provisions of the CRPD, for example Article 29,<sup>39</sup> Article 12 has the potential to play an instructive role in guiding legal reform and policy development. Article 12 offers a concrete set of standards which remoulds the relationship that persons with disabilities have with society by sending a clear message that persons with disabilities “enjoy legal capacity on an equal basis with others in all aspects of life”.

## 2.4 Violence and Abuse

Violence against persons with disabilities is an often overlooked issue when developing legal and policy measures to promote full and effective equality. Article 16 of the CRPD requires states to:

“[T]ake all appropriate legislative, administrative, social, educational and other measures to protect persons with disabilities, both within and outside the home, from all forms of exploitation, violence and abuse, including their gender-based aspects;<sup>40</sup> (...) take all appropriate measures to prevent all forms of exploitation, violence and abuse by ensuring, *inter alia*, appropriate forms of gender- and age-sensitive assistance and support for persons with disabilities and their families and caregivers;<sup>41</sup> (...) put in place effective legislation and policies (...) to ensure that instances of exploitation, violence and abuse against persons with disabilities are identified, investigated and (...) prosecuted<sup>42</sup>.”

The need for strong legal provisions, including a severe judicial response and enhanced penalties for hate crimes on a range of grounds including disability, has been identified by the Council of Europe's Commissioner for Human Rights.<sup>43</sup> Without effective provisions which require state authorities to prevent, prioritise and prosecute the violence and abuse targeted at persons with disabilities, efforts to document and report hate crimes are likely to fail. In several European countries, there are no laws in place which deal with aggravated offences on the grounds of disability and it appears that relatively few countries keep records of such crimes. In countries that have adopted such laws, for example the United Kingdom, it appears that both the reporting of these crimes and the rate of prosecution for reported crimes have been low.<sup>44</sup> Article 16 of the CRPD strengthens this area of disability equality law by placing strong obligations on States Parties to adopt law and policy measures aimed at protecting the safety of persons with disabilities. While adoption of legislation is an important first step, such laws require targeted awareness-raising campaigns to ensure that victims know their rights, understand the procedures for reporting abuse and violence and are comfortable in coming forward to report when they have been a victim of a crime. Alongside this, training and awareness-raising within the judiciary and law enforcement authorities would benefit victims with disabilities who report crimes in getting a fair shake within the criminal justice system. Part of the reason for the underreporting of violent attacks against persons with disabilities may be because there is an uncertainty among law enforcement authorities about how to deal with victims who have disabilities and are unable to express their experiences in a similar way to victims without disabilities. Consequently, when implementing

measures to protect persons with disabilities from violence and abuse, it is extremely important that training and awareness-raising measures among law enforcement officials are also put in place so that persons with disabilities can report crimes in a comfortable and sensitive environment which enables them to communicate their experiences effectively.

Law and policy development for some problematic issues, for example consultation or violence/hate crimes, can benefit from the lessons learnt during the successful implementation of mechanisms and safeguards in relation to discrimination on grounds of race or sex. Communication with some persons with disabilities remains a key issue in some areas. Therefore, it is important that processes are created which provide effective communication pathways for persons with disabilities. Other issues, for example, legal capacity and reasonable accommodation, are either unique to disability or have been traditionally perceived as disability issues. As such, they present greater practical and conceptual difficulties to law and policy makers. However, the CRPD sets clear and instructive standards which bind State Parties to adopt measures that improve the equality outcomes for persons with disabilities.

### **3. The Potential Impact of the CRPD on European Law and Policy**

#### **3.1 The European Union**

Anti-discrimination law in respect to disability was introduced in the European Union through the Council Directive 2000/78/EC of 27 November 2000 establishing a general framework for equal treatment in employment and occupation.<sup>45</sup> This Directive prohibited the direct and indirect discrimina-

tion, harassment and instruction to discriminate against disabled persons in the field of employment and occupation. In its early jurisprudence, the Court of Justice of the European Communities (ECJ) lent towards a medical definition of disability. Disability, the ECJ explained:

“[M]ust be understood as referring to a limitation which results in particular from physical, mental or psychological impairments and which hinders the participation of the person concerned in professional life. (...) However, by using the concept of ‘disability’ in Article 1 of that directive, the legislature deliberately chose a term which differs from ‘sickness’. The two concepts cannot therefore simply be treated as being the same.”<sup>46</sup>

Later jurisprudence has interpreted protection from discrimination on the ground of disability to include protection from discrimination by association on the ground of disability.<sup>47</sup> The practical implication of this decision is that now if persons without disabilities are discriminated against because of an association with a person with a disability - for example, a mother with caring responsibilities for her child who has a disability - they will be protected from discrimination under Article 2(a) of the Council Directive. The justification for this interpretation was made in the opinion of Advocate General Poiares Maduro:

“As stated, the effect of the Directive is that it is impermissible for an employer to rely on religion, age, disability and sexual orientation in order to treat some employees less well than others. To do so would amount to subjecting these individuals to unjust treatment and failing to respect their dignity and autonomy. This fact does not change in

cases where the employee who is the object of discrimination is not disabled herself. The ground which serves as the basis of the discrimination she suffers continues to be disability. **The Directive operates at the level of grounds of discrimination. The wrong that it was intended to remedy is the use of certain characteristics as grounds to treat some employees less well than others; what it does is to remove religion, age, disability and sexual orientation completely from the range of grounds an employer may legitimately use to treat some people less well.** Put differently, the Directive does not allow the hostility an employer may have against people belonging to the enumerated suspect classifications to function as the basis for any kind of less favourable treatment in the context of employment and occupation.”<sup>48</sup> (Emphasis added.)

Although the ECJ’s early interpretation of disability received some criticism for being overly medical, recent jurisprudence has grappled with key concepts and concerns for persons with disabilities in a progressive and welcome manner.

But what impact could the EU’s ratification of the CRPD have on the jurisprudence of the ECJ? In *Mangold v Helm* the ECJ referred to:

“[T]he source of the actual principle underlying the prohibition of those forms of discrimination [on the grounds of religion or belief, disability, age or sexual orientation] being found, as is clear from the third and fourth recitals in the preamble to the directive, in various international instruments and in the constitutional traditions common to the Member States.”<sup>49</sup>

Recital 4 of the Council Directive provides that the right of all persons to equality be-

fore the law and protection against discrimination:

“[C]onstitutes a universal right recognised by the Universal Declaration of Human Rights, the United Nations Convention on the Elimination of All Forms of Discrimination Against Women, the International Convention on the Elimination of all Forms of Racial Discrimination and the United Nations Covenants on Civil and Political Rights and on Economic, Social and Cultural Rights and by the European Convention for the Protection of Human Rights and Fundamental Freedoms, to which all Member States are signatories”.

The implication of ratifying the CRPD is that it must be read into Recital 4 of the Council Directive by the EU organs, including the ECJ. Therefore, the CRPD will form part of the foundation of the universal right to equality before the law and protection against discrimination. On this basis, the ECJ must seek consistency with the CRPD. In addition, with the entry into force of the Charter of Fundamental Rights of the European Union, the ECJ may be aided by the provisions of the CRPD in interpreting the scope of Article 21<sup>50</sup> and Article 26<sup>51</sup> of the Charter.

In relation to EU policy, the CRPD has had a major influence on the content of the European Disability Strategy 2010-2020.<sup>52</sup> The European Commission justified much of the strategy as necessary to effectively implement the CRPD in Europe and create consistency in EU disability policy. The strategy includes eight action points where EU level policy harmonisation is necessary.<sup>53</sup> Guided by the CRPD, the EU has undertaken to support and supplement national initiatives to implement the requirements of the CRPD through strategic action, including:

- Supporting and supplementing national policies and programmes to promote equality, for instance by promoting the conformity of Member State legislation on legal capacity with the CRPD; and
- Working where appropriate within a broader framework of non-discrimination to highlight disability as a human rights issue in the EU’s external action; raising awareness of the CRPD and the needs of people with disabilities, including accessibility, in the area of emergency and humanitarian aid; consolidating the network of disability correspondents; increasing awareness of disability issues in EU delegations; ensuring that candidate and potential candidate countries make progress in promoting the rights of people with disabilities.

In order to fully comply with the requirements of the CRPD, the EU will have to pass additional legislation to support Council Directive 2000/78/EC. Therefore, it is likely that the CRPD will provide the needed momentum for adopting a new anti-discrimination directive that would harmonise protection from discrimination on grounds of disability (and age, religion, sex, and sexual orientation) to the standards afforded to race. Given the commitment in Article 6(1) of the CRPD to combating multiple discrimination, the adoption of a new anti-discrimination directive seems to be the necessary starting point.

### 3.2 The Council of Europe

The European Court of Human Rights (ECtHR) has set an example which the ECJ should look to follow in respect to the CRPD. Benefitting from the standards contained in the CRPD, the ECtHR has pushed the issue of discrimination and intolerance against per-

sons with disabilities into focus in Strasbourg in two recent cases. In *Glor v Switzerland*,<sup>54</sup> the applicant, Swiss national Sven Glor, was deemed medically unfit to perform military service due to his diabetes. According to the Swiss authorities, his condition posed a problem on account of the particular restrictions related to military service including the limited access to medical care and medication, the significant physical efforts required and the psychological pressure exerted on military personnel. However, the authorities decided that Mr Glor's diabetes was not severe enough to relieve him from paying a non-negligible military service exemption tax on his annual earnings for several years. As a result, Mr Glor argued that he had been subjected to discrimination on the basis of his disability, contrary to Article 14 together with Article 8 of the European Convention on Human Rights (ECHR), because he had been prohibited from carrying out his military service, and was obliged to pay the exemption tax as his disability was judged not to be severe enough for him to forgo the tax.

While Article 14 of the ECHR contains an "other status" clause whereby a non-listed ground could be read into the right to non-discrimination, prior to *Glor v Switzerland* the ECtHR had never before found a violation of the right to non-discrimination on the basis of disability. It is also significant that the ECtHR concluded that diabetes constituted a disability. In handing down its decision, the ECtHR condemned disability discrimination committed by the Swiss authorities through failing to provide reasonable accommodation to Mr Glor by finding a solution which responded to his individual circumstances. The judgment is also praiseworthy for noting that the CRPD signalled the existence of a European and universal consensus on the need to protect persons with disabilities from dis-

crimatory treatment. This note was made in spite of the fact that Switzerland had not signed the CRPD.

The ECtHR built on the *Glor* decision in its 2010 judgment of *Alajos Kiss v Hungary*.<sup>55</sup> The applicant in this case suffered from manic depression and had for that reason been placed under partial guardianship. The Hungarian Constitution contained an absolute voting ban for people put under guardianship. Consequently, the applicant could not vote in the 2006 parliamentary elections. The ECtHR held unanimously that such an absolute ban violated the right to free elections of Article 3 of Protocol 1 ECHR. In reaching its decision the court stated:

"The Court further considers that the treatment as a single class of those with intellectual or mental disabilities is a questionable classification and **the curtailment of their rights must be subject to strict scrutiny**. This approach is reflected in other instruments of international law (...). The Court therefore concludes that an indiscriminate removal of voting rights, without an individualised judicial evaluation and solely based on a mental disability necessitating partial guardianship, cannot be considered compatible with the legitimate grounds for restricting the right to vote."<sup>56</sup> (Emphasis added.)

By stating that the curtailment of the rights of persons with intellectual or mental disabilities must be subject to strict scrutiny, the ECtHR indicated that a very high threshold must be met in order for it to be justified. Past decisions of the ECtHR have used this level of scrutiny in limited circumstances which apply to distinctions made on grounds such as race or sex.<sup>57</sup> The CRPD was a cornerstone of the ECtHR's finding that the same

level of scrutiny should be used to assess distinctions made on the ground of disability.<sup>58</sup>

The strength of the ECtHR's case law on discrimination and intolerance against persons with disabilities will surely be tested in the near future. For example, the record of interpreting the ECHR consistently with the standards contained in the CRPD is likely to be tested in the forthcoming case of *Kiyutin v Russia*.<sup>59</sup> In this case, the applicant is a national of Uzbekistan who lives in the Oryol region of Russia. He is married to a Russian national with whom he has a young child. Mr Kiyutin's application for a residence permit was however rejected by the Russian authorities on account of his HIV-positive status. According to Russia's Law on the Legal Status of Foreign Nationals, foreigners wishing to stay in the country long-term must demonstrate that they are HIV-negative. In his application to the ECtHR, Mr Kiyutin has argued that the rejection of his application for a residency permit violates his right to respect for his family life as well as his right to non-discrimination on the basis of HIV status (Article 14 of the ECHR in conjunction with Article 8). NGOs intervening in the case have argued that the right to equality and non-discrimination, set out in Article 5 of the CRPD, protects persons living with HIV/AIDS.<sup>60</sup> If the ECtHR accepts the applicant's position, it will represent not only a forceful use of the CRPD to interpret the ECHR but it will also open up an added dimension by protecting persons living with HIV/AIDS through the right to non-discrimination on grounds of disability.

It is unsurprising that the recent strengthening of ECHR jurisprudence in respect to disability has occurred shortly after the entry into force of the CRPD. A significant number of the countries which are bound by the ECHR are also parties to the CRPD and there ap-

pears to be an overarching consensus among these countries that disability rights must be promoted, protected and fulfilled. Admittedly, at times the ECtHR plays the role of a consensus-builder in reaching its decisions.<sup>61</sup> Hopefully, now that a consensus already exists around the CRPD, the ECtHR will be in a better position when calling to order states that discriminate against persons with disability and violate their basic human rights.

In its short lifetime, the CRPD has already added an extremely important new dimension to the fight against discrimination on grounds of disability in Europe. It has consolidated legal concepts such as reasonable accommodation, guided the jurisprudence of the ECtHR and energised European countries to develop new safeguards and measures to entrench disability rights and promote effective equality for persons with disabilities. Whether the ECJ will follow the example of the ECtHR and take into consideration the CRPD when handing down decisions on disability-related issues is yet to be tested. However, in light of the increased protection from discrimination and the promotion of equality on the ground of disability required by the Charter of Fundamental Rights of the European Union, one would expect that the CRPD would be a natural source of guidance.

## Conclusion

The CRPD has been described as "a paradigm shift" in relation to how human rights are to be understood in the 21<sup>st</sup> century.<sup>62</sup> This would be a significant burden to bear for any piece of international law, let alone a law which protects the rights of individuals who have for so long been overlooked in society. Yet in the short period since its entry into force, the impact of the CRPD offers much promise.

In Europe, it has been accepted almost universally that there is a need for strong human rights protection for persons with disabilities. The CRPD has already begun to shape EU policy and ECtHR jurisprudence and in many areas it is proving to be a key instrument for promoting law reform and requiring states to re-examine how persons with disabilities are perceived. Often it has asked fundamental questions of the paternalistic welfare policy adopted by most European countries towards disabled persons. Nonetheless, in Europe paternalistic rhetoric still underpins disability law, policy and practice. Consequently, these strategic developments will only lead to effective equality for persons with disabilities in key areas such as education, healthcare, criminal justice and political participation once the initial enthusiasm and goodwill shown to the CRPD is transformed through the difficult task of putting in place practical solutions for the challenges encountered by persons with disabilities.

Undoubtedly, a global convention on disability was needed due to the large gaps that existed in national, regional and international human rights and non-discrimination protection. This article has argued that the CRPD has started to influence the European Union and the Council of Europe mechanisms and institutions. But such mechanisms should have an impact on law and policy development at local levels. At these local levels it is clear that discrimination and intolerance against persons with disabilities is still pervasive throughout Europe. Whether the CRPD will be able to fulfil its promise will depend on how national authorities grapple with complex issues such as legal capacity during implementation. In any case, the energy and vision that the CRPD has imparted on the struggle for equality for persons with disabilities should not be underestimated.

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<sup>1</sup>Jarlath Clifford is a consultant for The Equal Rights Trust. This article is based on a presentation given at a conference on "Legal Problems of the Prohibition and Prevention of Xenophobia and Other Forms of Intolerance" held at the University of Vilnius, Lithuania, on 19 November 2010. The author thanks Amal de Chickera for comments on an earlier draft of this article.

<sup>2</sup>European Commission, *EU ratifies UN Convention on disability rights*, Press Release, Brussels, 5 January 2010, available at: <http://europa.eu/rapid/pressReleasesAction.do?reference=IP/11/4&format=HTML&aged=0&language=EN&guiLanguage=en>.

<sup>3</sup>European Commission, *European Disability Strategy 2010-2020: A Renewed Commitment to a Barrier-Free Europe*, SEC(2010) 1324 final, Brussels, 15 November 2010, available at: <http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=SEC:2010:1324:FIN:EN:PDF>.

<sup>4</sup>Similarly, in the Council of Europe, 26 Member States have ratified the CRPD, 19 have signed it and only two states have neither signed nor ratified it.

<sup>5</sup>See above, note 3.

<sup>6</sup>Council of Europe Commissioner for Human Rights, *Human Rights and Disability: Equal Rights for All*, ComDH/IssuePaper (2008)2, Strasbourg, 20 October 2008, available at: <https://wcd.coe.int/wcd/ViewDoc.jsp?id=1355349&Site=CM>.

<sup>7</sup> For example, schizophrenia or bipolar disorder.

<sup>8</sup> For example, learning limitations caused by Down's Syndrome.

<sup>9</sup> In Britain, HIV infection constitutes a disability under Schedule 1, Part 1, Para 6 of the Equality Act 2010. Further, the European Court of Human Rights has held that discrimination against a person living with diabetes constituted discrimination on the ground of disability in the case of *Glor v Switzerland*, Application No. 13444/04, 30 April 2009.

<sup>10</sup> Scotch, R. K., "Models of Disability and the Americans with Disabilities Act", *Berkeley Journal of Employment and Labor Law*, Vol. 21(1), 2000, p. 215.

<sup>11</sup> Many questions remain unresolved in relation to the nature and scope of state obligations for protecting the human rights of persons with disabilities. For example, on 11 December 2007, the Office of the High Commissioner for Human Rights convened an expert seminar, in collaboration with the Special Rapporteur on Torture, and the Committee against Torture, entitled "Freedom from torture and other cruel, inhuman and degrading treatment and punishment and persons with disabilities", which tried to clarify issues of discriminatory ill-treatment of persons with disability. The final report of the seminar is available at: <http://www2.ohchr.org/english/issues/disability/torture.htm>.

<sup>12</sup> Colin Barnes, for example, argues that institutional discrimination is embedded in the excessive paternalism of contemporary welfare systems which systematically ignore or inadequately meet the needs of disabled people. See Barnes, C., *Institutional Discrimination Against Disabled People: A Case for Legislation*, British Council of Organisations of Disabled People, London, 1991.

<sup>13</sup> International Labour Organisation, *Factsheet: Discrimination at Work in Europe*, available at: [http://www.ilo.org/wcmsp5/groups/public/---ed\\_norm/---declaration/documents/publication/wcms\\_decl\\_fs\\_90\\_en.pdf](http://www.ilo.org/wcmsp5/groups/public/---ed_norm/---declaration/documents/publication/wcms_decl_fs_90_en.pdf).

<sup>14</sup> European Union Agency for Fundamental Rights, *The Right to Political Participation of Persons with Mental Health Problems and Persons with Intellectual Disabilities*, October 2010, available at: [http://www.fra.europa.eu/fraWebsite/attachments/Report-vote-disability\\_EN.pdf](http://www.fra.europa.eu/fraWebsite/attachments/Report-vote-disability_EN.pdf).

<sup>15</sup> See Council of Europe Commissioner for Human Rights, "Persons with mental disabilities should be assisted but not deprived of their individual human rights", *Viewpoints*, 21 September 2009, available at: [http://www.coe.int/t/commissioner/Viewpoints/090921\\_en.asp](http://www.coe.int/t/commissioner/Viewpoints/090921_en.asp); *idem*, "A neglected human rights crisis: persons with intellectual disabilities are still stigmatised and excluded", *Viewpoints*, 14 September 2009, available at: [http://www.coe.int/t/commissioner/Viewpoints/090914\\_en.asp](http://www.coe.int/t/commissioner/Viewpoints/090914_en.asp); *idem*, "Respect and rights-based action instead of charity for people with disabilities", *Viewpoints*, 20 October 2010, available at: [http://www.coe.int/t/commissioner/Viewpoints/081020\\_en.asp](http://www.coe.int/t/commissioner/Viewpoints/081020_en.asp).

<sup>16</sup> Council of Europe Commissioner for Human Rights, "A neglected human rights crisis: persons with intellectual disabilities are still stigmatised and excluded", note 15 above.

<sup>17</sup> For example, Belgium, Czech Republic, Germany, Ireland, Poland and Portugal exclude persons with mental health problems and persons with disabilities from the right to political participation. See above, note 14.

<sup>18</sup> See European Committee on Social Rights, *International Association Autism Europe v France*, Complaint No. 13/2002, 4 November 2003.

<sup>19</sup> European Committee on Social Rights, *Mental Disability Advocacy Centre (MDAC) v Bulgaria*, Complaint No. 41/2007, 3 June 2008. In this case the European Committee on Social Rights handed down the opinion that a failure to take appropriate measures to take account of existing differences may amount to discrimination. Consequently, the Committee found a violation of Article 17 (2) of the Revised European Social Charter read in conjunction with Article E because of the discrimination against children with moderate, severe or profound intellectual disabilities residing in homes for mentally disabled children as a result of the low number of such children receiving any type of education when compared to other children.

<sup>20</sup> See Shakespeare, T., "The Cruel Toll of Disability Hate Crime", Comment is Free, Guardian Newspaper (Online Edition), 12 March 2010, available at: <http://www.guardian.co.uk/commentisfree/2010/mar/12/disability-hate-crime-david-askew>.

<sup>21</sup> The nine countries are Belgium, Cyprus, Finland, France, Georgia, Germany, Moldova, the Netherlands, and the United Kingdom. See Organisation for Security and Cooperation in Europe, *Hate Crimes in the OSCE Region - Incidents and Responses: Annual Report for 2009*, Office for Democratic Institutions and Human Rights, October 2010, available at: <http://www.osce.org/odihr/documents/73636>.

<sup>22</sup> CRPD, Article 1.

<sup>23</sup> United Nations, *Convention on the Rights of Persons with Disabilities: Advocacy Toolkit*, 1 July 2008, available at: [http://www2.ohchr.org/english/issues/disability/docs/CRPD\\_Advocacy\\_Tool.pdf](http://www2.ohchr.org/english/issues/disability/docs/CRPD_Advocacy_Tool.pdf).

<sup>24</sup> A list of the states that have signed and ratified the CRPD is available at: [http://treaties.un.org/Pages/ViewDetails.aspx?src=TREATY&mtdsg\\_no=IV-15&chapter=4&lang=en](http://treaties.un.org/Pages/ViewDetails.aspx?src=TREATY&mtdsg_no=IV-15&chapter=4&lang=en).

<sup>25</sup> De Burca states that the drafting process of the CRPD, both substantively and procedurally, was driven by factors such as the central role of NGOs and other non-state actors in the negotiation process. See De Burca, G., "The EU in the negotiation of the UN Disability Convention", *Fordham Law Legal Studies Research Paper No. 1525611*, available at: [http://papers.ssrn.com/sol3/papers.cfm?abstract\\_id=1525611](http://papers.ssrn.com/sol3/papers.cfm?abstract_id=1525611). See also Stein, M., "Jacobus tenBroek, Participatory Justice, and the UN Convention on the Rights of Persons with Disabilities", *Texas Journal on Civil Liberties & Civil Rights*, 2008, Vol. 13, p.167 (William & Mary Law School Research Paper No. 9-36).

<sup>26</sup> See, for example, CRPD, Article 14 (Liberty and Security of the Person).

<sup>27</sup> See, for example, CRPD, Article 24 (Education). An overarching challenge to fulfilling the human rights of persons with disabilities, regardless of whether they are civil, political, social or economic is that it often requires states to take steps which result in significant public expenditure. But it should be emphasised that the social and economic rights of persons with disabilities are indivisible from all other human rights and are necessary in order to overcome the historical disadvantage of persons with disabilities. Consequently, the public expenditure argument must not be allowed to justify the failure to promote, protect and fulfil these rights.

<sup>28</sup> See CRPD, Article 33 (National implementation and monitoring), and note that Article 33(3) provides that civil society, in particular persons with disabilities and their representative organisations, shall be involved and participate fully in the monitoring process.

<sup>29</sup> CRPD, Article 14(2).

<sup>30</sup> CRPD, Article 24(2)(c) and Article 24(5).

<sup>31</sup> CRPD, Article 27(i).

<sup>32</sup> Council Directive 2000/78/EC of 27 November 2000 establishing a general framework for equal treatment in employment and occupation, Article 5.

<sup>33</sup> For example, in the British Equality Act 2010, there is a duty to make reasonable adjustments (reasonable accommodation) for persons with disabilities in areas outside employment, including housing and education. However, this is hardly sufficient to ensure equal rights in all areas of life, including civil, political, economic, social and cultural.

<sup>34</sup> For an example on how legal capacity is denied or restricted is the Czech Republic, see Inclusion Europe, *Legal capacity and guardianship procedures, Czech Republic: Summary*, available at: [http://www.inclusion-europe.org/Justice/CZ/EN\\_NC\\_CZ.pdf](http://www.inclusion-europe.org/Justice/CZ/EN_NC_CZ.pdf).

<sup>35</sup> See above, note 14.

<sup>36</sup> See *Legal Opinion on Article 12 of the CRPD*, 21 June 2008, available at: [http://www.leeds.ac.uk/disability-studies/archiveuk/legal%20opinion/LegalOpinion\\_Art12\\_FINAL.pdf](http://www.leeds.ac.uk/disability-studies/archiveuk/legal%20opinion/LegalOpinion_Art12_FINAL.pdf).

<sup>37</sup> The Equal Rights Trust, "Interview: Promoting a Paradigm Shift: ERT talks with Gabor Gombos and Gerard Quinn about the UN Convention on the Rights of Persons with Disabilities and its Optional Protocol", *The Equal Rights Review*, Vol. 2, 2008, p. 90, available at: [http://www.equalrightstrust.org/ertdocumentbank/err\\_issue02%20reduced.pdf](http://www.equalrightstrust.org/ertdocumentbank/err_issue02%20reduced.pdf).

<sup>38</sup> *Ibid.*

<sup>39</sup> CRPD, Article 29 (Participation in political and public life) requires states to: "[e]nsure that persons with disabilities can effectively and fully participate in political and public life on an equal basis with others"; ensure "that voting procedures, facilities and materials are appropriate, accessible and easy to understand and use"; protect "the right of persons with disabilities to vote by secret ballot in elections and public referendums without intimidation, and to stand for elections, to effectively hold office and perform all public functions at all levels of government"; and "[p]romote actively an environment in which persons with disabilities can effectively and fully participate in the conduct of public affairs, without discrimination and on an equal basis with others, and encourage their participation in public affairs".

<sup>40</sup> CRPD, Article 16(1).

<sup>41</sup> CRPD, Article 16(2)

<sup>42</sup> CRPD, Article 16(5).

<sup>43</sup> See Council of Europe Commissioner for Human Rights, "Hate crimes – the ugly face of racism, anti-Semitism, anti-Gypsyism, Islamophobia and homophobia", *Viewpoints*, 21 July 2008, available at: [http://www.coe.int/t/commissioner/Viewpoints/080721\\_en.asp](http://www.coe.int/t/commissioner/Viewpoints/080721_en.asp).

<sup>44</sup> See Disability Now, *The Hate Crime Dossier*, available at: <http://www.disabilitynow.org.uk/the-hate-crime-dossier>.

<sup>45</sup> See above, note 33.

<sup>46</sup> *Sonia Chacón Navas v Eures Colectividades SA*, Case C-13/05, 11 July 2006, Paras 43 – 44. See also Bell, M., "Advancing EU Anti-Discrimination Law: the European Commission's 2008 Proposal for a New Directive", *The Equal Rights Review*, Vol. 3, 2009, pp. 7 – 18.

<sup>47</sup> *Coleman v Attridge Law and Steve Law*, Case C-303/06, 17 July 2008.

<sup>48</sup> Opinion of Advocate General Poiares Maduro, delivered on 31 January 2008, in *Coleman v Attridge Law and Steve Law*, Case C-303/06, Para 22.

<sup>49</sup> *Mangold v Helm*, Case C-144/04, 22 November 2002, Para 74.

<sup>50</sup> Article 21 of the Charter of Fundamental Rights of the European Union states: "1. Any discrimination based on any ground such as sex, race, colour, ethnic or social origin, genetic features, language, religion or belief, political or any other opinion, membership of a national minority, property, birth, disability, age or sexual orientation shall be prohibited. 2. Within the scope of application of the Treaty establishing the European Community and of the Treaty on European Union, and without prejudice to the special provisions of those Treaties, any discrimination on grounds of nationality shall be prohibited." See *Official Journal of the European Communities*, 18 December 2000, C 364/13.

<sup>51</sup> Article 26 of the Charter of Fundamental Rights of the European Union states: "The Union recognises and respects the right of persons with disabilities to benefit from measures designed to ensure their independence, social and occupational integration and participation in the life of the community." See *Official Journal of the European Communities*, 18 December 2000, C 364/14.

<sup>52</sup> Furthermore, within the Council of Europe, clear parallels exist between the CRPD and the Committee of Ministers Recommendation Rec(2006)5 of the Committee of Ministers to member states on the Council of Europe Action Plan to promote the rights and full participation of people with disabilities in society: improving the quality of life of people with disabilities in Europe 2006-2015, 5 April 2006.

<sup>53</sup> The eight main areas for action are: accessibility, participation, equality, employment, education and training, social protection, health, and external action.

<sup>54</sup> See above, note 9.

<sup>55</sup> *Alajos Kiss v Hungary*, Application no. 38832/06, 20 May 2010.

<sup>56</sup> *Ibid.*, Para 44.

<sup>57</sup> See, for example, *Abdulaziz, Cabales, and Balkandali v UK*, Application nos. 9214/80, 9473/81, and 9474/81, 28 May 1985, in relation to sex; and *Nachova and Others v Bulgaria*, Application nos. 43577/98 and 43579/98, 6 July 2005, in relation to race.

<sup>58</sup> See above, note 55, Para 44 in conjunction with Para 14.

<sup>59</sup> *Kiyutin v Russia*, Application no. 2700/10. See third party legal submission by Interights, available at: <http://www.interights.org/documentbank/index.htm?id=588>. 60 *Ibid.*

<sup>61</sup> See Letsas, G., "The Truth in Autonomous Concepts: How to Interpret the ECtHR", *European Journal of International Law*, Vol. 15, 2004, pp. 279–305; see also Wintemute, R., "Consensus is the right approach for the European Court of Human Rights", *Comment is Free*, Guardian Newspaper (Online Edition), 12 August 2010, available at: <http://www.guardian.co.uk/law/2010/aug/12/european-court-human-rights-consensus>.

<sup>62</sup> See above, note 23.

# Discriminatory Ill-Treatment of Women in Moldova

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## Introduction

One of the most serious human rights problems in the Republic of Moldova at present is the prevalence of a range of abuses which can be characterised as discriminatory ill-treatment.<sup>2</sup> Instances of discriminatory ill-treatment are often not recognised as such by the Moldovan public authorities. The ill-treatment involved is not seen as resulting from the victims' membership of certain groups, whether they be women, persons with disabilities, LGBT persons, or another vulnerable group. Even when this is recognised, the lack of experience or understanding of such cases results in public prosecutors being unfamiliar with the legislation applicable in such cases, while investigators may not have the skills and knowledge necessary to build the strongest possible cases in support of the victims. Such a failure to understand fully the nature of these types of cases hampers attempts to secure adequate legal redress for the victims involved. More generally, it is no doubt clear that the task of preventing discriminatory ill-treatment in society is all the more difficult so long as the phenomenon itself is unknown to, or misunderstood by, the public authorities.

Being a party to most of the main human rights treaties of the United Nations and the Council of Europe, Moldova still falls behind in its efforts to effectively prevent all forms of ill-treatment within its jurisdiction. In re-

cent reports on the human rights situation in Moldova, UN treaty bodies and Special Rapporteurs have highlighted that gender, race, disability, religion and perceptions based on stereotyping were all causes of ill-treatment.<sup>3</sup> This widespread problem is compounded by a lack of relevant expertise within the civil society sector. There are very few non-governmental organisations in Moldova with experience of representing victims of discriminatory ill-treatment, or of lobbying the public authorities on this issue.

This article examines the specific phenomenon of discriminatory ill-treatment against women in Moldova, with reference to research and casework carried out recently by The Promo-LEX Association (Promo-LEX).<sup>4</sup>

## 1. Obligations under International and Regional law

Moldova has ratified several major international and regional human rights instruments. It is a signatory to eight of the nine core UN human rights treaties,<sup>5</sup> with the one exception being the International Convention on the Protection of the Rights of All Migrant Workers and Members of their Families. Moldova has also yet to ratify the International Convention for the Protection of All Persons from Enforced Disappearance.

The most relevant of Moldova's international obligations under these treaties relating to the discriminatory ill-treatment of women are found in the International Covenant on Civil and Political Rights (ICCPR), the Convention Against Torture and Inhuman and Degrading Treatment and Punishment (CAT) and the Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW). In addition, Moldova has also adopted significant obligations relating to discriminatory ill-treatment under the European Convention for the Protection of Human Rights and Fundamental Freedoms (ECHR).

In 1993, Moldova acceded to the ICCPR. Under Article 2 of ICCPR, Moldova is obliged to guarantee all rights under the Covenant "without distinction of any kind, such as race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status", and under Article 26, Moldova is obliged to "prohibit any discrimination and guarantee to all persons equal and effective protection against discrimination on any ground such as race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status". Gender equality is further protected by Article 3 which obliges States Parties to ensure "the equal rights of men and women to the enjoyment of all civil and political rights". Article 7 of the ICCPR sets out Moldova's obligations regarding the prevention of torture and cruel, inhuman or degrading treatment or punishment. In its General Comment 28, the Human Rights Committee provides guidance for the interpretation and application of Article 3 of the ICCPR.<sup>6</sup> It provides examples of gender-based discriminatory ill-treatment which include female infanticide, the burning of widows and dowry killings,<sup>7</sup> domestic and other types of violence against women, including rape, forced abortion or forced sterilisation,

genital mutilation<sup>8</sup>, trafficking and forced prostitution.<sup>9</sup>

Moldova acceded to CEDAW in 1994. Under Article 2 of CEDAW, Moldova has condemned discrimination against women and agreed to "pursue by all means and without delay a policy of eliminating discrimination against women" through undertaking various measures listed in that article. General Recommendation 19 issued by the Committee on the Elimination of Discrimination against Women addresses the issue of Violence against Women.<sup>10</sup> It confirms that "gender-based violence is a form of discrimination that seriously inhibits women's ability to enjoy rights and freedoms on a basis of equality with men",<sup>11</sup> and that the full implementation of CEDAW requires States Parties to take positive measures to eliminate all forms of violence against women.<sup>12</sup> General Recommendation 19 explains that gender-based violence "includes acts that inflict physical, mental or sexual harm or suffering, threats of such acts, coercion and other deprivations of liberty".<sup>13</sup> It also clarifies that the obligation of States Parties to protect individuals from gender-based violence is not restricted to protection from violence perpetrated by or on behalf of the state. States Parties "may also be responsible for private acts if they fail to act with due diligence to prevent violations of rights or to investigate and punish acts of violence, and for providing compensation".<sup>14</sup> General Recommendation 19 also provides examples of gender-based violence, including:

i) Family violence and abuse, forced marriage, dowry deaths, acid attacks, female circumcision;<sup>15</sup>

ii) Trafficking and exploitation of the prostitution of women;<sup>16</sup>

iii) Sexual harassment in the workplace;<sup>17</sup>

iv) Compulsory sterilisation and abortion;<sup>18</sup> and

v) Family violence, including battering, rape, other forms of sexual assault, mental and other forms of violence, which are perpetuated by traditional attitudes.<sup>19</sup>

In conclusion to General Recommendation 19, the Committee on the Elimination of Discrimination against Women makes a series of specific recommendations, including:

“(a) States Parties should take appropriate and effective measures to overcome all forms of gender-based violence, whether by public or private act;

(b) States Parties should ensure that laws against family violence and abuse, rape, sexual assault and other gender-based violence give adequate protection to all women, and respect their integrity and dignity. Appropriate protective and support services should be provided for victims. Gender-sensitive training of judicial and law enforcement officers and other public officials is essential for the effective implementation of the Convention;

(c) States Parties should encourage the compilation of statistics and research on the extent, causes and effects of violence, and on the effectiveness of measures to prevent and deal with violence;

(d) Effective measures should be taken to ensure that the media respect and promote respect for women;

(...)

(g) Specific preventive and punitive measures are necessary to overcome trafficking and sexual exploitation;

(h) States Parties in their reports should describe the extent of all these problems and the measures, including penal provisions, preventive and rehabilitation measures that have been taken to protect women engaged in prostitution or subject to trafficking and other forms of sexual exploitation. The effectiveness of these measures should also be described;

(...)

(k) States Parties should establish or support services for victims of family violence, rape, sexual assault and other forms of gender-based violence, including refuges, specially trained health workers, rehabilitation and counselling.”<sup>20</sup>

In 1995, Moldova acceded to CAT and, in so doing, assumed obligations to protect individuals within its territory from treatment which meets the thresholds of “torture”<sup>21</sup> or “cruel, inhuman or degrading treatment”.<sup>22</sup> As part of the commitment to protect individuals within its territory from such treatment, Moldova has also assumed obligations to impose appropriate penalties against those responsible for carrying out such treatment.<sup>23</sup> In its General Comment 2, the UN Committee against Torture states that:

“Non-discrimination is included within the definition of torture itself in article 1, paragraph 1 of the Convention, which explicitly prohibits specified acts when carried out for ‘*any reason based on discrimination of any kind.....*’. The Committee emphasises that the discriminatory use of mental or physical violence or abuse is an important factor in determining whether an act constitutes torture.”<sup>24</sup>

In addition to its obligations under the aforementioned international treaties, as a signa-

tory of the ECHR,<sup>25</sup> in relation to discriminatory ill-treatment, Moldova is obliged to secure the following rights to individuals within its jurisdiction:

a) Protection from being subjected to torture or to inhuman or degrading treatment or punishment;<sup>26</sup> and

b) The right to enjoy all of the rights and freedoms set out in the convention “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”.<sup>27</sup>

## 2. Current Situation in Moldova

### 2.1 Domestic Law

Moldova lacks a comprehensive non-discrimination legislation which provides definitions of direct and indirect discrimination, as well as provisions on adequate sanctions, compensation and on shared burden of proof. However, in relation to discrimination against women, the Parliament of Moldova approved the Law No. 5-XVI on Ensuring Equal Opportunities for Men and Women (Law No. 5-XVI) on 9 February 2006.<sup>28</sup> Article 1 of Law No. 5-XVI stipulates that the purpose of the law is to ensure equal rights to women and men in political, economic, social, cultural and other spheres of life - rights guaranteed by the Constitution of the Republic of Moldova<sup>29</sup> - in order to prevent and eliminate all forms of gender-based discrimination. Law No. 5-XVI has therefore become the legal platform for the development of a national mechanism for the integration of gender perspectives at all levels, and also for the implementation of the National Plan of Action on Gender Promotion in 2006-2009, which was adopted in August 2006.<sup>30</sup>

Law No. 5-XVI provides definitions relevant to discrimination of women, including the “comprehensive approach to equality between women and men”;<sup>31</sup> “affirmative action”;<sup>32</sup> “gender-based discrimination”;<sup>33</sup> “direct discrimination on grounds of sex”;<sup>34</sup> “indirect discrimination on grounds of sex”;<sup>35</sup> “equal opportunities”;<sup>36</sup> “equality between women and men”;<sup>37</sup> “gender”;<sup>38</sup> “sexual harassment”;<sup>39</sup> “sex”;<sup>40</sup> and “gender unit”.<sup>41</sup> Article 5 of Law No. 5-XVI prohibits discrimination on grounds of sex. Article 15 places responsibility for ensuring equality between women and men with the following state entities: (i) Parliament; (ii) the Government; (iii) the Governmental Committee for equality between women and men; (iv) the Ministry of Health (specialised body); and (v) the gender units of other central and local administrative authorities. Law No. 5-XVI does not, however, envisage any role for the Moldovan courts in ensuring equality between men and women.

Article 24 of Law No. 5-XVI sets out the liability for gender-based discrimination. Whilst it confirms that persons subject to forms of gender-based discrimination are entitled to compensation, and that those responsible for committing gender-based discrimination are liable according to law, it does not give the courts a role in this process. As such, it is notable that there are no known cases in which any woman has ever been recognised by a court or other authority as having suffered any form of gender-based discrimination in Moldova and, therefore, Law No. 5-XVI has not led to the development of a well-established legal practice in the area of gender-discrimination.

The government of Moldova recently took the decision to harmonise its national legislation so as to better include and promote the principles of gender equality, and to prohibit

any form of gender-based discrimination. In 2010, it created a working ministerial group with the participation of national experts. A draft law to amend various pieces of national legislation is currently under consideration,<sup>42</sup> although there has been no indication of when this law will be enacted.

## 2.2 Key Issues

### 2.2.1. Domestic Violence

In 2007, UNICEF experts stated that every third woman in Moldova has suffered violence within her family at least once. The aggressors are the husbands or ex-husbands in more than 73% of cases, and fathers in 14% of cases. In many cases, women divorce their aggressive husbands. 60% of divorced women have recognised that they have suffered from violence at home, as compared to 28% of married women.<sup>43</sup>

Domestic violence in Moldova is a complex phenomenon generated by psychological problems and aggravated by educational, economic and social factors. Victims of domestic violence are mainly women. According to the most recent report by the International Centre for Women's Rights Protection and Promotion "La Strada", which is based on data gathered from La Strada's Trust Line for Women, most calls from victims are received from women who have been subjected to domestic violence by their husbands (66%), former husbands (10%), children (6%), parents (3%), parents-in-law (2%), lovers (1%), brothers (1%) and other family members (2%).<sup>44</sup>

From the total number of victims, around 45% are from socially vulnerable strata (for example, both spouses are unemployed or seasonally employed, or do not have a pro-

fession, or are students), whilst 40% of victims are in an average financial position and 15% of the victims are in a very good financial position. This data shows, therefore, that domestic violence is a widespread phenomenon in Moldova and occurs throughout the economic spectrum.

According to the La Strada report referred to above, irrespective of their status, education, place of residence and age, victims of domestic violence have some common characteristics. They frequently come from violent families, have been witnesses or victims of violence in their family of origin, have little to no aspirations or future plans, display low self-esteem, and have manifested a high level of victimisation in their personalities (through being highly dependent upon the aggressor and therefore being unable to proceed with changes).

The conclusions of the analysis show that in Moldova domestic violence has a strong gender character reflected in the popular mentality that domestic violence is not a public issue, but rather a private matter. It is perceived as a natural part of family life and of normal lifestyle. There is even a culture of gender violence, which distorts the perception of future generations about the family – the abusive model is transmitted from family to family and from generation to generation. Common expressions in Moldova, such as: "A woman unbeaten is like a house unswept"; "Woe to the house where the hen sings"; and "People should know who wears the hat in this house", reflect the acceptable norm in many families. Many of the victims of violence, being educated in families where violence was a real phenomenon, are not aware that there is another way of behaviour or other ways to solve conflicts.

### 2.2.1.1. Relevant Legislation

According to the Note to Law No. 45-XVI on Preventing and Combating Domestic Violence (Law No. 45-XVI)<sup>45</sup> which came into force on 18 September 2008, “preventing and combating domestic violence are a part of the National Policy for Family Protection and Support, and represent a major public health problem”. Law No. 45-XVI is aimed at strengthening, protecting and supporting the family, to ensure respect for fundamental principles of law in the family, and to ensure equal opportunities between women and men in their human right to a life without violence.

In Article 2 of Law No. 45-XVI, family violence is defined as: “any action or deliberate inaction, except for self-defence or defence of others, manifested verbally or physically, by physical, sexual, psychological, spiritual or economic abuse, or by infliction of material or moral damage, committed by a family member on another family member/members, including against children and against the common or personal property”. Article 3 of Law No. 45-XVI confirms that the protection from domestic violence provided by this legislation applies as follows:

“(1) This law applies to: the aggressor and the victim citizens of the Republic of Moldova and to foreign citizens and stateless persons who live in the Republic of Moldova.

(2) This law applies:

a. In cases of cohabitation – persons in relationship of marriage, divorce, intimate cohabitation, guardianship and tutorship, their direct or collateral relatives, relatives’ spouses, or other persons who are maintained by the such persons;

b. In cases of separate habitation – persons in a relationship of marriage; their children, including adopted children; those born outside the marriage; those under guardianship or tutorship; or other persons who are maintained by such persons.”

Therefore, Law No. 45-XVI offers protection to “family members” in both formal and informal family relationships.

Article 15 of Law No. 45-XVI introduced the Protection Order - the legal instrument by which the court can apply measures which offer protection to the victims of domestic violence. Protection Orders are intended to provide emergency protection to the victim, such as: (i) ordering the aggressor to leave the joint residence; and/or (ii) prohibiting the aggressor from approaching the victim (including a distance-specific restraining order). Prior to Law No. 45-XVI being adopted, the only option available to the victim was to look for refuge which often forced them to leave their home and children.

Since entering into force, however, Law No. 45-XVI has been somewhat redundant, as there is no mechanism for implementing its requirements. This is partly because the Criminal Code of the Republic of Moldova does not include provisions on domestic violence. Domestic violence was interpreted as a private issue, and victims were regarded as “women having family problems”. Such acts of violence were sometimes prosecuted under the general criminal law provisions regarding the infliction of bodily harm or assault, or under administrative law. Depending on the gravity of the harm, however, the aggressor could be punished with only a fee or community service. In many cases, however, spouses would be “reconciled” and the aggressor would escape any punishment at all.

Further, none of the modifications set out in Article 15 of Law No. 45-XVI, which included the establishment of a Protection Order regime, have been integrated into civil procedural norms. Consequently, an examining magistrate could refuse to issue a Protection Order for the victim. In the period since Law No. 45-XVI was enacted, for the first time in Moldovan history, Protection Orders have been issued by courts in order to protect victims of domestic violence. There have been in the region of 60 such orders issued to date, primarily in the region of central Moldova, and this certainly contrasts remarkably with the fact that there are no recorded judgments by the courts under Law No. 5-XVI. The Protection Orders which have been issued, however, are rarely implemented and enforced in practice for reasons including the incompetence and the attitudes of the implementing authorities.

### 2.2.1.2. Recent Developments

On 3 September 2010, a new Law No. 167 entered into force as an amendment to certain other pieces of legislation (including the Criminal Code, the Code of Criminal Procedure and Law No. 45-XVI).<sup>46</sup> Law No. 167 aimed to solve the problems of non-implementation of Law No. 45-XVI. Perhaps most significantly, Law No. 167 inserted a new provision in the Criminal Code – Art 201<sup>1</sup> on domestic violence,<sup>47</sup> according to which domestic violence is established as a criminal offence and described as:

“(...) intentional action or inaction that is manifested physically or verbally, committed by a family member on another family member, causing physical pain, slight bodily injury, distress, material or moral damage. For family violence causing consequences for the victims’ bodily integrity and

health, the aggressor may be subjected to 15 years imprisonment especially if the victim died, attempted suicide or suffered serious bodily harm as a result of the violence.”

A Protection Order for victims of domestic violence can now be issued both in the criminal and civil proceedings. Under the civil procedure set out in Article 15 of Law No. 45-XVI, the court is required to issue a Protection Order within 24 hours of receiving the claim. Under the criminal procedure, the investigating body is obliged to submit a request to the judge to examine the application for a Protection Order within 24 hours. Under both procedures, the court may oblige the aggressor: (i) to leave the house, regardless as to whether it is a common property or not; (ii) to stay away from the victim's whereabouts and maintain a distance that would ensure the victim's security; (iii) to not contact the victim; (iv) to not visit the victim at a workplace or place of residence; and (v) to abstain from keeping and carrying firearms.

Additionally, during criminal proceedings, the court may require the aggressor to undergo a medical examination to determine whether he is dependent on alcohol and/or drugs and, where necessary, to submit to medical treatment, including participation in a detoxification program or a counselling program for offenders. In civil proceedings, the accused may incur costs to cover the repair of any damaged property, the medical treatment and the maintenance of any minor children.

Whilst the laws in Moldova which aim to prevent and combat domestic violence appear to provide sufficient protection mechanisms, their application in practice remains a cause for serious concern. The key issues relating

to the enactment of protection mechanisms are set out below.

### 2.2.1.3. Key Issues Regarding Domestic Violence

Based on the Promo-LEX caseload, the most problematic issues relating to domestic violence against women in Moldova are:

**(1) Failure to enforce the Protection Order:** One of the most frequently encountered problems in the domestic violence area is the failure to enforce the Protection Order by the relevant public authorities, who by law are responsible for its implementation in practice. In many cases, the local social worker and the police remain unaware of the existence of the Protection Order, so they do not have the knowledge necessary to enforce the order. In many cases where the police do know about the domestic violence and the Protection Order, they choose to limit their involvement to informing the aggressor about the existence of the order, even when the Protection Order text imposes an obligation on the aggressor to leave the house. The explanation commonly given by the police for failing to enforce such orders is the lack of space or alternative accommodation to which the aggressor could move.

**(2) Delayed start of criminal prosecution:** Although domestic violence has been a crime under the Criminal Code since 3 September 2010, many petitions submitted to the prosecution on behalf of the victims have yet to be resolved. While many petitions have been filed, the ongoing subjection of the victims to domestic violence continues.

**(3) Refusal to issue Protection Orders:** There are cases when courts have refused to issue a Protection Order because the aggressor

does not recognise the acts of violence, and also presents witnesses who submit statements in their favour. In these situations, the statements of the victim are often disregarded. Further, despite Law No. 45-XVI referring to a range of violent behaviours, including physical, sexual, psychological, spiritual and economic violence, courts often associate domestic violence only with physical violence. Other forms of violence, such as psychological or economic violence are often deemed to be a normal part of a family routine. Victims therefore face a hostile attitude from the courts, particularly from judges, which often results in the credibility of the reported offence being further disregarded, and therefore the risk which victims face is not minimised.

**(4) Delay in issuing Protection Orders:** The essence of the Protection Order is to provide immediate protection for victims of domestic violence, and this is the justification for the 24-hour time-limit imposed under both the civil and criminal procedures. In many cases, delays mean that a Protection Order is not granted until, for example, two weeks after the application is made, which is often too late to prevent the victim from being subjected to further violence.

**(5) Role of active non-governmental organisations (NGOs):** While there are cases in which Protection Orders have been issued, these are often issued primarily as a result of the intervention of several active NGOs, supported and assisted by the United Nations Population Fund (UNFPA), the International Organisation for Migration (IOM) and, among others, the Prosecutor's Office in the Causeni district of Moldova.<sup>48</sup> Protection orders have only been issued in a limited number of district jurisdictions, namely Causeni, Falesti, Rezina, Anenii Noi, Vulcanesti and Chişinău.

It is a point of concern that the courts issuing Protection Orders for victims of domestic violence are mostly in those jurisdictions where an activist NGO is present.

**(6) Reports of UN Special Rapporteurs:** In each of their 2009 reports, Manfred Novak (UN Special Rapporteur on torture and other cruel, inhuman or degrading treatment and punishment) and Yakin Ertürk (UN Special Rapporteur on Violence against Women) highlighted that the failure of the law enforcement bodies in Moldova to respond to allegations of domestic violence discriminates against women in their access to an effective remedy and may constitute complicity in such ill-treatment.<sup>49</sup> In Moldova, crimes of violence against women are not perceived as a problem warranting legal intervention, unless they result in serious injury.

#### 2.2.1.4. Examples

The following examples from the Promo-LEX caseload are provided as illustrations of the findings listed above:

**(1) Case X:** In this case, Promo-LEX represents a 71-year-old woman, with the aim of stopping domestic violence against her. Over the last year, numerous complaints have been made to the police and the Prosecutor's office, and requests have been made to the Social Assistance Department and the Ministry of Internal Affairs. Two Protection Orders have been obtained. The first was issued on 22 June 2010 for a period of 30 days, and the second was issued on 23 July 2010 for a period of 90 days. Neither of these Protection Orders was enforced. Following the complaints made on behalf of the victim by Promo-LEX, certain police officers were sanctioned and subsequently resigned. However, the officers replacing them have similarly not ensured the enforcement of the Protection Orders.

The aggressor has not been removed from the victim's house and he continues to beat her. A new application for a Protection Order was recently submitted along with a request for the Prosecutor to give an explanation of the measures being taken. The Prosecutor's office insists in its responses that the aggressor suffers from schizophrenia and cannot be brought to account. However, the attempts of the victim's lawyer to ensure that the aggressor be housed in a psychiatric unit – given the danger he continues at present to the victim – have been met with no response. This case, therefore, involves a victim of 71 years of age who continues to be beaten while the authorities are hesitating to take any meaningful action.

**(2) Case Y:** Promo-LEX was instructed on this case in June 2010. The victim is divorced but she continues to share an apartment with her ex-husband. Her ex-husband has been abusing her for many years. On 22 June 2010, her ex-husband beat her very badly. She managed to escape and went to the police station. The policemen accompanied her home and took the aggressor to the police station, prepared a report on the violation and then released him. He returned home and beat her even more savagely. The cries for help were heard by a neighbour who called the police and the medical services. The following day, the victim wanted to file a complaint with the Police Department, but they refused to register it. Promo-LEX applied for the issuance of a Protection Order which was issued on 30 June 2010 for a period of three months. The aggressor did not abide by the terms of the Protection Order, and the authorities failed to enforce those terms. However, the victim refused to submit a complaint on the non-execution of the Protection Order. She also refused to proceed with a criminal case against the aggressor on charges of domestic violence as stipulated in Article 201<sup>1</sup> of the

Criminal Code. It is possible that the victim's refusal to pursue a criminal case was a result of her fear of the aggressor.

**(3) Case Z:** The victim in this case divorced her husband in 2003 but continues to share a flat with him. The court divided the flat into quarters; the victim, her two daughters and her ex-husband were each allocated one quarter of the flat. The kitchen, bathroom and corridor remain as common spaces where incidents of violence continue to occur against the victim. Promo-LEX lodged a request with the police to address the court for a Protection Order in which the victim's ex-husband would be forbidden to insult and use force against her. On 22 June 2010, the district court issued a Protection Order. However, the violence continued and the ex-husband ignored the Protection Order. Therefore, on 22 September 2010, a complaint was submitted to the Prosecutor of the district aiming to initiate a criminal investigation on the issue of domestic violence, in accordance with Article 201<sup>1</sup> of the Criminal Code, and the complaint was examined by the police. Promo-LEX also submitted a request to the Social Assistance Department requesting information on the social worker's actions to ensure enforcement of the Protection Order and to prevent further acts of violence. The response received by Promo-LEX on 11 November 2010 confirmed that a case study had been opened, and the situation will be monitored over time.

Following a further violent incident against the victim by her ex-husband and his mistress on 29 November 2010, another complaint was made to the Ministry of Internal Affairs. On 10 December 2010, a Protection Order was urgently requested on the basis that the previous Protection Order had not been executed and the victim continued to suffer violence at the hands of her ex-hus-

band. On 13 December 2010, the victim's lawyer was informed that the request of 10 December 2010 had not been recorded on the court's computer. Since then, further complaints have been made on behalf of the victim and Promo-LEX lawyers continue to work on this case.

### 2.2.1.5. Conclusions

The cases described above clearly illustrate that despite the enactment of domestic legislation which provides for domestic violence to be addressed both as a criminal offence and in civil proceedings, the victims of such ill-treatment often struggle to obtain a Protection Order and, in the majority of cases, the process takes longer than the 24 hours stipulated by the Criminal Code. In the majority of cases, those Protection Orders which are issued are ignored by the aggressors, while the responsible authorities fail to execute and enforce them.

At a press conference held on 3 November 2010 on the recent legislative changes regarding domestic violence, the Prosecutor-General, Mr Valeriu Zubco, declared that in cases where victims of domestic violence face indifference and lack of professionalism on the part of the police, Prosecutors and social workers, they should complain to the superior authorities such as the Prosecutor-General and the Ministry of Internal Affairs.<sup>50</sup> At the press conference, the Prosecutor-General also stated that during the past two years, his offices had registered about 300 petitions and requests relating to domestic violence.

Promo-LEX does not consider the approach of the Prosecutor-General to be a constructive one and does not believe that it is likely to help in preventing and combating domestic violence. It is not acceptable to place the

responsibility for supervision of the activities of state authorities squarely upon the shoulders of the victim. It is instead necessary for the Prosecutor-General, the Ministry of Internal Affairs and the Ministry of Labour, Family and Social Protection to train professionals in the field of domestic violence and carry out internal controls to monitor how the legal norms on domestic violence are implemented. Services for the victims of domestic violence must become more proactive, flexible and, if necessary, mobile, and the establishment of specialised services for aggressors must remain a priority.

There is, however, reason to be positive as important steps have been, and continue to be, made in relation to the problem of domestic violence in Moldova as follows:

(1) The Government continues, with the support of UNFPA, to improve the normative framework related to domestic violence. For example, (i) on 22 February 2010, it approved the Regulations for the Shelters for Domestic Violence Victims; and (ii) it has developed the profession-specific guidelines on implementation of domestic violence legislation for social assistants, medical staff and police and the Standards for the Shelters for Domestic Violence Victims. The latter two documents are currently pending governmental approval.

(2) In order to address the lack of services for perpetrators of domestic violence, the first rehabilitation centre for such perpetrators has been established in the Drochia district of Moldova. It is envisaged that this centre will provide psychological, information, medical and social services to perpetrators of domestic violence.

(3) The above efforts are complemented by nationwide awareness-raising events, aimed

at creating a non-tolerant attitude towards domestic violence; advocacy events are being conducted by La Strada.

## 2.2.2. Sexual Violence

According to the most recent statistics provided by the Ministry of Internal Affairs, during 2010, in Moldova, 504 cases of sex crimes were reported, categorised as follows: (i) 323 cases of rape (a 32.4% increase from 2009); and (ii) 181 cases of sexual violence (a 39.2% increase from 2009).<sup>51</sup> This data does not necessarily show an increase in the number of actual incidents of sex crimes, but it does show an increase in the number of such incidents which were reported. According to the same source, of the total number of 504 cases of sex crimes reported in Moldova during 2010, only 251 (50%) were sent for court examination. 139 of the cases resulted in a cessation of criminal proceedings and 112 remained unresolved or still remain in the process of examination.

### 2.2.1.1. Relevant Legislation

Crimes of sexual violence are stipulated as criminal offences under the Criminal Code. According to Article 171 of the Criminal Code:

“Rape, i.e. sexual intercourse committed by the physical or mental coercion of the person, or by taking advantage of the victim’s incapacity to defend himself/herself or to express his/her will, shall be punished by imprisonment for 3 to 5 years.”<sup>52</sup>

Law No. 167 included an amendment to Article 171 of the Criminal Code, according to which rape was recognised as an act that can also take place in the family.<sup>53</sup> As a result, marital rape became recognised as a criminal offence in Moldova.

Article 172 of the Criminal Code defines “Violent Actions of a Sexual Character”, the most severe cases of which can be punished by lifetime imprisonment, as follows:

“Homosexuality or satisfying sexual needs in perverted forms committed through the physical or mental coercion of the person or by taking advantage of the person’s incapacity to defend himself/herself or to express his/her will shall be punished by imprisonment for 3 to 5 years.”

Law No. 167 also includes a new provision according to which violent actions of sexual character can also take place in the family.<sup>54</sup> Law No. 45-XVI defines “sexual violence” as:

“[A]ny violence of a sexual nature or any illegal sexual conduct within the family or other interpersonal relationships, such as marital rape, prohibiting any methods of contraception, sexual harassment; any unwanted and imposed sexual behaviour; forced prostitution; any illegal sexual conduct in relation with a minor family member, including caresses, kisses and other unwanted touching of a sexual nature; other actions with similar effects”.<sup>55</sup>

One of the most problematic issues relating to the problem of sexual violence in Moldova is the way in which the crimes of “rape” and “violent actions of a sexual nature” are investigated. The prosecution focuses on the behaviour of the victim, not the aggressor, and the investigation therefore seems to focus on collecting evidence to undermine and contradict the victim’s story. “The Methodological Guidelines on the Investigation of Sexual Crimes” issued on 15 August 2008 by the Prosecutor-General’s Department of Criminal Investigation included a set of practical recommendations for prosecutors in the prosecution of sexual offences. According to

these guidelines, the prosecution must demonstrate the victim’s physical resistance to the act. The assumption, therefore, is that the victim has consented to the sexual act unless there is evidence of physical resistance. Further, the guidelines include the suggestion that in some cases, such as those incidents where sexual intercourse involves a teenager, some sort of physical force may be necessary given the “shyness” of the teenager. The implication here, therefore, is that even where evidence of physical resistance or undue force is present, this will not in all cases be sufficient to prove the crimes of either “rape” or a “violent action of a sexual nature”.

These guidelines demonstrate the problematic approach to the prosecution of rape and sexual violence in Moldova which is further demonstrated by the example provided below.

### 2.2.1.2. Example

The case of *I.G. v Moldova* (Application no. 53519/07) was lodged with the European Court of Human Rights (ECtHR) on 6 October 2007.<sup>56</sup> This case provides a useful example of the problematic way in which cases of sexual violence are dealt with in Moldova.

The applicant (I.G.) was born on 10 December 1989. At the time of the alleged events, she was 14 years old. On the evening of 21 August 2004, I.G. accompanied V.R. to a disco bar. V.R. was 23 years old at the time. The applicant and V.R. had known each other for many years and had met before on different occasions. I.G. recalls consuming approximately 100ml of vodka with V.R. On their way back home, V.R. raped I.G. in his car and allegedly threatened her with death should she tell anyone what had happened. I.G. told her mother that she had been raped by V.R. and her mother subsequently confronted

V.R. at his house and he admitted having had sex with her daughter. I.G.'s mother therefore reported the rape on her daughter's behalf at the police station of Singerei district on 25 August 2004. On 26 August 2004, the Prosecutor's Office of Singerei district opened a criminal investigation of the alleged crime of rape committed "knowingly" on a minor (pursuant to Article 171(2)(b) of the Criminal Code). After three years of examination of the case by the domestic courts, V.R. was cleared of the charges on the basis that the medical examination of I.G. had found no evidence of bruises, injuries, blood or sperm.

I.G. sought psychological help after the conclusion of proceedings in the domestic courts. Given the absence of government-provided specialised services for victims of sexual assault, in the period of July to August 2007, she was seen by a psychiatrist from a local non-governmental organisation "Memoria"<sup>57</sup> working on issues of sexual violence. An excerpt from I.G.'s medical file, issued on 18 August 2007, confirms that she was suffering from a post-traumatic disorder caused by a combination of: (i) the sexual assault; (ii) the failure of the courts to render an effective conviction; and (iii) the public humiliation to which I.G. was subjected during the domestic proceedings in her case.

In 2007, Promo-LEX lawyers took I.G.'s case to the ECtHR. I.G. claims that her right not to be subjected to inhuman and degrading treatment under Article 3 (Prohibition of torture) and the right to respect for her private life under Article 8 (Right to respect for family and private life) had been violated by the State's failure to observe its positive obligations to effectively investigate and prosecute crimes of sexual violence. In particular, I.G. argues that the domestic courts' failure to assess effectively the issue of consent of a minor fell short of the state's positive obligation to enact criminal law provisions effectively

in punishing the crimes of sexual assault of minors. I.G. also argues that she had no effective domestic remedy at her disposal to seek reparation and redress for the violation of her rights. She submits that there has been a violation of Article 13 (Right to an effective remedy) taken in conjunction with Articles 3 and 8 of the Convention.

I.G. further submits that insistence on corroborative evidence of resistance violated her right to non-discrimination under Article 14 (Prohibition of discrimination) taken together with Article 8 of the ECHR. I.G. argues that the corroboration requirement represents discrimination against women because it is based on erroneous assumptions about the reliability of women's ability to report rape and because it does not reflect the reality of rape as a crime, therefore resulting in ineffective prosecution of genuine cases. The case was communicated to the Government of Moldova in September 2009. Promo-LEX Lawyers submitted a Reply to the Government's Observations in February 2010 and I.G. currently awaits the judgment of the ECtHR.

The case of the I.G. clearly illustrates the above-mentioned problems which feature in investigations of claims of rape in Moldova. Promo-LEX hopes that this case will result in: (i) the progressive development of the Moldovan criminal justice system in investigating rape cases through the abolition of the discriminatory procedure in which corroborative evidence is sought; and (ii) the development of the ECtHR's jurisprudence with regard to the state's positive obligations in protecting women from violence and discrimination.

### **2.2.3. Sexual Harassment**

In its General Recommendation 19, the Committee on the Elimination of Discrimination

against Women refers to sexual harassment in the workplace as a form of gender-specific violence,<sup>58</sup> stating that such conduct “can be humiliating and may constitute a health and safety problem”.<sup>59</sup> Harassment becomes a form of discrimination “when unwanted conduct related to any prohibited ground takes place with the purpose or effect of violating the dignity of a person or of creating an intimidating, hostile, degrading, humiliating or offensive environment.”<sup>60</sup> Given that sexual harassment can violate the dignity of a person, or create a degrading environment for an individual to work in, such discriminatory behaviour may meet the threshold of “cruel, inhuman or degrading treatment”.

While “sexual harassment” is defined under Law No. 5-XVI as a form of gender-based discrimination, and Article 10(3)(d) of the same law requires that employers must “undertake measures to prevent sexual harassment of women and men at their place of work, as well as to prevent persecution for submitting complaints of discrimination to the competent body”, there is no provision for enforcement of such obligations or for victims of sexual harassment to seek redress. There is, therefore, no civil procedure in Moldova whereby victims of sexual harassment can challenge such discriminatory ill-treatment.

Law No. 167, however, introduced “sexual harassment” as a sexual crime under Article 173 of the Criminal Code. “Sexual harassment” is defined as “the manifestation of physical, verbal or nonverbal behaviour that violates the dignity or creates an unpleasant, hostile, degrading and humiliating atmosphere with the purpose of coercing another person to engage in sexual intercourse or other unwanted sexual actions committed by threat, coercion or blackmail”.<sup>61</sup> Sexual harassment can be punishable by: (i) a fine of 300 to 500 conventional units; (ii) unpaid

community work from 140 to 240 hours; or (iii) imprisonment for up to three years.

The inclusion of sexual harassment in the Criminal Code is, however, likely to remain unworkable. This is owing to the fact that the criminal law of Moldova abides by the principle of presumption of innocence; once a person has been recognised as a suspect, the onus lies with the victim to produce evidence sufficient to prove that the crime was committed. The reversal of the burden of proof is only possible in civil law. The particular nature of the acts which amount to sexual harassment makes it difficult for the victim to meet the burden of proof required for the criminal prosecution of such acts. Sexual harassment is often committed in the absence of witnesses and without any written documentation. Therefore, by addressing the problem of sexual harassment through the criminal law, which will often result in a direct conflict between the respective evidence of the victim and the aggressor, it is difficult to secure a conviction and therefore obtain justice for the victim. Further, this can also lead to the re-victimisation of the victim and the withdrawal of the complaint. Once a complaint is withdrawn by the victim, there follows a cessation of the criminal procedure and no redress is provided to the victim.

Four important observations can be made regarding the factors that perpetuate the occurrence of sexual harassment. Firstly, many women do not understand what sexual harassment amounts to in practice. In particular, women have difficulty in understanding that sexual harassment can take place in schools and places of work. Secondly, many women are unaware of the national legislation which seeks to prevent the occurrence of sexual harassment, and more significantly, how such legislation seeks to address and punish such ill-treatment. This is partly explained by the

fact that the new criminal legislation on sexual harassment has only recently come into force and a well-established legal practice in this field has yet to develop. Thirdly, managerial staff in workplaces throughout Moldova is not aware of the problem of sexual harassment and what their responsibilities are in this regard. Employers should be encouraged to take a firm stance against sexual harassment in the workplace, and to develop internal guidelines as to how such ill-treatment should be handled. Finally, cases of sexual harassment would be more appropriately addressed under a civil procedure where the burden of proof could be reversed, and the onus is less upon the victim to “prove” that she has experienced this form of discriminatory ill-treatment.

### 3. Conclusion

Based on the above analysis of current practices and legislation, along with the examples provided from the Promo-LEX case-load, it is evident that women in Moldova continue to be subjected to discriminatory ill-treatment. Whilst this article focused on three examples of such ill-treatment - domestic violence, sexual violence and sexual harassment - it is also important to acknowledge that these examples do not represent the full range of discriminatory ill-treatment which women face in Moldova. Coercive sterilisation and forced abortions in mental institutions and elsewhere, as well as trafficking of women for sexual exploitation are further practices of discriminatory ill-treatment in Moldova which have not been addressed in this article.

The international treaties to which Moldova is a signatory, alongside recent developments in national legislation, demonstrate that the government is willing, in theory, to accept responsibility for the protection of women

from gender-based discriminatory ill-treatment. However, the case studies included in this article demonstrate that the legal framework is not adequately enforced. The relevant enforcement bodies are either unwilling to comply with the legislative procedures or are unaware of them. It is also notable that in a high number of cases there is an ingrained attitude of indifference towards, and in many cases an acceptance of, discriminatory ill-treatment within those bodies responsible for investigating and ultimately upholding the relevant laws.

In order to address this situation, it is imperative that the relevant state authorities take a stronger managerial approach to dealing with non-execution of Protection Orders and against gender-based and sexual violence. It is also highly important to increase awareness among law enforcement officers of the new legislative provisions on domestic violence, gender equality, non-discrimination and sexual harassment through effective training. The Moldovan government should also adopt a stronger approach to dealing with officials who fail, or refuse, to implement the legislated procedures.

Finally, civil society should take responsibility for: (i) monitoring the activities of the relevant state authorities in implementing the legal framework; and (ii) educating the general public on the changes to the law and how it affects rights. This should include targeting those most at risk and informing them of the paths to legal redress which are available to them. Civil society should also put pressure on the wider international community to be more proactive in offering assistance to Moldova in its implementation of the new legal provisions and also in ensuring that the Moldova government fulfils its obligations under the international treaties to which it is a party.

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<sup>2</sup> For the purposes of this article, “discriminatory ill-treatment” means any act of torture or cruel, inhuman or degrading treatment or punishment, as defined in the UN Convention against Torture and interpreted by the Committee against Torture, when such an act is related to a particular characteristic of the victim, such as racial or ethnic origin, colour of skin, religion, sex, sexual orientation, disability, etc., which is, or should be, a prohibited ground of discrimination.

<sup>3</sup> UN Human Rights Council, *Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, Manfred Nowak: Mission to the Republic of Moldova*, A/HRC/10/44/Add.3, 12 February 2009; UN Human Rights Council, *Report of the Special Rapporteur on violence against women, its causes and consequences, Yakin Ertürk: Mission to the Republic of Moldova*, A/HRC/11/6/Add.4, 8 May 2009; UN Committee on the Elimination of Racial Discrimination, *Concluding Observations of the Committee on the Elimination of Racial Discrimination: Moldova*, CERD/C/MDA/CO/7 16 May 2008; UN Committee on the Elimination of Discrimination against Women, *Concluding comments of the Committee on the Elimination of Discrimination against Women: Republic of Moldova*, 25 August 2006.

<sup>4</sup> In 2010, The Promo-LEX Association launched a project in partnership with The Equal Rights Trust entitled “Strengthening Legal Protection from and Raising Awareness of Discriminatory Ill-Treatment in the Republic of Moldova, including the Transnistrian region”. Funded under the European Instrument for Democracy and Human Rights, the project aims at helping to prevent ill-treatment resulting from discrimination against various vulnerable groups. The project activities commenced in March 2010 and will be completed in September 2011. They include: (i) taking strategic litigation cases which involve elements of discriminatory ill-treatment; (ii) providing training to human rights lawyers and activists on discriminatory ill-treatment; (iii) translating and disseminating *The Equal Rights Review* in Romanian; (iv) producing a report on discriminatory ill-treatment in Moldova; and (v) undertaking advocacy actions aimed at promoting non-discrimination principles and norms in Moldova.

<sup>5</sup> The nine core UN human rights treaties are as follows: International Covenant on Civil and Political Rights, G. A. Res. 2200A (XXI) (1966) (ICCPR); International Covenant on Economic, Social and Cultural Rights, G. A. Res. 2200A (XXI) (1966) (ICESCR); Convention on the Elimination of All Forms of Racial Discrimination, G. A. Res. 2106A (XX) (1965) (CERD); Convention on the Elimination of All Forms of Discrimination against Women, G. A. Res. 34/180 (1979) (CEDAW); Convention against Torture and Other Cruel, Inhuman or Degrading Treatment and Punishment, G. A. Res. 39/46 (1984) (CAT); Convention on the Rights of the Child, G.A. Res. 44/25 (1989) (CRC); Convention on the Protection of the Rights of All Migrant Workers and Members of Their Families, G.A. Res. 45/158 (1990) (CRMW); Convention on the Rights of Persons with Disabilities, G. A. Res. 61/106 (2006) (CRPD); and the International Convention for the Protection of All Persons from Enforced Disappearance, G.A. Res. 61/177 (2006) (CPPED).

<sup>6</sup> UN Human Rights Committee, *General Comment 28: Equality of rights between men and women (article 3)*, CCPR/C/21/Rev. 1/Add. 10, 29 March 2000.

<sup>7</sup> *Ibid.*, Para 10.

<sup>8</sup> *Ibid.*, Para 11.

<sup>9</sup> *Ibid.*, Para 12.

<sup>10</sup> UN Committee on the Elimination of Discrimination against Women, *General Recommendation 19: Violence against Women*, 11<sup>th</sup> Session, 1992.

<sup>11</sup> *Ibid.*, Para 1.

<sup>12</sup> *Ibid.*, Para 4.

<sup>13</sup> *Ibid.*, Para 6.

<sup>14</sup> *Ibid.*, Para 9.

<sup>15</sup> *Ibid.*, Para 11.

<sup>16</sup> *Ibid.*, Para 13.

<sup>17</sup> *Ibid.*, Para 17.

<sup>18</sup> *Ibid.*, Para 22.

<sup>19</sup> *Ibid.*, Para 23.

<sup>20</sup> *Ibid.*, Para 24.

<sup>21</sup> "Torture" is defined in Article 1 of CAT as "any act by which severe pain or suffering, whether physical or mental, is intentionally inflicted on a person for such purposes as obtaining from him or a third person information or a confession, punishing him for an act he or a third person has committed or is suspected of having committed, or intimidating or coercing him or a third person, or for any reason based on discrimination of any kind, when such pain or suffering is inflicted by or at the instigation of or with the consent or acquiescence of a public official or other person acting in an official capacity. It does not include pain or suffering arising only from, inherent in or incidental to lawful sanctions".

<sup>22</sup> CAT, Article 16.

<sup>23</sup> CAT, Articles 2 and 4; See also UN Committee against Torture, *Keppa Urra Guridi v Spain*, Communication No. 212/2002, U.N. Doc. CAT/C/34/D/212/2002, 17 May 2005.

<sup>24</sup> UN Committee against Torture, *General Comment 2: Implementation of Article 2 by States Parties*, CAT/C/GC/2, 24 January 2008, Para 20.

<sup>25</sup> Moldova signed the European Convention for the Protection of Human Rights and Fundamental Freedoms (ECHR) in July 1995 and subsequently ratified it in September 1997.

<sup>26</sup> ECHR, Article 3.

<sup>27</sup> ECHR, Article 14.

<sup>28</sup> Law on ensuring equal opportunities for women and men, No. 5-XVI of 9 February 2006, *The Official Monitor of the Republic of Moldova*, No. 47-50/200 of 24 Mart 2006. An English translation is available at: <http://www.iwraw-ap.org/laws/genderequalitylaws.htm>.

<sup>29</sup> Article 2 of The Constitution of The Republic of Moldova, adopted on 29 July 1994. An English translation is available at: <http://confinder.richmond.edu/admin/docs/moldova3.pdf>.

<sup>30</sup> Government of The Republic of Moldova, *National Plan of Action on Gender Promotion in 2006-2009*, 25 August 2006, available in Romanian at: [http://www.google.md/url?sa=t&source=web&cd=1&ved=0CBAQFjAA&url=ht tp%3A%2F%2Fmpsc.gov.md%2Ffile%2Fegalitategen%2Fplan\\_%2520nat\\_ega\\_md.doc&rct=j&q=Planului%20 na%25%20A3ional%20%E2%80%9EPromovarea%20egalit%C4%83%C5%A3ii%20genurilor%20umane%20 %C3%AEn%20societate%20pentru%20perioada%202006-2009%E2%80%9D%2C&ei=LHJjTeD5HY6XOuS9jdcC &usg=AFQjCNG46\\_8Ge3vtQEOjIN4gldTSSjWvMA&cad=rja](http://www.google.md/url?sa=t&source=web&cd=1&ved=0CBAQFjAA&url=ht tp%3A%2F%2Fmpsc.gov.md%2Ffile%2Fegalitategen%2Fplan_%2520nat_ega_md.doc&rct=j&q=Planului%20 na%25%20A3ional%20%E2%80%9EPromovarea%20egalit%C4%83%C5%A3ii%20genurilor%20umane%20 %C3%AEn%20societate%20pentru%20perioada%202006-2009%E2%80%9D%2C&ei=LHJjTeD5HY6XOuS9jdcC &usg=AFQjCNG46_8Ge3vtQEOjIN4gldTSSjWvMA&cad=rja).

<sup>31</sup> See above, note 30, Article 2: "Comprehensive approach to equality between women and men' - to integrate the principle of equality between men and women in policies and programs in all areas and at all levels of adoption and implementation of decisions."

<sup>32</sup> *Ibid.*: "Affirmative action' - special temporary measures to accelerate the achievement of real equality between women and men, intended to eliminate and prevent discrimination or disadvantages resulting from the attitudes, behaviours and structures."

<sup>33</sup> *Ibid.*: "Gender-based discrimination' - any difference, exception, restriction or preference aiming or impairing the limitation or nullifying the recognition, the performance and implementation based on equality between women and men of human rights and fundamental freedoms."

<sup>34</sup> *Ibid.*: "Direct discrimination on grounds of sex' - any action that in similar situations discriminates a person against another person of another sex, including because of pregnancy, motherhood or fatherhood."

<sup>35</sup> *Ibid.*: "Indirect discrimination on grounds of sex' - any action, rule, criterion or practice identical for women and men, but with an unequal effect or result to one sex, except for affirmative action."

<sup>36</sup> *Ibid.*: "Equal opportunities' - lack of barriers to participation based on equality between women and men to activities in the political, economic, social, cultural and other spheres of life."

<sup>37</sup> *Ibid.*: "Equality between women and men' - equal rights, equal opportunities in the exercise of rights, equal participation in all spheres of life and equal treatment of women and men."

<sup>38</sup> *Ibid.*: "Gender' - the social aspect of relations between women and men, which manifests itself in all spheres of life."

<sup>39</sup> *Ibid.*: "Sexual harassment' - any form of physical, verbal or nonverbal behaviour of a sexual nature which violates dignity or creates an unpleasant, hostile, degrading, humiliating or offensive environment."

<sup>40</sup> *Ibid.*: "Sex' - all the anatomic and physiological characteristics that distinguish human beings as women and men."

<sup>41</sup> *Ibid.*: "Gender unit' - a specialist tasked with duties to promote equality between women and men in the institution in which it operates."

<sup>42</sup> A version of the draft law (which is currently untitled) in Romanian is available at: <http://mmpsf.gov.md/file/proiecte/Proiect%20Lege%20final.pdf>.

<sup>43</sup> UNICEF Moldova, "Fiecare a treia femeie din Republica Moldova a fost cel puțin o dată victimă a violenței în familie" (author's translation: "Every third woman in Moldova has been at least once a victim of domestic violence"), undated, available in Romanian at: <http://www.hr.un.md/news/210/>.

<sup>44</sup> International Centre for Women's Rights Protection and Promotion "La Strada", *Trust Line for Women: Analytical Operating Report*, 2010, available at: [http://www.lastrada.md/publicatii/ebook/Raport\\_linia\\_fierbinte\\_2010\\_EN.pdf](http://www.lastrada.md/publicatii/ebook/Raport_linia_fierbinte_2010_EN.pdf).

<sup>45</sup> Law on Preventing and Combating Family Violence, Law Number 45-XVI of 1 March 2007, *The Official Monitor of the Republic of Moldova*, No. 55-56/178, 18 March 2008. This law entered into force on 18 September 2008. An English translation is available at: [http://www.coe.int/t/dghl/standardsetting/violence/Moldovan%20law%20on%20family%20violence%20\\_EN.pdf](http://www.coe.int/t/dghl/standardsetting/violence/Moldovan%20law%20on%20family%20violence%20_EN.pdf).

<sup>46</sup> Parliament of The Republic of Moldova, Law No. 167, available in Romanian at: <http://lex.justice.md/index.php?action=view&view=doc&lang=1&id=335828>.

<sup>47</sup> The Criminal Code of the Republic of Moldova, No. 985-XV dated 18 April 2002, as amended.

<sup>48</sup> The current prosecutor of the Causeni district, Ion Oboroceanu, is the former president of a human rights NGO - Centrul de Drept Causeni - and he was involved as a lawyer in obtaining one of the first Protection Orders in Moldova in 2009. Further information about Ion Oboroceanu is available at: <http://www.europalibera.org/content/article/1867714.html>.

<sup>49</sup> UN Human Rights Council, see above, note 3.

<sup>50</sup> Press conference given by Valeriu Zubco (Prosecutor-General), "Preventing and combating domestic violence through the work of Prosecutors", 2 November 2010, available in Romanian at: <http://www.jurnaltv.md/ro/news/ordonanta-de-protectie-179699/#>.

<sup>51</sup> Ministry of Internal Affairs of the Republic of Moldova, *Operational information on the situation regarding delinquency in Moldova during 2010*, available in Romanian at: <http://www.mai.md/content/6945>.

<sup>52</sup> See above, note 47, Article 171.

<sup>53</sup> See above, note 47, Article 171(2)(b).

<sup>54</sup> See above, note 47, Article 172(2)(b).

<sup>55</sup> See above, note 45, Article 2.

<sup>56</sup> *I. G. v Moldova*, Application no. 53519/07, lodged with European Court of Human Rights on 6 October 2007.

<sup>57</sup> For further information, see website of Rehabilitation Centre for Torture Victims "Memoria", available at: <http://www.memoria.md/?lang=en>.

<sup>58</sup> See above, note 10, Para 17.

<sup>59</sup> See above, note 10, Para 18.

<sup>60</sup> The Equal Rights Trust, *Declaration on Principles of Equality*, 2008, available at: <http://www.equalrightstrust.org/endorse/index.htm>.

<sup>61</sup> See above, note 47, Article 173.

# The Pain of a Nation: The Invisibility of Uyghurs in China Proper

M. Rayila<sup>1</sup>

## Introduction

On 5 July 2009, Uyghurs in the city of Urumchi, the capital of Xinjiang Uyghur Autonomous Region (XUAR) of China, participated in an initially peaceful protest against the government's inaction in response to the killing of at least two Uyghur migrant workers by Han Chinese workers at a toy factory in the city of Shaoguan in the southern province of Guangdong.<sup>2</sup> The demonstrators were reported to have initially numbered at least one thousand,<sup>3</sup> mostly young men and women, and they demanded an investigation into the Shaoguan killings.<sup>4</sup> By the evening of 5 July 2009, the protest had turned violent, causing the deaths of 197 people and injuries to more than 1,600 people.<sup>5</sup>

In response to this event, the Chinese government insisted that the protests were orchestrated by a small number of separatists inside XUAR, in league with international agitators, such as Rebiya Kadeer (the President of the US-based Uyghur American Association),<sup>6</sup> but they failed to provide any credible evidence in support of these claims. Independent human rights groups such as Human Rights Watch stated that the root causes for the protest lay in the longstanding discriminatory policies of the Chinese government towards Uyghur minorities. James Millward has also suggested that the protest was a result of Uyghur discontent towards the policies of the Chinese government.<sup>7</sup>

This protest in Urumchi drew the attention of the international community to the long-standing political pressures and human rights abuses suffered by the Uyghurs in China, and particularly the discrimination which they face in many aspects of life. This article focuses on the plight of the Uyghurs living in China Proper.<sup>8</sup> Whilst many books have been written addressing various themes related to the Uyghurs living in XUAR,<sup>9</sup> very little attention has been given to those Uyghurs who have migrated to China Proper from XUAR (described here as "Floating Uyghurs") and their daily lives.<sup>10</sup> To the author's knowledge, there has previously only been one article published on this topic by Steve Hess in the *Central Asian Survey*.<sup>11</sup>

This article references cases and examples obtained through interviews with members of the Floating Uyghur communities which were carried out by a group of researchers at Beijing AIZHIXING Institute between 2007 and 2009.<sup>12</sup> Beijing AIZHIXING Institute started its Uyghur Health Education and Social Integration project in 2006. The project focused on the Floating Uyghur communities in Beijing, Kunming, Wuhan and Chengdu.<sup>13</sup>

The examples provided in this article of the challenges faced by the Floating Uyghurs highlight the serious levels of racial discrimination which result in this "invisible popu-

lation” experiencing lack of access to basic public services including healthcare and housing. These challenges are referred to here as “the pain of a nation”.

In a speech given during the National City Ethnic Work Forum in September 2008, Professor Ma Rong stated that the number of Uyghurs living in China Proper had increased seven times during the period from 1982 to 2000, reaching a total of 53,771.<sup>14</sup> Even though the exact number of Floating Uyghurs is not currently known, according to Beijing AIZHIXING Institute’s Uyghur project among Floating Uyghurs in urban areas in China Proper, the number has increased further in the past 10 years.

According to a report entitled “The 2010 Report on the Development of China’s Floating Population”, based on the survey by the National Population and Family Planning Commission launched in July 2009, the size of China’s floating population reached 211 million,<sup>15</sup> including minorities. While the Floating Uyghurs make up a very small part of the total migrant population in China Proper, the treatment experienced by the Floating Uyghurs contributes to the social unrest and ethnic conflict between the Floating Uyghurs and the majority Han people as a whole. The widespread HIV/AIDS epidemic among the Floating Uyghurs has also made the situation of this community worse. It is necessary to advocate on behalf of the Floating Uyghurs and bring their situation to the attention of the relevant Chinese government agencies, such as the State Ethnic Affairs Commission, the Ministry of Health and the Ministry of Public Security, which could and should defend the rights of the Floating Uyghurs. The discrimination experienced by the Floating Uyghurs is part of a broader problem, as migrant workers in China generally face many

kinds of discrimination.<sup>16</sup> In the case of the Floating Uyghurs, however, ethnic and racial discrimination has certainly been an added obstacle as the Uyghurs are suspected of wanting to secede from the People’s Republic of China (PRC).<sup>17</sup> The Government of China must be asked to respect the rights of the Floating Uyghurs in accordance with the domestic laws of China and the international human rights treaties which China has signed and ratified.

## **1. Background**

### **1.1 The Uyghurs**

The Uyghurs (sometimes referred to as the Uighurs) originate from the XUAR which lies in the North-West of China, on the border with Central Asia. Covering one-sixth of the country’s total territory, the XUAR is a vast but sparsely populated area with about 19 million inhabitants. Some 8 million of those inhabitants are Turkic-speaking Uyghur Muslims, concentrated in the south of the region around cities such as Kashgar, known to the Chinese as Kashi, which lies 2,500 miles west of Beijing. The Uyghurs (pronounced Wee-gurs) make up about 45% of the XUAR’s population.<sup>18</sup> Uyghur human rights organisations abroad which have been formed by Uyghur dissidents and exiles have called this part of far West China East Turkestan,<sup>19</sup> which refers to the two independent states which were formed during the 20<sup>th</sup> century – the Turkish-Islamic Republic of Eastern Turkestan of the 1930s<sup>20</sup> and the East Turkestan Republic of the 1940s.<sup>21</sup>

### **1.2 Socio-economic Reasons for Migration to the East**

In order to describe fully the situation facing the Floating Uyghurs living in the urban cen-

tres referred to previously, it is necessary to review the process of social changes and economic development which have taken place in China. The economy has been among the most successful aspects of China's development since 1990. The minority populations in China have participated in this economic improvement yet there has been a strong tendency for members of such minority populations to be at the poor end of the widening disparities within China. In an uneven and imbalanced economic growth, areas on the eastern seaboard have advanced far faster than the rest of the country, whilst almost all of the minority populations live in the western part of the country, which includes the poorest provinces and autonomous regions.<sup>22</sup> Ethnic minorities, who comprise the majority of the population in many rural areas, have had limited input into the state-driven development model imposed upon them. In the west, the Inner Mongolia Autonomous Region (IMRA), the Tibet Autonomous Region (TAR), and the XUAR, along with nine other provinces, an autonomous region and one provincial-level municipality, have undergone major development campaigns, such as the Great West Development Project which was launched in 2000 by the Chinese government,<sup>23</sup> but the minorities in these regions have experienced limited benefits and much disruption.<sup>24</sup>

With the deepening of opening and reform since 1978, the cities along the coast have become areas in which all nationalities from around the country gather.<sup>25</sup> As many Uyghurs have pursued opportunities for development, in order to improve their economic situation, they have also followed this trend and moved to those coastal cities.

A study entitled "An Investigation on the Xinjiang Village in Beijing - The Changes of Xin-

jiang Village in Beijing", which was carried out by Yang Sheng-min from the Sociology Department of Beijing University and Wang Han-sheng from the School of Ethnology and Sociology of Minzu University of China, focused on the Floating Uyghur population in Beijing. The research involved the distribution of questionnaires to the minority people living in an area of Beijing called "Xinjiang Village". The results of this research showed that Uyghurs made up 92.1% of the respondents. Of the 203 participants in the investigation, 187 were Uyghurs and 11 were members of other minorities. The identity of 5 respondents was unknown. Unfortunately, even though this investigation was carried out in October 2000, and the statistical analysis was finalised in 2001, the study was then not published until 2008.<sup>26</sup> By that time, the "Xinjiang Village", which is also known as Weigongcun, had been bulldozed in 2005. There are now only two big Uyghur restaurants, and there are not as many Uyghurs living there as before. While there has so far been no academic research carried out into the reasons for the eviction of Weigongcun, a few government-hosted websites have claimed that the evacuation was carried out in order for municipal construction to take place in Beijing.<sup>27</sup> Other commentators have suggested that the evacuation was carried out in order to enhance the security arrangements for the 16<sup>th</sup> meeting of the Chinese Communist Party in Beijing.<sup>28</sup> It has also been suggested that the destruction of Weigongcun was a deliberate move by the authorities to expel Floating Uyghurs from the Chinese capital.

### **1.3 The Composition of Uyghurs Living in China Proper**

The Uyghurs living in China Proper can be divided into the following categories:<sup>29</sup>

1) Uyghurs who were born and grew up in China Proper, who are fluent in Chinese, but are unable to speak well in their mother tongue of Uyghur;

2) Uyghur students who are studying in universities in China Proper, most of whom are fluent in both Chinese and Uyghur;

3) The Floating Uyghur population which is fluent in Uyghur but speaks poor Chinese and has a very limited education; and

4) Uyghurs who are working in factories in cities such as Beijing and Tianjin and the provinces like Zhejiang and Shandong,<sup>30</sup> most of whom are young people who are fluent in Uyghur but have only completed compulsory education and thus have very limited ability in speaking Chinese.

## 2. The Pains Faced by Uyghurs in China Proper

### 2.1 Serious Health Issues

“On 27<sup>th</sup> August 2009, a patient died who was 28 years old. It was only about six months after he found out that he was HIV positive. He had been living in Beijing for many years. He had been using drugs for five years. He lived alone. He didn’t have too much contact with his home (Xinjiang Uyghur Autonomous Region). He had no job. He died in the street in the capital of China where many Uyghur youths came with high hopes that they could have a better life than in Xinjiang and that they could share the modernization of our country.”<sup>31</sup>

HIV/AIDS represents one of the main health crises currently facing Uyghurs living in China Proper.<sup>32</sup> According to a report from the government-created Think Tank Research

Centre for Health Development,<sup>33</sup> the only organisation other than Beijing AIZHIXING Institute which conducted a needle-exchange program among Uyghurs in Beijing, the percentage of Uyghur drug-users who have been diagnosed with HIV/AIDS is a shocking 51.97%.<sup>34</sup> In an open letter to the Beijing Public Security Bureau, Wan Yanhai (a prominent Chinese human rights activist and the director of Beijing AIZHIXING Institute) stated:

“On January 11, 2009, accompanied by the volunteers, I went to the Beijing Daxing District to visit a female AIDS patient. When we arrived at her home, we found that she was lying on the bed in pain. (...) We promised to take her to the hospital the next day. Unfortunately, in the same evening, we got the news that the woman had died. (...) During the same week we heard that two other Uyghur women had died because of HIV. I not only feel sorry for the women, but also realised that our city is not treating the Uyghur people from Xinjiang well. They died not because of a lack of medical treatment, but because of the lack of healthcare, which our government is supposed to provide to poor AIDS patients.”<sup>35</sup>

Marginalisation, drug use and the inability to access healthcare in the area in which they are living have become common features of life for the Floating Uyghurs.<sup>36</sup> Despite the existence in Beijing and other urban centres of a State Ethnic Affairs Commission, whose responsibilities include conducting studies related to ethnic issues, making relevant policies, and coordinating and monitoring the conduct of other agencies with obligations relating to ethnic minorities,<sup>37</sup> there are no government-supported projects or funds available to solve the health crisis which the Floating Uyghurs face. Even when the Chi-

nese government invested significant funds in support of HIV/AIDS projects in XUAR,<sup>38</sup> very little attention was given to the Floating Uyghurs living in China Proper, despite the seriousness of their healthcare problems being clearly evident.

## 2.2 Access to Housing

In addition to suffering from lack of access to adequate healthcare, the Floating Uyghurs also face challenges in obtaining access to housing. The housing issue has become yet another concern and difficulty in the lives of the Uyghurs in China Proper. A report entitled "A Glimmer of Ethnic Harmony", published in a high profile political magazine, stated:

"Over 100 Uyghurs are living in Daxing district in Beijing. Before October 2009, nobody would rent rooms to them. When it turned dark, they went to internet bars or public bathrooms to spend the night. Two months ago, a staff member who is working for AIZHIXING Institute came to them and started to help them with rental. The staff knocked on the door one by one and communicated with homeowners. Until now, he arranged rooms for more than 30 people. If each of them could help another person, then there would be more than 60 people settled down."<sup>39</sup>

The same report cited part of an interview with a female migrant:

"We are no wolves! No need to drive me out, I'm not entering your home!" said Mlika, a 40-year-old Uyghur woman, with trembling voice, and who couldn't hide her emotions. 'It is your home not ours. If I ever did anything bad, you could drive me out.... if you let, we stay; if not, we leave. We are not servants, not wolves, why do you keep yelling 'out' 'out' at us!'"<sup>40</sup>

During a site visit carried out by Beijing AIZHIXING Institute as part of its Uyghur Project, members of the Floating Uyghur population expressed their anger at not being able to rent houses from the local residents. The few Floating Uyghurs who were able to rent accommodation found themselves paying much more than other Han Chinese renters in the same area.<sup>41</sup>

Another common form of discrimination against the Floating Uyghurs is that it is also very difficult for them to stay in a hotel.<sup>42</sup> This makes their lives even more difficult and frustrating as they cannot live as real Chinese citizens, as the Han people, and they are always treated like second class citizens. The case given below is a typical example:

"On 22<sup>th</sup> October, Beijing AIZHIXING Institute planned to have a meeting in Beijing Zhongshilong Hotel. Finally we chose not to hold one there since in the agreement we found a clause saying: 'In accordance with the Municipal Regulation our hotel will not accept customers from XUAR and Tibet'"<sup>43</sup>

These cases demonstrate the violation of the fundamental rights of Uyghurs who should clearly be protected by the principle of non-discrimination established in many international treaties, as well as the PRC Constitution. Owing to a lack of sufficient evidence, it is very hard to challenge such violations so the Floating Uyghurs continue to face these difficulties.

## 2.3 Access to Employment

Given the difficulties which many Floating Uyghurs have with speaking the Chinese language, it has become extremely hard for Uyghurs, especially those who have received limited education, to find employment in China Proper. No solid estimates of unem-

ployment rates among the Floating Uyghurs are available. However, when interviewed in 2009, a Uyghur man in a Uyghur restaurant in Weigongcun told Beijing AIXHIXING Institute:

“I can be a security guard, or I can start my own small business, but they never will hire us. And to get a license is not easy. You need to know some people in related agencies.”<sup>44</sup>

A Uyghur interviewee in Shenzhen stated:

“One day after lunch I saw many Han local residents just chasing someone. Out of curiosity, I asked them in English what had happened. One of them told me that they were some thieves from XUAR. Now finally they had been caught. I feel very bad. I even cannot tell them that I am Uyghur too.”<sup>45</sup>

Many Uyghurs who work in China Proper and who belong to the first and second categories referred to in section 1.3 above, are not willing to talk about the Floating Uyghurs, since many of them feel ashamed. They feel that such people do not deserve to be helped since they are ruining the reputation of Uyghurs.<sup>46</sup> They tend to be students who choose to find a job after graduating from University. The desire to become a good Uyghur is widespread amongst Uyghurs living in China Proper, since Uyghurs feel one individual’s reputation could influence the whole nation.

In a society like China which does not have freedom of information or free media, the relationship between the Han Chinese and the Floating Uyghurs has grown even worse. In many public discussions, when Uyghurs speak of the discrimination which they face and their own situation in general, they are branded as “separatist”.<sup>47</sup> This reflects the

fact that China has become noticeably more nationalist since the early 1990s<sup>48</sup> and, also, it represents the Han Chinese government’s hard-line reaction to the rising desire for independence amongst the Uyghurs.<sup>49</sup>

#### 2.4 Routine Checks and “Special” Treatment before Big Events

As the Floating Uyghurs mostly originate from the XUAR, they have been affected by the governmental policy towards Uyghurs in the XUAR in many respects. For instance, shortly after the terrorist attacks on the United States of America on 11 September 2001, public statements by Chinese authorities signalled the official decision to use the “global war on terror” to intensify the repression of Uyghur people.<sup>50</sup> When it comes to Floating Uyghurs, the situation might be more serious. Some of the Floating Uyghurs are involved in criminal acts.<sup>51</sup> The statements of the authorities relating to the Uyghur population gave police extensive rights to check Uyghurs arbitrarily, to examine their identity cards and their temporary residential cards, to carry out urine tests, and to expel them from big events. This happened on a number of occasions, including: (i) the 2008 Beijing Olympic Games; (ii) the 2009 60<sup>th</sup> Anniversary of the PRC; (iii) the Shanghai expo of 2010; and (iv) the Guangzhou Asian Games.<sup>52</sup> In the summer of 2009, during a site visit of Beijing AIXHIXING Institute to the Daxing district of Beijing, members of the Floating Uyghur community expressed their response to such violations:

“If the police have enough evidence to arrest us, they can do it. And we will say nothing to this. But they will check us whenever they want, and treat us like criminals all the time. Tell me are we Chinese or not?”<sup>53</sup>

A woman named Guli said: "As soon as we want to say something to protest against unjust treatment, they will accuse us of 'separatism' or some other crimes related to politics." A Uyghur man added: "So we just try to be quiet."<sup>54</sup>

Although the Chinese propaganda about the threat of Uyghur terrorism occasionally noted that only a small number of Uyghurs were "separatist-fundamentalist-terrorists", policies such as the general round-up and relocation of Uyghurs residing in Beijing and Shanghai before the Olympics implied that no Uyghurs were to be trusted. A stereotype developed, even among well-educated urban Han Chinese, through which Uyghurs came to be viewed as ungrateful, lazy, violent, knife-carrying, pick-pocketing criminals, in addition to being potential terrorists.<sup>55</sup>

### 3. Legal Analysis

There are many domestic laws in China which cite the principles of non-discrimination and equal treatment before the law.<sup>56</sup> However, the examples provided in this article demonstrate that in practice the domestic laws do not protect and fulfil the equal rights of the Floating Uyghurs.

#### 3.1 The Rights to Equality and Non-discrimination

According to Article 33 of the 1984 PRC Constitution, all Chinese citizens should be treated equally. This constitutional principle is bolstered by the obligations which China has assumed under many international treaties including, for example, the International Convention on the Elimination of All Forms of Racial Discrimination (ICERD).<sup>57</sup>

#### 3.2 Domestic Laws

Article 4 of the PRC Constitution provides the fundamental principles of non-discrimi-

nation and equality of all nationalities, while carrying a prohibition against secessionism. It states:

"The state protects the lawful rights and interests of the minority nationalities and upholds and develops the relationship of equality, unity and mutual assistance among all of China's nationalities. Discrimination against and oppression of any nationality are prohibited; any acts that undermine the unity of the nationalities or instigate their secession are prohibited. The state helps the areas inhabited by minority nationalities speed up their economic and cultural development in accordance with the peculiarities and needs of the different minority nationalities. Regional autonomy is practised in areas where people of minority nationalities live in compact communities; in these areas organs of self-government are established for the exercise of the right of autonomy. All the national autonomous areas are inalienable parts of the People's Republic of China. The people of all nationalities have the freedom to use and develop their own spoken and written languages, and to preserve or reform their own ways and customs."

It is clear that this provision of the PRC Constitution should offer protection to the Floating Uyghurs. The Chinese government should take responsibility for the protection and fulfilment of Uyghur rights, as clearly required by the domestic laws.

As regards the healthcare and housing issues facing the Uyghurs, along with their inability to obtain legal assistance, and especially the problems facing the much more vulnerable Floating Uyghurs, it is evident that the Uyghurs are not being provided with sufficient state protection. Even worse, their fundamental rights of equality are being violated by the state. It should be added that whilst

this article addresses the particular problems facing the Floating Uyghur population, the Chinese government fails to comply with its constitutional obligations towards many of China's migrant workers.

Article 3 of the PRC Employment Promotion Law provides that all workers have the right to choose their job: "The employment of the workers cannot be discriminatory in terms of nationality, race, gender, and religious belief."<sup>58</sup> This provision affirms the right of all persons to have equal opportunity in choosing jobs within the employment market. In the context of the Floating Uyghurs, these laws are simply not being enforced, as is evident from the interviews of Uyghurs referenced in this article, and those featured in Beijing AIZHIXING Institute's report, *Human Rights Report on Uyghurs Living in Innerland China - According to Uyghurs in Beijing*.<sup>59</sup>

### 3.3 International obligations

Non-discrimination and equality are fundamental principles of international human rights law, and apply to ethnic minorities. They are provided in the Universal Declaration of Human Rights (UDHR), and international treaties have built on these basic principles.<sup>60</sup> The ICERD, for example, includes prohibitions against all forms of racial discrimination, whether based on race, colour, descent, or national or ethnic origin, and calls for the pursuance of a policy eliminating racial discrimination. More recently, the 1992 UN Declaration on the Rights of Persons Belonging to National or Ethnic, Religious and Linguistic Minorities (UNDM)<sup>61</sup> elaborated the full range of minority rights. An authoritative interpretation of the UNDM stated that in the absence of a UN treaty directed entirely towards minority rights, the UNDM represents a universal baseline standard for minority rights under international law.<sup>62</sup>

In addition, as a State Party to the International Covenant on Economic, Social and Cultural Rights,<sup>63</sup> the International Convention on the Elimination of Racial Discrimination,<sup>64</sup> the International Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW),<sup>65</sup> the Convention Against Torture and other Cruel, Inhumane, or Degrading Treatment or Punishment (CAT),<sup>66</sup> and the Convention on the Rights of Child,<sup>67</sup> the Chinese government is bound to implement these rights, including non-discrimination and additional protections for minorities, and report on its compliance and implementation.<sup>68</sup> Compliance with such obligations would go a long way to protecting the rights of the Floating Uyghurs.

### 3.4 China's Failure to Meet its Obligations

While many laws, regulations, policies and statements address the importance of equality among Chinese ethnic groups, the Chinese government is not meeting its obligations, at either the domestic or international level, to protect and fulfill the rights of minorities. The examples referred to in this article provide evidence of this failure.

The obstacles for meeting these obligations include: (i) gaps between central policies and local implementation; (ii) the lack of a legal definition of discrimination; (iii) the lack of systematic and effective monitoring and assessment of implementation; and (iv) poor institutional capacity.<sup>69</sup> Further, when it comes to the Floating Uyghurs, in most situations they seem to have become invisible through living in isolation, and the government is therefore less willing to address the violations which they face.

## 4. Conclusions - The Pain Continues

In recent years, China has acknowledged some of its problems, particularly in relation

to the growing economic gap between the coastal provinces and the Western regions. Despite this acknowledgement and some progress being made in relation to these problems, China continues to use its “developing” country status to defend itself against criticism of its human rights policies.<sup>70</sup> These tactics simply ignore the “pains” of the Floating Uyghurs. As mentioned above, there were not enough funds given to implement the health project for all Floating Uyghurs living in China Proper. Further, as the only NGO conducting a Uyghur healthcare and legal assistance project in Beijing and Kunming, Beijing AIZHIXING Institute has faced significant interference from the Chinese government.<sup>71</sup> The harassment, intimidation and threats peaked during periods in which China was in the international spotlight. A month before both the Olympic Games in 2008 and the 60-year anniversary of the People’s Republic Of China in 2009, Beijing AIZHIXING Institute was forced to cease operation temporarily.<sup>72</sup> According to a report in *Global Times*, Deng Shengguo, Deputy Director of the NGO Research Centre at Tsinghua University, stated that the government is imposing tighter regulations on NGOs because it fears that they are a potential source of social unrest through political mobilisation.<sup>73</sup> As a result of such interferences, Beijing AIZHIXING Institute has been forced to delay some of its outreach projects in several communities. Along with this, the Uyghur project targeting the Uyghur population in Beijing has been delayed, while the Uyghur staff members of the Beijing AIZHIXING Institute were compelled to leave Beijing for Kunming.

In January 2006, an online project was launched by Ilham Tokhti, an outspoken Uyghur Professor of Economics,<sup>74</sup> who hopes to discuss openly the issues which Uyghurs face in China. Professor Tokhti said in a recent interview in *The New York Times*: “I am wor-

ried that many of my people might be driven to extremism.”<sup>75</sup>

While this comment mainly relates to the Uyghurs in XUAR, the similar situation facing the Floating Uyghurs in China Proper suggests that another alarm should be sent to the authorities in relation to the Floating Uyghurs. Aside from the two independent groups, Beijing AIZHIXING Institute and the Uighurbiz Network, who have openly spoken out on behalf of the Floating Uyghurs, there are very few groups who are working to resolve the problems and discrimination which the Floating Uyghurs face in China Proper. Minority issues in China are hugely sensitive, as demonstrated to the international community, as well as the Chinese government, when the riot took place in Urumqi on 5 July 2009.<sup>76</sup> If the Chinese government does not provide legal enforcement to protect the Floating Uyghurs from all forms of discrimination and inequality, then it will be hard to avoid another conflict of this nature.

## 5. Urgent Action

Investigations must be carried out in order to establish who is responsible for the systemic failures in protecting the rights of the “invisible” Floating Uyghurs, and the government must be encouraged to take action in order to fulfil its obligations to every citizen in its territory. In his open letter to the Beijing Municipal Bureau, Wan Yanhai wrote that:

“[T]he government should stop unfriendly actions towards Uyghurs in Innerland China, such as separatist propaganda; the government should allocate funds to help the Uyghur community, including the development of education, community social organizations, employment opportunities and medical services; it should encourage organizations to carry out comprehensive

health education and provide health services among Uyghur floating populations in China Proper; it should make urgent arrangements for medical treatment and HIV/AIDS care among them as well; it should provide drug treatment services and carry out harm reduction programmes among Uyghur drug users living in China Proper.”<sup>77</sup>

To protect the Floating Uyghurs, the Chinese government must also ensure effective protection against discrimination.<sup>78</sup> The Chinese government should be encouraged to implement its obligations under the ICERD and other international treaties. In its report, *China: Minority Exclusion, Marginalization and Rising Tensions*, Human Rights in China addresses issues relating to minority rights. It recommends that the Chinese government should give full effect in its domestic law to ICERD’s provisions and all other international human rights treaties ratified by China, and should ensure that individuals are afforded access to effective protection and legal and administrative remedies through competent and independent institutions and processes.<sup>79</sup> Without taking such steps, China will not only trigger the discontent of the Uyghurs but in the long term, the Han people will also suffer and a “chain reaction” effect will impact on the stability of the whole society as the ordinary Han people may become the object of revenge, as seen in the tragic events of 5<sup>th</sup> July 2009.<sup>80</sup>

There are currently very limited freedoms given to reporters in China. Some independ-

ent reports relating to the lives of the Floating Uyghurs could be found,<sup>81</sup> and it is hoped that these will help the public to see the pains that the Floating Uyghurs are suffering whilst living far from their homeland and familiar culture. It is hoped that these reports will add to the understanding of human feeling and the common sense of brotherhood and real friendship. The immediate action of the media is inevitably required in order to raise public awareness.<sup>82</sup>

Finally, any project aiming to help or promote the rights of the Floating Uyghurs should consider encouraging the people from that community to become actively involved in the project and to communicate with the local Han people in any possible way. On the one hand, it is only when the voice of the Floating Uyghurs is heard by the policy-makers, legislators and local officials responsible for implementation, that the rights of those people will be protected adequately and effectively. On the other hand, it will only be when it is ensured that people from the suffering Floating Uyghur community are actively involved in those processes or projects, that they will really receive benefits.

In reality, the relationship between the Han Chinese and the Floating Uyghurs will be improved only when the two communities have a mutual understanding of one another’s culture and respect for one another’s customs. Only then could real social harmony be achieved.<sup>83</sup>

<sup>1</sup> M. Rayila formerly worked for Beijing AIXHIZING Institute and is now participating in a Fellowship Programme at The Centre for Applied Human Rights at The University of York.

<sup>2</sup> Human Rights Watch, *China: "We Are Afraid to Even Look for Them": Enforced Disappearances in the Wake of Xinjiang's Protests*, 20 October 2009, available at: <http://www.hrw.org/en/node/86103/section/1>.

<sup>3</sup> Congressional -Executive Commission on China, "Details of the July 5 Demonstration", available at: [www.cecc.gov/pages/virtualAcad/index.phpd?showsingle=125582](http://www.cecc.gov/pages/virtualAcad/index.phpd?showsingle=125582).

<sup>4</sup> Rebiya Kadeer, "Unrest in East Turkestan: What China is Not Telling the Media", 20 July 2009, available at: <http://www.uhrp.org/articles/2539/1/Unrest-in-East-Turkestan-What-China-is-Not-Telling-the-Media-/index.html>.

<sup>5</sup> See above, note 2, p. 8.

<sup>6</sup> Bovington, G., *The Uyghurs: Strangers in Their Own Land*, Columbia University Press, 2010, p. 170.

<sup>7</sup> Millward, J. A., "Introduction: Does the 2009 Urumchi violence mark a turning point?", *Central Asian Survey*, Vol. 28 (4), 2010, p. 11.

<sup>8</sup> Editor's note: "China Proper" is the name used to describe the part of inner-land China which has traditionally been occupied by Han Chinese. Today, "China Proper" is a controversial term in China, since the current official discourse does not contrast the core and the periphery of China. The term "China Proper" is officially avoided as it may be interpreted to justify separatism. On the other hand, many authors use this term to make a difference between "China Proper" as a culturally defined nation and "China" as a political entity.

<sup>9</sup> See, for example, Millward, J. A., *Eurasian Crossroads: A History of Xinjiang*, Columbia University Press, 2007; Tyler, C., *Wild West China: The Taming of Xinjiang*, Rutgers University Press, 2004; Frederick Starr, S. (ed.), *Xinjiang: China's Muslim Borderland*, M. E. Sharpe, 2004; also see above, note 6.

<sup>10</sup> During two years of working for Beijing AIZHIXING Institute, the author had the opportunity to engage in a Uyghur project in Beijing, through which many of the difficulties facing the Uyghurs in China Proper in their daily lives were witnessed. As a Floating Uyghur living in Beijing, the author has faced discrimination at the hands of the majority Han Chinese people, even though the author is in a better situation than many other Floating Uyghurs as a result of her education and ability to speak Mandarin.

<sup>11</sup> Hess, S., "Dividing and Conquering the Shop Floor: Uyghur Labor Export and Labor Segmentation in China's Industrial East", *Central Asian Survey*, Vol. 28(4), 2009, pp. 403-416.

<sup>12</sup> Beijing AIZHIXING Institute is one of the largest health rights NGOs in China established in 1994. Its purpose is to fight discrimination, advocate for equal access to health and social services among marginalised communities and also to advocate for an accountable legal system and government transparency in order to build a more robust platform for human rights in China, and to participate in community service programs. The author withholds the names of her colleagues for their own safety. For more information, see the organisation's website: [www.aizhi.net](http://www.aizhi.net). See also: <http://uob0w1.chinaw3.com/en/?p=12>.

<sup>13</sup> It is unfortunate that owing to lack of resources, Beijing AIXHIXING Institute was unable to extend the scope of the Uyghur Project to include other cities where Floating Uyghurs live, such as Guangzhou, Shanghai, Zhenzhou and Nanjing. Further research into the daily experiences of the Floating Uyghurs in these cities should also be carried out in order to assess whether the patterns of discrimination identified in this article are more widely spread as is believed by the author to be the case.

<sup>14</sup> The speech is transcribed in Ma, R., "Several Issues in Ethnic Relations in Urban China", *North West Ethno-national Studies*, Issue 1, 2009, pp. 6-19.

<sup>15</sup> National Population and Family Planning Commission of China, *The 2010 Report on the Development of China's Floating Population*, 2010, available at: [http://www.chinapop.gov.cn/xwzx/zwyw/201006/t20100626\\_208390.html](http://www.chinapop.gov.cn/xwzx/zwyw/201006/t20100626_208390.html).

<sup>16</sup> Hays, J., "Facts and Details. Migrant Workers in China", 2008, last updated February 2011, available at: <http://factsanddetails.com/china.php?itemid=150&catid=11&subcatid=72#11>.

<sup>17</sup> The International Work Group for Indigenous Affairs, *The Indigenous World 2010*, 2010, available at: [http://www.iwgia.org/graphics/Synkron-Library/Documents/publications/Downloadpublications/IndigenousWorld/IW\\_%202010\\_WEB.pdf](http://www.iwgia.org/graphics/Synkron-Library/Documents/publications/Downloadpublications/IndigenousWorld/IW_%202010_WEB.pdf).

<sup>18</sup> Branigan, T. and Weaver, M., "Q&A: China and the Uighurs", *guardian.co.uk*, 6 July 2009, available at: <http://www.guardian.co.uk/world/2009/jul/06/china-muslim-uighurs-background>.

<sup>19</sup> See, for example, The Uyghur American Association website: [www.uyghuramerican.org](http://www.uyghuramerican.org).

<sup>20</sup> Millward, J. A., and Perdue, P. C., "Political and Cultural History of Xinjiang Region through the Late Nineteenth Century", in Frederick Starr, S. (ed.), *Xinjiang: China's Muslim Borderland*, M. E. Sharpe, 2004, p. 77.

<sup>21</sup> *Ibid.*, p. 81.

<sup>22</sup> Mackerras, C., *China's Ethnic Minorities and Globalization*, Routledge-Curzon, 2003, p. 56.

<sup>23</sup> See the related Chinese website: <http://www.chinawest.gov.cn/>.

<sup>24</sup> Human Rights in China and Minority Rights Group International, *China: Minority Exclusion, Marginalization and Rising Tensions*, 2007, available at: [www.hrichina.org/public/PDFs/MRG-HRIC.China.Report.pdf](http://www.hrichina.org/public/PDFs/MRG-HRIC.China.Report.pdf).

<sup>25</sup> Xiao-wen, L., "On the Relationship Between Multi-nationality and Multi-culture of City - Taking Coastal Cities in Guang Dong Province as Example", *Journal of Youjiang Teachers College for Nationalities Guangxi*, Issue 1, 2005, p. 18.

<sup>26</sup> Han-sheng, W. and Sheng-min, Y., "Formation and Evolution of Compact Community for Minority Floating Population in Big City - A Case Study of Xinjiang Village in Beijing", *North West Ethno-National Studies*, Issue 3, 2008, pp. 6-16.

<sup>27</sup> See the comment from Fengping, P. (ed.), *China National Religion*, 27 October 2009, available at: <http://www.mzzjw.cn/html/report/107627-1.htm>.

<sup>28</sup> "Beijing Xinjiangcun more than 100 residents sent back to Xinjiang", *China Watch*, 6 November 2002, available at: <http://www.kanzhongguo.com/node/27977>.

<sup>29</sup> This categorisation is taken from an online conversation between Wan Yanhai and other web users about the social issues and human rights of Uyghurs in Inner-land China on 26 August 2010, available at: [www.1984bbs.com](http://www.1984bbs.com).

<sup>30</sup> See above, note 14, p. 7.

<sup>31</sup> Zhuhe, "When will the dying stop?", *Outreach Diary of Beijing AIZHIXING Institute Uyghur Project*, August 2009.

<sup>32</sup> Deutscher, J., "Public Health and Social Pathologies in Xinjiang", in Frederick Starr, S. (ed.), see above, note 20, p. 276.

<sup>33</sup> Chinese name 北京新探健康发展研究中心, available at: <http://www.healthtt.org.cn/>.

<sup>34</sup> This figure was taken from a power-point presentation by Cao Xue-yi entitled "Concerning the HIV/AIDS Assistance and Treatment of Migrant Drug Users" which was given at a conference at the Beijing Think Tank Health Development Centre on 4 December 2009.

<sup>35</sup> Yanhai, W., "An Open Letter to Beijing Municipal Security Bureau: Regarding the Uyghur Residents in Beijing", January 2009, available at: [www.aizhi.net](http://www.aizhi.net). Translated from Chinese by the author.

<sup>36</sup> *Ibid.*

<sup>37</sup> A description of The State Ethnic Affairs Commission (Chinese version) is available at: [http://www.seac.gov.cn/gjmw/mwjs/M08index\\_1.htm](http://www.seac.gov.cn/gjmw/mwjs/M08index_1.htm). For an English translation, see the website of the US-China Business Council, available at: [http://www.uschina.org/public/china/govstructure/govstructure\\_part5/26.html](http://www.uschina.org/public/china/govstructure/govstructure_part5/26.html).

<sup>38</sup> See, for example, the description of the joint programme carried out by the Chinese Government and AusAID entitled "Xinjiang HIV/AIDS Prevention and Care Project", available at: [http://www.usaid.gov/australia/projects/xin\\_hiv.cfm](http://www.usaid.gov/australia/projects/xin_hiv.cfm). See also the description of the joint programme carried out by The Joint United Nations Programme on HIV/AIDS and the Chinese Government entitled "UN Joint Programme on AIDS in China (2007- 2010)", available at: <http://www.unaids.org.cn/en/index/page.asp?id=159&class=2&classname=UN+Joint+Programme>.

<sup>39</sup> Jian-feng, Z., "A Glimmer of Ethnic Harmony", *Nan Feng Chuang*, Issue 12, 2009. Translated from Chinese by an anonymous volunteer of Beijing AIZHIXING Institute.

<sup>40</sup> *Ibid.*

<sup>41</sup> See *Outreach Diary of Beijing AIZHIXING Institute Uyghur Project*, above note 31.

<sup>42</sup> "Uyghur Civil Rights Movement: No Uyghurs in Our Hotel!", *The New Dominion*, 20 October 2008, available at: <http://www.thenewdominion.net/395/the-uyghur-civil-rights-movement-no-uyghurs-in-our-hotel/>. See also

York, G., "Beijing welcomes world but not its own ethnic minorities", *Scripps News*, 18 July 2008, available at: <http://www.scrippsnews.com/node/34853>.

<sup>43</sup> Beijing AIZHIXING Institute, *Human Rights Report on Uyghurs Living in Inner-land China - According to Uyghurs in Beijing*, April 2010. Translated from Chinese by the author.

<sup>44</sup> See *Outreach Diary of Beijing AIXHIXING Institute Uyghur Project*, above note 31.

<sup>45</sup> Unpublished interview with a Uyghur man working in Shenzhen conducted by the author in December 2010.

<sup>46</sup> Taken from a discussion which the author participated in with Uyghurs working in China Proper on an online chat forum in March 2009.

<sup>47</sup> Uyghur Human Rights Project, *Persecution of Uyghurs in the Era of "War on Terror"*, 16 October 2007, p. 7, available at: [http://uhrp.org/docs/Persecution\\_of\\_Uyghurs\\_in\\_the\\_Era\\_of\\_the\\_War\\_on\\_Terror.pdf](http://uhrp.org/docs/Persecution_of_Uyghurs_in_the_Era_of_the_War_on_Terror.pdf).

<sup>48</sup> See above, note 22, p. 37.

<sup>49</sup> See above, note 6, pp. 170-171.

<sup>50</sup> See above, note 47, p. 1.

<sup>51</sup> See above, note 22, p. 65.

<sup>52</sup> See above, note 43, p.19.

<sup>53</sup> See *Outreach Diary of Beijing AIXHIXING Institute Uyghur Project*, above note 31.

<sup>54</sup> *Ibid.*

<sup>55</sup> See above, note 7, pp. 4-5.

<sup>56</sup> See, for example, Article 20 of The Labor Law of People's Republic of China 1995 (available at: <http://www.usmra.com/china/Labour%20Law.htm>), Article 3 of PRC Employment Promotion Law 2008 (available at: <http://www.chinalawandpractice.com/Article/1777243/Channel/9931/PRC-Employment-Promotion-Law.html>), and The Notice on Strict Implementation of the State Policy on Minorities issued in May 2008.

<sup>57</sup> China signed the International Convention on the Elimination of Racial Discrimination on 29 December 1981 and subsequently ratified it on 28 January 1982.

<sup>58</sup> PRC Employment Promotion Law 2008, available at: <http://www.chinalawandpractice.com/Article/1777243/Channel/9931/PRC-Employment-Promotion-Law.html>.

<sup>59</sup> See above, note 43.

<sup>60</sup> *Ibid.*, p. 10.

<sup>61</sup> UN Declaration on the Rights of Persons Belonging to National or Ethnic, Religious and Linguistic Minorities, A/RES/47/135, 18 December 1992.

<sup>62</sup> See above, note 24, p. 12.

<sup>63</sup> China signed the International Covenant on Economic, Social and Cultural Rights on 27 October 1997 and subsequently ratified it on 27 March 2001.

<sup>64</sup> See above, note 57.

<sup>65</sup> China signed the Convention on the Elimination of All Forms of Discrimination Against Women on 17 July 1980 and subsequently ratified it on 4 November 1980.

<sup>66</sup> China signed the Convention Against Torture and Other Cruel, Inhuman and Degrading Treatment or Punishment on 12 December 1986 and subsequently ratified it on 4 October 1988.

<sup>67</sup> China signed the Convention on the Rights of the Child on 29 August 1990 and subsequently ratified it on 2 March 1992.

<sup>68</sup> See above, note 24, p. 31.

<sup>69</sup> *Ibid.*, p. 32.

<sup>70</sup> *Ibid.*, p. 33.

<sup>71</sup> The Congressional-Executive Commission on China, *Annual Report 2010*, One Hundred Eleventh Congress,

Second Session, 10 October 2010, available at: <http://www.cecc.gov/pages/annualRpt/annualRpt10/CECCannRpt2010.pdf>.

<sup>72</sup> Yanhai, W., "My Departure from China: Testimony from a Human Rights Defender", *The Equal Rights Review*, Vol. 5, 2010, pp. 93-98.

<sup>73</sup> Han, Z., "NGOs Feel the Squeeze", *Global Times*, 19 May 2010, available at: <http://special.globaltimes.cn/2010-05/533426.html>.

<sup>74</sup> Ilham Tokhti is an Economics Professor at The Central National University. See also blogs by Zhangjin, H. and Goodbye, I., 12 July 2009, available at: <http://www.bullogger.com/blogs/huangzhangjin/archives/305303.aspx>.

<sup>75</sup> "Uighur Intellectual who won't back down in China", *The New York Times*, 20 August 2010, available at: <http://www.nytimes.com/2010/08/21/world/asia/21china.html>.

<sup>76</sup> See above, note 2, p. 8.

<sup>77</sup> See above, note 35.

<sup>78</sup> See above, note 24, p. 33.

<sup>79</sup> *Ibid.*, p. 34.

<sup>80</sup> "Death toll of Urumqi riot rises to 192", *China View*, 15 July 2009, available at: [http://news.xinhuanet.com/english/2009-07/15/content\\_11713238.htm](http://news.xinhuanet.com/english/2009-07/15/content_11713238.htm). According to reports of the Chinese government, 134 of those who died in the riot were Han Chinese.

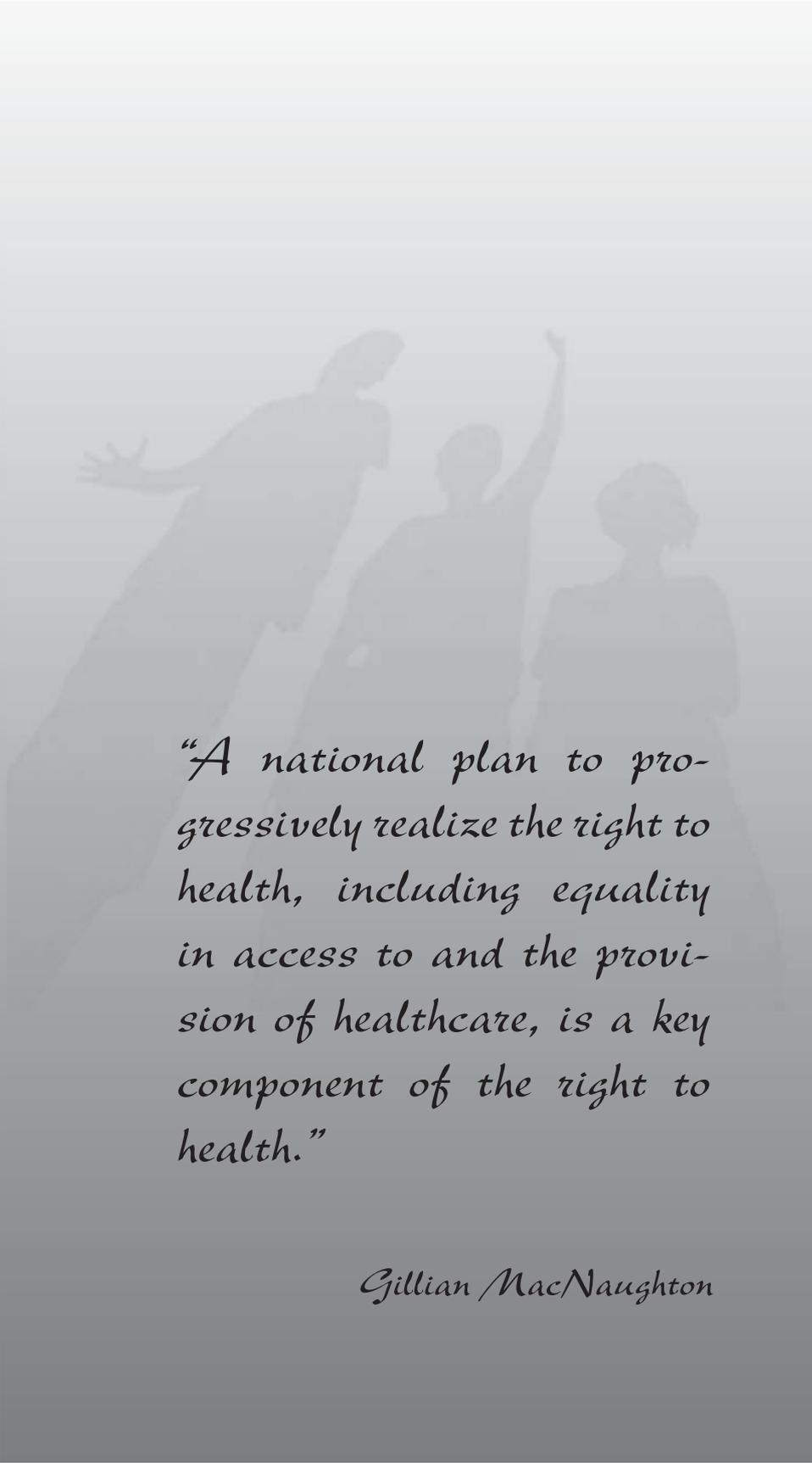
<sup>81</sup> See, for example, Deng, L. and Muzapar, K., "Innerland China Street Children Investigation", *Phoenix Weekly*, Issue 17, 2007.

<sup>82</sup> See above, note 43, p. 21.

<sup>83</sup> Acknowledgement: Thanks to Beijing AIZHIXING Institute and its staff with particular mention for Izzet and Akbar. I am also grateful for the useful information which I obtained from Uyghur organizations abroad and The Minority Rights Group International. I would also offer special thanks to Libby Clarke of The Equal Rights Trust.



# SPECIAL



*“A national plan to progressively realize the right to health, including equality in access to and the provision of healthcare, is a key component of the right to health.”*

*Gillian MacNaughton*



# Healthcare Systems and Equality Rights

Gillian MacNaughton<sup>1</sup>

## Introduction

Health and equality are inextricably linked. As Richard Wilkinson and Kate Pickett document in *The Spirit Level: Why More Equal Societies Almost Always Do Better*, inequality is simply unhealthy.<sup>2</sup> More unequal societies are associated with lower life expectancy, higher rates of infant mortality, lower birth weight, and greater rates of depression, among other poor health indicators.<sup>3</sup> Additionally, for individuals, lower social status correlates to worse health outcomes at every level of the social hierarchy.<sup>4</sup> In short, inequality at both the individual and societal level impacts adversely on health. Moreover, unequal healthcare systems in most countries – so-called tiered systems – exacerbate unequal health outcomes and other inequalities in society because they inevitably provide the least healthcare benefits to those most in need of healthcare.<sup>5</sup> In this light, this article proposes that equality rights – both negative and positive equality rights – could contribute more to promoting the right to health for all.

This article also serves to illustrate the importance of integrating equality rights with social rights. The rights to equality and non-discrimination have great potential to advance social rights, including the right to health. Yet, the relationship between equality and social rights remains underdeveloped and controversial.<sup>6</sup> Indeed, legal scholars have struggled for decades to create a framework that integrates these rights.<sup>7</sup> Commonly, they limit the discussion of equality and social rights to status-based or

“negative equality”. Thus, they rely on data to demonstrate the close correlation of status-based discrimination to socio-economic disadvantage and judicial decisions in cases in which status-based groups are denied social rights.<sup>8</sup> The U.N. Committee on Economic, Social and Cultural Rights similarly asserts that “individuals and groups of individuals continue to face socio-economic inequality, often because of entrenched historical and contemporary forms of discrimination”.<sup>9</sup> Importantly, these discussions reveal the close connections between marginalised groups and marginalized rights.<sup>10</sup>

While recognising that women and other disadvantaged groups are often disproportionately denied their social rights, this article focuses particularly on those disadvantaged in socio-economic terms, poor people. Rather than asserting that the denial of social rights has a disparate impact on legally protected groups – such as women, people with disabilities or certain religious, racial or ethnic groups – it first seeks to establish “economic status” or “poverty” in and of itself as a legally prohibited ground of discrimination in the International Bill of Human Rights.<sup>11</sup> Then moving beyond the notion of status-based or “negative equality”, the article proposes that the International Bill of Human Rights also recognises a positive right to equality.

Legal scholars have long recognised the difference between negative and positive concepts of equality.<sup>12</sup> Mathew Craven, for example,

has explained that positive equality “would require that everyone be treated in the same manner unless some alternative justification is provided”.<sup>13</sup> On the other hand, negative equality would “allow differences in treatment unless they are based upon a number of expressly prohibited grounds”.<sup>14</sup> In other words, positive equality demands equality as the norm and requires justification for any inequality. In contrast, negative equality allows all inequalities and requires justification only in the limited circumstance when a specific inequality is shown to be based on a particular ground that is prohibited in law.

In international human rights law, equality is generally recognised only in its negative form, commonly known as “non-discrimination”.<sup>15</sup> Indeed, numerous international human rights treaties address non-discrimination, including the International Convention on the Elimination of All Forms of Racial Discrimination and the Convention of the Elimination of All Form of Discrimination Against Women.<sup>16</sup> Conversely, the positive right to equality is rarely recognised in international or domestic law. This article proposes recognising that the positive right to equality, derived from Article 26 of the International Covenant on Civil and Political Rights, applies to social rights just as it applies to civil and political rights.<sup>17</sup> In this manner, the article argues that a right to social equality is enshrined in the holistic human rights framework established in the International Bill of Human Rights.

The U.N. Committee on Economic, Social and Cultural Rights asserts: “Guarantees of equality and non-discrimination should be interpreted, to the greatest extent possible, in ways which facilitate the full protection of economic, social and cultural rights.”<sup>18</sup>

This article proposes ways in which the rights to equality and non-discrimination in the International Bill of Human Rights may be interpreted to more fully protect social rights, particularly the right to health. Only by addressing these rights in an integrated and holistic human rights framework can the challenges of realising them be fully understood.

### **1. Health and Inequality**

Inequality is closely connected to poor health outcomes and reduced life expectancy. The disparity in life expectancy between countries is well known. In 2008, the World Health Organization (WHO) Commission on Social Determinants of Health reported that a child born in Lesotho has a life expectancy at birth of 42 years, while a child born in Japan or Sweden has a life expectancy greater than 80 years.<sup>19</sup> Less well known is that there are also enormous health gaps within countries, where life expectancy between social groups varies as much as twenty years.<sup>20</sup> In Australia, for example, the life expectancy for indigenous people is about sixteen years less than the life expectancy for all Australians.<sup>21</sup> In the United States, there is a similar life expectancy gap between blacks living in poor areas and whites living in rich areas.<sup>22</sup> Wilkinson reports the shocking fact that the death rates in the poorest areas of the United States are higher than those in Bangladesh, one of the poorest countries in the world.<sup>23</sup>

The WHO Commission concluded that the “health gap” is caused by inequalities in the social determinants of health, including education, living conditions, employment, social protection and healthcare.<sup>24</sup> It reported that 200 million children globally are not achieving their full development potential because of inadequate nutrition, lack of maternal and

child healthcare, and limited developmental and educational opportunities.<sup>25</sup> Further, urbanisation and the spread of slums are adversely impacting on the quality of air, water and other living conditions.<sup>26</sup> The rise in temporary and part-time work to create a “flexible” and competitive workforce results in employment insecurity for workers adversely impacting on their health.<sup>27</sup> Poverty is a major obstacle to improving population health and reducing health inequality; yet, four out of five people in the world lack basic social security coverage.<sup>28</sup> Finally, 1.3 billion people have no access to healthcare because they cannot afford to pay for it when they need it, while over 100 million people per year are driven below the poverty line due to catastrophic healthcare costs.<sup>29</sup>

In response to these inequalities, the WHO Commission recommended that governments (1) implement universal early childhood development programmes; (2) provide quality universal, compulsory and free primary and secondary education; (3) ensure greater availability of affordable housing and upgrade slums by providing water, sanitation and electrical services for all; (4) provide quality work for men and women with a living wage that takes into account the real cost of healthy living; (5) establish and strengthen universal social protection that supports income sufficient for healthy living; and (6) ensure universal access to healthcare regardless of ability to pay.<sup>30</sup> Notably, these “social determinants of health” correlate closely to the economic and social rights in the International Bill of Human Rights, including the rights to education, adequate housing, clean water and adequate sanitation, social security, full employment and decent work, and the highest attainable standard of health.<sup>31</sup> There is no doubt that ensuring the enjoyment of these human rights by all would im-

prove the health and lives of many people in the world today.

Beyond advancing social rights, Wilkinson and others argue that inequality in a society also impacts adversely on health. In rich countries, he maintains, differences in health outcomes are related to inequalities in income and social status, rather than to an absolute standard of living.<sup>32</sup> To support this contention, Wilkinson documents studies showing that in Taiwan, Canada and the United States, death rates are lowest in areas with the smallest income differentials, rather than in areas with the highest incomes.<sup>33</sup> He maintains that the data “shows very clearly that it is the most egalitarian states and provinces, rather than the richest, that are the healthiest”.<sup>34</sup> Similarly, Wilkinson reports that “at all levels of economic development infant mortality rates tend to be lower in more egalitarian countries”.<sup>35</sup> Even in developing countries, infant death rates are higher for more unequal societies.<sup>36</sup> In sum, there is much evidence to show that “there is indeed a strong tendency for more unequal societies to have lower average standards of health and shorter life expectancies”.<sup>37</sup>

Not only are infant mortality rates greater and life expectancy shorter in more unequal societies, but individuals lower down the social hierarchy have greater social and psychological stress, including depression and anxiety, and shorter life expectancies.<sup>38</sup> Life is shorter and the quality is poorer the farther down the social hierarchy people live.<sup>39</sup> For Wilkinson, these extreme health inequalities must be equated to violations of the right to life.<sup>40</sup> Highlighting this assertion, he suggests: “perhaps we should liken the injustice of health inequalities to that of a government that executed a significant portion of its population each year without cause”.<sup>41</sup>

Indeed, where social policy results in health inequalities that significantly reduce life expectancy, the rights to equality, health and life are all implicated.

In sum, the evidence leaves no doubt that inequality, poor health and low life expectancy are closely connected in many complex ways. In this light, this article discusses avenues for linking equality rights and social rights – particularly the right to health – in a holistic human rights legal framework.

## **2. The Rights to Equality and Non-discrimination**

### **2.1 Meanings of Equality**

Although the right to equality is central to human rights, the meaning of the term continues to be widely debated. Theorists often consider the simplest form of equality to be one-to-one equality.<sup>42</sup> This type of equality is best illustrated in law by the example of one-person-one-vote.<sup>43</sup> The UN Human Rights Committee explains that this principle requires that each elector have one vote and further that each vote count equally.<sup>44</sup> Any inequality between two votes is a violation.<sup>45</sup> This same form of simple one-to-one equality applies to many civil and political rights, such as the rights to freedom of opinion and expression, rights against arbitrary arrest and the right to a fair trial.<sup>46</sup> It also applies in the laws requiring free and compulsory school for all children,<sup>47</sup> and to general rules, such as no-parking signs and speed limits, which also apply equally to everyone.<sup>48</sup>

Another form of equality frequently addressed in law is “bloc equality”.<sup>49</sup> Bloc equality requires equality between blocs but not within blocs. For example, bloc equality might require that the incomes of women on

average be equal to the incomes of men on average.<sup>50</sup> The achievement of bloc equality, however, does not imply the achievement of simple one-to-one equality.<sup>51</sup> Thus, the average incomes of women and men might be equal and yet there might be gross inequality in incomes within each bloc between the men and between the women.<sup>52</sup> Bloc equality is completely consistent with gross inequalities within a bloc as long as, on average, the two blocs are equal.<sup>53</sup> These two types of equality – simple individual equality and bloc equality – respond to the question “equality for whom?”

Separate from the question “equality for whom?” is the question “equality of what?”<sup>54</sup> This is often the point of ideological disagreement. Market liberals can be described as narrowly egalitarian, meaning that they support the equal distribution of minimal property rights and certain civil and political rights.<sup>55</sup> They oppose, however, any broadening of equality beyond the narrow limits of this sphere.<sup>56</sup> More leftward ideologies seek to broaden the spheres to which equality applies.<sup>57</sup> Thus, as Douglas Rae explains in *Equalities*, the conflict often construed between “liberty” and “equality” is really between “equality in the narrow” and “equality in the broad”.<sup>58</sup>

Much of the dispute about the breadth of equality is resolved in the International Bill of Human Rights because it mandates the scope of its equality and non-discrimination provisions. Basically, the International Bill of Human Rights enshrines the compromise reached on what it is that States must distribute equally and without discrimination. States accept this compromise when they become parties to the international human rights treaties. The next step therefore is to clarify the precise meanings of the non-dis-

crimination and equality provisions in the International Bill of Human Rights, rather than to debate whether the Bill encompasses “equality in the narrow” or “equality in the broad”.

## 2.2 International Bill of Human Rights

Over the past sixty years, international human rights law has focused primarily on bloc equality, also called non-discrimination, status-based equality or negative equality.<sup>59</sup> There has been little scholarly work on individual one-to-one equality, also called positive equality, and much less on how it applies to social rights or other economic and social fields regulated by the government. Legal scholars, as noted above, have focused on demonstrating that people denied their social rights, most often poor people, are disproportionately defined by race, sex, language, religion or other legally recognised status. The equality and non-discrimination provisions in the International Bill of Human Rights could address social rights more directly, however, if “poverty” were recognised as a status and one-to-one equality as a complement to social rights.<sup>60</sup> Both approaches find support in the International Bill of Human Rights.

### 2.2.1 Negative Equality

Together, the Universal Declaration on Human Rights (UDHR), the International Covenant on Civil and Political Rights (ICCPR) and the International Covenant on Economic, Social and Cultural Rights (ICESCR) form the International Bill of Human Rights, which contains multiple provisions on equality and non-discrimination.<sup>61</sup> There are two key provisions in the UDHR.<sup>62</sup> The first is Article 2, which entitles everyone to all the rights in the UDHR “without distinction of any kind,

such as race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status”.<sup>63</sup> This provision prohibits discrimination based on an enumerated or other status. Importantly, “property” is one of the grounds of distinction prohibited.

According to the drafting history of the UDHR, the word “property” was proposed in the Sub-Commission by the expert from the Soviet Union as part of a larger amendment extending the grounds – race, sex, language or religion – that were recognised in the UN Charter.<sup>64</sup> Later in the Commission on Human Rights, the United Kingdom proposed deleting the word “property” but the Soviet Union objected, stating that “it was most important that rich and poor should have the same rights”.<sup>65</sup> It is well recognised by commentators that “property” in the non-discrimination provision refers to economic status, in other words wealth or poverty status.<sup>66</sup> In fact, the Spanish version of the UDHR states “*posición económica*” in the place “property” in the Article 2 list of prohibited grounds of distinction.<sup>67</sup>

The non-discrimination provision in the UDHR, therefore, prohibits wealth-based distinctions. It also applies to all of the rights in the UDHR. This means that it prohibits wealth-based distribution of education, healthcare and social security just as it prohibits wealth-based access to voting in public elections or to justice in the courts. According to Johannes Morsink, the drafters of the UDHR understood that the non-discrimination provision, as it attaches to all the rights in the UDHR, calls for far-reaching egalitarianism.<sup>68</sup> Both the ICCPR and the ICESCR contain similar non-discrimination provisions, requiring State Parties to ensure the rights in the Covenants without distinction on the

basis of these same enumerated grounds, including “property” or economic status.

Nonetheless, public financing systems frequently do discriminate against poor people in the delivery of social rights. In response, the Committee on Economic, Social and Cultural Rights has urged governments to protect poor people from discrimination on the basis of their “economic status”.<sup>69</sup> Oddly however, the Committee on Economic, Social and Cultural Rights does not recognise that “property” in Article 2 of the ICESCR means “economic status” but has chosen to recognise “economic status” instead under “other status”.<sup>70</sup> This is unfortunate as the grounds explicitly enumerated in Article 2 are likely to require higher scrutiny than those covered by “other status”.<sup>71</sup> Moreover, it is certainly easier for states to refuse to recognise an “other status” than it is for them to ignore a status that is explicitly listed in the Covenant. Whether under “property” or “other status”, however, the prohibition against discrimination on the basis of economic status should serve to secure social rights for people most in need of these rights.<sup>72</sup>

### 2.2.2 Positive Equality

The second key provision in the UDHR is Article 7, which entitles everyone to “equality before the law” as well as “equal protection of the law”.<sup>73</sup> Although the drafters did not clarify or define the meaning of these terms, it is clear that most of them understood that there is a difference between the concepts of non-discrimination, equality before the law and equal protection of the law.<sup>74</sup> Indeed, the presence of separate provisions indicates that they viewed these rights as distinct. The ICCPR contains a similar provision recognising “equality before the law” and “equal protection of the law”. Article 26 of the ICCPR provides:

“All persons are equal before the law and are entitled without any discrimination to the equal protection of the law. In this respect, the law shall prohibit any discrimination and guarantee to all persons equal and effective protection against discrimination on any ground such as race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status.”<sup>75</sup>

The drafting history of Article 26 of the ICCPR reveals considerable debate and no consensus was reached on the meaning of the terms non-discrimination, equality before the law and equal protection of the law.<sup>76</sup> According to Manfred Nowak, “equality before the law” means simply that the law must be applied in the same manner to all.<sup>77</sup> In his view, this provision contains no guarantee of substantive equality but is rather aimed exclusively at enforcement.<sup>78</sup> On the other hand, “equal protection of the law”, is directed at the national legislature and imposes both negative and positive obligations.<sup>79</sup> Nowak maintains that this interpretation reflects the historical roots of the two phrases, “equality before the law” originating from the French Revolution, and “equal protection of the law” from the Fourteenth Amendment to the US Constitution.<sup>80</sup>

Two conclusions about the meanings of these terms can be drawn certainly from the express language of Articles 2 and 26 of the ICCPR in conjunction with the drafting history. First, Articles 2 and 26 of the ICCPR were intended to protect distinct rights; the notion of non-discrimination as well as the ideas of equality before the law and equal protection of the law.<sup>81</sup> Second, the express language of the non-discrimination provision in Article 2 obligates State Parties to provide legal protection against status-based discrimination with respect to the rights in the ICCPR.<sup>82</sup> By

comparison, the equality clauses in Article 26 are not limited to the rights in the ICCPR but extend beyond to any field in which the government acts.<sup>83</sup>

In 1989, the Human Rights Committee, responsible for monitoring the implementation of the ICCPR, issued General Comment 18, interpreting Articles 2 and 26 as well as the other references to equality and non-discrimination in the ICCPR.<sup>84</sup> As the term “discrimination” is not defined in the ICCPR, the Committee drew on the definitions in the International Convention on the Elimination of All Forms of Racial Discrimination (ICERD) and the Convention of the Elimination of All Forms of Discrimination against Women (CEDAW) and defined discrimination in the ICCPR to be:

“[A]ny distinction, exclusion, restriction or preference which is based on any ground such as race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status, and which has the purpose or effect of nullifying or impairing the recognition, enjoyment or exercise by all persons, on an equal footing, of all rights and freedoms.”<sup>85</sup>

Although recognising that the principles of equality before the law and equal protection of the law are also guaranteed by Article 26, the Committee did not define these rights or explain how they might be distinguished from the principle of non-discrimination.<sup>86</sup> The Committee did confirm that the scopes of Articles 2 and 26 are distinguishable:

“In the view of the Committee, Article 26 does not merely duplicate the guarantee already provided for in article 2 but provides in itself an autonomous right. It prohibits discrimination in law or fact in any field regulated and protected by the public

authorities. Article 26 is therefore concerned with the obligations imposed on States Parties in regard to their legislation and the application thereof.”<sup>87</sup>

In other words, Article 26 is not limited to ensuring equality of the rights in the ICCPR but extends the equality guarantees to any field the government regulates.<sup>88</sup> Because the government is obligated to regulate the fields involving the rights in the ICESCR, the equality guarantees in ICCPR Article 26 extend to the rights in the ICESCR for those states that have ratified it.

Despite multiple equality and non-discrimination provisions in the ICCPR, the Human Rights Committee has limited its discussion to one type of equality - non-discrimination. In its concluding observations on the United States, for example, the Committee notes its concern “that some 50% of homeless people are African American although they constitute only 12% of the United States population”.<sup>89</sup> Similarly, in the concluding observations on Canada, the Committee:

“(…) is concerned by information that severe cuts in welfare programs have had a detrimental effect on women and children, for example in British Columbia, as well as on Aboriginal people and Afro-Canadians.”<sup>90</sup>

For New Zealand, the Committee regrets that “Maori still experience disadvantages in access to healthcare, education and employment”.<sup>91</sup> As to Japan,

“(…) the Committee is concerned about discrimination against lesbian, gay, bisexual and transgender persons in employment, housing, social security, health care, education and other areas regulated by law”.<sup>92</sup>

These are all concerns about status-based discrimination.

This overview of the equality and non-discrimination provisions in international human rights law, as well as the drafting history, raises the possibility that the multiple provisions might well guarantee more than status-based non-discrimination. Indeed, a similar argument has been made in Canada, where the Charter of Rights and Freedoms (the Charter) contains multiple provisions on equality and non-discrimination. Section 15(1) of the Charter, like the International Bill of Human Rights, includes several distinct equality provisions. Section 15(1) states:

“Every individual is equal before and under the law and has the right to equal protection and equal benefit of the law without discrimination based on race, national or ethnic origin, colour, religion, sex, age, or mental or physical disability.”<sup>93</sup>

Despite multiple equality provisions, in *Andrews v. Law Society of British Columbia*,<sup>94</sup> the Canadian Supreme Court construed Section 15(1) to cover only status-based non-discrimination. In *Andrews*, the Court decided that, to bring a claim under Section 15(1), a plaintiff must show: (1) differential treatment; (2) an enumerated ground; and (3) discrimination in a substantive sense involving factors such as prejudice, stereotyping, and disadvantage.<sup>95</sup> In so doing, the Court reduced four different equality clauses to one meaning – non-discrimination. As one Justice wrote, “it can reasonably be argued that the opening words, which take up half the section, seem somewhat excessive to accomplish the modest role attributed to them.”<sup>96</sup> Indeed, the drafting history of the equality provisions in the Charter amply evidences

the intent for the equality clauses to address more than status-based discrimination.<sup>97</sup>

Current interpretations of the equality and non-discrimination provisions in the International Bill of Human Rights raise the same concerns.<sup>98</sup> Multiple provisions, intended to protect distinct rights, are conflated to protect only against discrimination, in other words, negative equality. Moreover, non-discrimination claims often impose significant hurdles for claimants. Proving that a specific differentiation correlates to an enumerated or similar status, as well as showing that this differentiation also involves stereotype, prejudice or disadvantage, are not trivial burdens.<sup>99</sup> In contrast, if one vote is not equal in weight to another vote, there is no need to also prove that the differentiation is based on any particular status or historical disadvantage. One-to-one equality of votes is required regardless of one’s status. This concept of one-to-one equality, often recognised in conjunction with civil and political rights, such as the right to vote, might prove helpful to realising social rights.

### 3. The Right to Health

The inequalities in the enjoyment of one social right – the right to health – reveal the complex relationship between equality rights and social rights. The right to health is enshrined in the UDHR, numerous international human rights treaties and the majority of national constitutions.<sup>100</sup> The ICESCR, however, provides the most comprehensive legal obligation as it applies to all the people in the 160 countries that are currently parties to the Covenant.<sup>101</sup> Article 12 of the ICESCR requires these countries to “recognize the right of everyone to the enjoyment of the highest standard of physical and mental health.”<sup>102</sup>

Further, it calls on the governments to take steps to achieve this right by providing maternal and child healthcare, ensuring safe workplaces, maintaining a healthy environment, preventing and controlling epidemics and securing healthcare for all.<sup>103</sup>

In 2002, the Committee on Economic, Social and Cultural Rights issued General Comment 14, which provides additional detail on the normative content of the right to health.<sup>104</sup> The Comment states that “the right to health must be understood as a right to the enjoyment of a variety of facilities, goods, services and conditions necessary for the realization of the highest attainable standard of health”.<sup>105</sup> It also clarifies that the right to health includes both timely and appropriate healthcare and the underlying determinants of health, such as potable water, adequate sanitation, nutritious food, secure housing, healthy working and environmental conditions and access to health-related education and information.<sup>106</sup>

Significantly, parties to the ICESCR must ensure equal access for all to healthcare and the underlying determinants of health.<sup>107</sup> Accordingly, payment for healthcare services must be equitable; governments should not burden poor households disproportionately, compared to rich households, with health expenses.<sup>108</sup> Additionally, health resource allocations should not favour expensive curative healthcare, which is often accessible only to privileged people, at the expense of primary and preventative healthcare, which benefits the larger population.<sup>109</sup> The ICESCR acknowledges that governments have constraints due to limited resources, and thus it allows for progressive realisation of the right to health. Nonetheless, it imposes an immediate obligation upon governments to guarantee the enjoyment of the right to

health without discrimination.<sup>110</sup> Further, governments have the immediate obligation “to ensure equitable distribution of all health facilities, goods and services”.<sup>111</sup>

The Committee on Economic, Social and Cultural Rights is troubled by status-based inequalities and notably by inequalities that adversely impact on poor people. For example, in its 2004 Concluding Observations on Colombia, the Committee indicated concern about the reduction in subsidies for healthcare, which made access to healthcare in rural areas more difficult and adversely impacted on women and indigenous groups.<sup>112</sup> The Committee urged the government:

“(…) [T]o allocate a higher percentage of its GDP to the health and education sector and to ensure that its system of subsidies does not discriminate against the most disadvantaged and marginalized groups”.<sup>113</sup>

Similarly, in 2004 the Committee urged the government of Ecuador to allocate a higher percentage of GDP to the health sector, and to address discrimination against indigenous peoples and Afro-Ecuadorians in health and other fields.<sup>114</sup>

To the United Kingdom, the Committee indicated its concern in 2009 that health inequalities had widened among social classes, “especially with regard to health care goods, facilities and services”.<sup>115</sup> It therefore recommended that the government “intensify efforts to overcome the health inequalities and unequal access to health care”, and urged the government “to reduce health inequalities by 10% by 2010, measured by infant mortality and life expectancy at birth”.<sup>116</sup> As to Brazil, the Committee noted with concern a significant difference in life expectancies between the black and white populations and recom-

mended that the government take a sharper focus on health and poverty eradication programmes to address this discrepancy.<sup>117</sup> The Committee also noted with concern the gap in key health indicators between indigenous and non-indigenous people in Australia, in particular among women and children, and called on the government to take immediate steps to improve their health situation.<sup>118</sup>

Additionally, the Committee highlights, in General Comment 20 on non-discrimination, several areas of concern for healthcare systems. For example, the Committee states: "In relation to young persons, unequal access by adolescents to sexual and reproductive health information and services amounts to discrimination."<sup>119</sup> Further, denial of access to health insurance on the basis of health status may also amount to discrimination.<sup>120</sup> Notably, the Committee indicates that governments should not discriminate on the basis of a person's place of residence; thus, governments must ensure "even distribution in the availability and quality of primary, secondary and palliative health care facilities" in all regions, including urban and rural areas.<sup>121</sup> Overall, the Committee seeks to eliminate status-based inequalities, both formal and substantive.<sup>122</sup> It understands "other status" to be flexible and commonly recognises new social groups that are vulnerable and suffer marginalisation.<sup>123</sup>

In addition to the Committee, Paul Hunt, the UN Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health from 2002 to 2008 (Special Rapporteur on the right to health), addressed, in particular, a right-to-health approach to health systems. In his 2008 annual report to the Human Rights Council, he explained:

"At the heart of the right to the highest attainable standard of health lies an ef-

fective and integrated health system encompassing health care and the underlying determinants of health, which is responsive to national and local priorities, and accessible to all. Without such a health system, the right to the highest attainable standard of health can never be realized."<sup>124</sup>

Hunt also views equality and non-discrimination as core features of a health system.<sup>125</sup> In the 2008 report, he stated that governments have "a legal obligation to ensure that a health system is accessible to all without discrimination", and "that disadvantaged individuals and communities enjoy, in practice, the same access as those who are more advantaged".<sup>126</sup>

In sum, both the Committee on Economic, Social and Cultural Rights and the Special Rapporteur on the right to health deem equality and non-discrimination to be important features of a health system that respects human rights. Further, they both urge governments to ensure that adequate resources are allocated to health systems so that poor people have equal access to health facilities, goods and services and the underlying determinants of health. To realise the right to health for all people, however, governments must recognise that "economic status", in other words "poverty", is a prohibited ground of discrimination and that positive or one-to-one equality requires health systems to offer the same health facilities, goods and services, as well as the same underlying determinants of health, to all.

## 4. Equality Rights in Healthcare Systems

### 4.1 Negative Equality

Non-discrimination in healthcare is guaranteed by the non-discrimination provision in Article 2 of the ICESCR, and it is also a

key feature of the right to health in Article 12. Even those States that do not recognise the right to health are prohibited by Article 26 of the ICCPR from discriminating in any field in which the government acts. Virtually every national government acts in the field of health and is therefore prohibited from discriminating in that field. Nonetheless, structural inequalities are widespread in domestic healthcare systems, which are often purposefully designed to allocate benefits on the basis of status.

One strikingly obvious example was the two-tiered healthcare system in apartheid South Africa,<sup>127</sup> which discriminated on the basis of race much like the education system challenged in *Brown v. Board of Education*,<sup>128</sup> which the United States Supreme Court held violated the Equal Protection Clause of the United States Constitution. Such two-tiered systems for health, education or social security, which discriminate on the basis of race, violate the equality and non-discrimination provisions in the ICCPR and the ICESCR. Healthcare systems are, however, more often tiered on the basis of economic status. Tiered healthcare systems, also called “segmented” systems, exist in numerous forms.<sup>129</sup>

In Mexico, for example, healthcare is delivered via two separate systems.<sup>130</sup> The social security system provides services to individuals who are formally employed and to their families. The Ministry of Health provides services for the remaining population, including individuals who are informally employed, occasionally employed and unemployed, as well as their families.<sup>131</sup> A group of non-governmental organisations conducting an analysis of the 2002 health budget discovered that about 65% of health spending was allocated to the formally employed population while only 35% to the informally employed and unemployed, although each

group contained about 50% of the population.<sup>132</sup> Thus, the informally employed and unemployed population received significantly less per capita funding for healthcare, although they were likely to have more healthcare needs.

This two-tiered healthcare system, by distinguishing between groups on the basis of employment status, discriminates essentially on the basis of economic status. Although the government’s intent in creating the “second” tier was to provide healthcare to millions of people who had none,<sup>133</sup> this cannot justify continuation of such a discriminatory system.<sup>134</sup> A national plan to progressively realise the right to health, including equality in access to and the provision of healthcare, is a key component of the right to health.<sup>135</sup>

In 2008, the Constitutional Court of Colombia was faced with a challenge to a similar two-tiered system of healthcare.<sup>136</sup> In Colombia, the healthcare system is divided along similar lines as the healthcare system in Mexico; a “contributory” system for formally employed people and their families and a separate “subsidised” system for other people, providing substantially less benefits than the contributory system.<sup>137</sup> The 1993 law establishing this scheme, however, also called for the unification of the two systems by 2001.<sup>138</sup> Nonetheless, the two systems were never unified. In a July 2008 decision, the Constitutional Court ordered the government to unify the benefits in the two systems, first for children and then progressively for adults.<sup>139</sup> In reaching this decision, the Court relied upon ICESCR Article 12 as well as the Committee’s General Comment 14 on the right to health.<sup>140</sup> In particular, the Court noted that the right to health includes the right to a system of health protection that provides equal opportunity for all to enjoy the highest attainable level of health.<sup>141</sup> The continued

inequality of the two-tiered system was simply unacceptable to the Court.<sup>142</sup>

Another type of two-tiered system is created by “segmenting out” middle and high-income groups into private health insurance schemes, leaving the public sector health services to focus on poor people.<sup>143</sup> Indeed,

“[t]he World Bank and others have encouraged private healthcare financing in recent years as a way of allowing the diminished public sector to concentrate on providing comprehensive coverage for a ‘basic’ or ‘minimum’ package of services”.<sup>144</sup>

This type of segmented health care system also creates separate systems for rich and poor people.<sup>145</sup> Not surprisingly, segmenting out is likely to result in unequal health services, reflecting and reinforcing socio-economic inequalities.<sup>146</sup> According to David McCoy,

“[a] significant private medical sector weakens the public provision of healthcare, especially as the resources to patient load is more favourable in the private sector – it sucks out more health resources than it relieves the public sector of workload”.<sup>147</sup>

The World Health Report 2010 also confirms that multiple pools, each with their own administrations, “are inefficient and make it difficult to achieve equity”.<sup>148</sup>

It is not difficult to reach the conclusion that public healthcare delivered in two tiers, as exemplified in Mexico and in Colombia, does not comply with Article 2 of the ICESCR on non-discrimination or with Article 12 on the right to health. The evidence suggests that other types of two-tiered systems, such as those that allow the wealthier population to opt out of the public system, might also

violate the right to non-discrimination on the basis of economic status by resulting in unequal health facilities, goods and services for the two populations. These systems might also conflict with the obligation to use maximum available resources to progressively realise the right to health because the administrative costs for multiple systems are higher than for a single system as they lose resources to inefficiency. These issues, as well as many others concerning the structure and financing of multi-tiered healthcare systems, require more attention from human rights scholars and practitioners, as well as the UN Human Rights Committee and the Committee on Economic, Social and Cultural Rights.

#### 4.2 Positive Equality

The positive right to equality, one-to-one equality, is not linked to status. In the two International Covenants, Article 26 of the IC-CPR has the only provision that is not linked to particular groups or particular rights. This is, therefore, the most likely foundation from which to derive a positive right to equality. On the other hand, one-to-one equality could be implied in the substantive rights of the ICESCR, just as the right to vote implies a right to one vote of equal weight to other votes. Indeed, a universal system of primary education, compulsory and free to all, which is guaranteed by Article 13 of the ICESCR, also implies one-to-one equality. Similarly, Article 12 of the ICESCR should require a universal system of healthcare that provides equal benefits to all, enshrining the right to one-to-one equality. On these bases, healthcare systems that do not provide universal and equal benefits to all do not comply with the positive right to equality or the right to health.

Decentralisation is one threat to positive equality.<sup>149</sup> For example, in *Mashavha v. President of the Republic of South Africa*, the Constitutional Court of South Africa held invalid a presidential proclamation made under the Interim Constitution that assigned the administration of social services to provincial governments.<sup>150</sup> The Court recognised that historically gross inequalities had been legally imposed on the basis of race and also on the basis of geographical area, and that therefore, “the need for equality could not be ignored” in interpreting the Interim Constitution.<sup>151</sup> Accordingly, the Court found that it would offend human dignity and the fundamental right of equality to allow higher old age pensions or child benefits in one province than that allowed in another. Such a system would “create different classes of citizenship and divide South Africa into favoured and disfavoured areas”.<sup>152</sup> In so doing, the Court recognized a right to individual one-to-one equality with respect to social benefits.

*Mashavha* demonstrates that decentralisation of resource allocations may raise concerns about one-to-one equality. Similarly, inequality in the availability of services and medicines across districts in the United Kingdom implicates the positive right to equality.<sup>153</sup> Christopher Newdick points out that with so many Primary Care Trusts in the country, “there is potential for significant differences in policy between them”.<sup>154</sup> And he questions whether this is desirable in a national health service.<sup>155</sup> In response, Newdick suggests that, in the absence of guidance from the central government, Primary Care Trusts should form consortia to increase equity and consistency throughout the National Health Service.<sup>156</sup> As he notes, it is important to be able to explain decisions on individual requests, as well as to “demonstrate that like cases are treated alike”.<sup>157</sup> To do so, Primary

Care Trusts must balance individual rights against the needs of a community system.<sup>158</sup>

In the same vein, the positive right to equality also has considerable potential to equalise health care spending in Brazil and Colombia where individual right-to-health claims are widespread. In Brazil, for example, poorer individuals may not have equal access to the medicines that wealthier individuals obtain from the public healthcare system as the latter have better access to courts and are able to bring right-to-health claims, which are routinely granted.<sup>159</sup> Similarly, in Colombia, the great number of individual right-to-health claims – 674,612 health-related constitutional claims between 1999 and 2008 – risks jeopardising one-to-one equality.<sup>160</sup> Most of these claims were brought by individuals in the healthcare tier with better benefits, skewing the system more than the two tiers system already did.<sup>161</sup>

When courts grant health benefits to one individual that cannot also be universalised, this violates the positive right to equality. This results from a failure to balance the individual right to health with the collective right to a system of equal health benefits.<sup>162</sup> As the Constitutional Court of South Africa stated in *Soobramoney v. Minister of Health, KwaZulu-Natal*, to manage limited resources sometimes the State will need “to adopt a holistic approach to the larger needs of society rather than focus on the specific needs of particular individuals”.<sup>163</sup> Importantly, to ensure the positive right to equality, the state will need to ensure it can universalise any health benefit it provides.

The Canadian case *Chaoulli v. Quebec* is likely the most notable case raising the issue of one-to-one equality in healthcare.<sup>164</sup> In that case, the claimants challenged as unconsti-

tutional the Quebec statutes that prohibited private insurance for healthcare services that were available in the public system. They argued that given the serious delays in the public healthcare system the statutes preventing them from buying private insurance violated their rights to life and personal security under the Canadian and Quebec Charters of Rights and Freedoms.<sup>165</sup> At trial, the court found that the purpose of the statutes was “to guarantee equal and adequate access to health care for all Quebecers”, which “was motivated by considerations of equality and dignity”.<sup>166</sup> Although the waiting lines were long, the trial court found, as a matter of fact based on the expert testimony, that creating a parallel private system would not solve the waiting times.<sup>167</sup> Indeed, the evidence at trial indicated that a parallel private system would have a negative impact on waiting times.<sup>168</sup> Accordingly, the trial court dismissed the claims, as did the court of appeal.

The Supreme Court of Canada, however, held in a four-to-three decision, that the Quebec statutes infringed on the rights to life and security under the Quebec Charter by denying the claimants a solution to avoid the waiting lines.<sup>169</sup> Moreover, after surveying the systems in other provinces and OECD countries, the Court held that the government had failed to justify the infringement on these rights as there were a number of other measures available “to protect the integrity of Quebec’s health care plan”.<sup>170</sup> In contrast, the dissent agreed with the findings of the trial judge that “[t]he only way to guarantee that all the health care resources will benefit all Quebecers without discrimination is to prevent the establishment of a parallel private health care system”.<sup>171</sup> Thus, the dissent concluded that the claimants had failed to show that the Quebec statutes were arbitrary.<sup>172</sup> “Indeed, the evidence prove[d] the contrary.”<sup>173</sup>

*Chaoulli* has been severely criticised.<sup>174</sup> Among the concerns, commentators maintain that the majority found facts contrary to the evidence at trial, failed to defer to the Legislature on a social policy issue, and mischaracterised the government interest as preserving the *existence* of the Quebec health care system as opposed to the *equality* of the system.<sup>175</sup> Martha Jackman contends that the Court’s decision “is directly at odds with the underlying equality-based premises of the Canadian medicare system”.<sup>176</sup> Here, the government chose to establish a one-tier system of healthcare that provides equity between the wealthy and the poor, as well as between the healthy and the ill.<sup>177</sup> Against this system of equalised health care, the majority would have the government create a two-tiered system in which those with the ability to do so purchase healthcare in a private system, while those who cannot pay or who are denied private insurance because they are already ill or disabled “are left to languish and die on public waiting lists”.<sup>178</sup>

According to Jackman, *Chaoulli* violates equality rights under both the Quebec and Canadian Charters as well as under international human rights law.<sup>179</sup> She sums it up this way:

“The majority’s reasoning and remedial order in *Chaoulli*, which recognize only the health care rights of the advantaged, and which ignores the rights of those who, by reason of poverty, chronic illness, or disability, are forced to rely exclusively on the public system, is profoundly at odds with the right to life, right to health, and equality guarantees set out under both the ICCPR and the ICESCR.”<sup>180</sup>

Notably, the Canadian and Quebec Charters do not include positive social rights such as

the right to healthcare. In such circumstances, there is the danger that the civil and political rights, which have constitutional status, will outweigh economic and social “interests” such as healthcare. As Jeff King points out, had the Charters recognised a positive right to healthcare, the *Chaoulli* Court would have had to confront the competing “right” of Quebecers to equality in healthcare.<sup>181</sup>

These cases illustrate that the positive right to equality in healthcare may be threatened by decentralisation of resource allocations, the absence of constitutional social rights and even the right to bring individual claims for healthcare services and goods. The holistic approach in the International Bill of Human Rights, however, points the way toward a balanced approach in which the right to equality applies across all the rights – not only civil and political rights – and to all people – not just those who can afford to exercise their individual rights. One-to-one equality is an essential aspect of the right to healthcare, no less than it is an essential aspect of the right to vote.

### **Conclusion**

Legal scholars, courts and human rights bodies are exploring the relationship between equality rights and social rights but are often restricted by some legal impediment in the jurisdiction. In some instances, the constitutional framework lacks social rights. In others, the right to equality is limited by legal precedent that has merged the right to equality with the right to non-discrimination, obliterating any positive right to equality. In the holistic human rights framework estab-

lished in the International Bill of Human Rights, however, equality and non-discrimination are distinct and are also intrinsically related to social rights. The interrelation of these rights is reflected in the text of the human rights instruments and in their drafting history. Moreover, the language, the overall framework and the historical record all support the notion that the unrestricted equality provisions – those that are not explicitly limited to specific rights – apply across all rights, including the social rights. Indeed, the positive right to equality applies to all fields in which the government acts.

Over the past decade, a renewed recognition of social rights as “real” human rights combined with empirical evidence that the denial of equality with respect to these rights impacts on all human rights, presents a new context for defining a positive right to equality. Additionally, experience has shown that civil and political equality is simply not possible without some level of social equality. In this context, drawing on the original holistic human rights framework of the International Bill of Human Rights promotes a broader understanding of the right to equality, one that is linked to all the human rights in the Bill, a positive right to equality that is distinct from non-discrimination. This positive right to equality demands one-to-one equality with respect to social rights – such as the right to healthcare – just as it demands one-to-one equality with respect to civil and political rights – such as the right to vote. In this holistic human rights framework, both negative and positive rights to equality are essential complements to social rights.

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<sup>2</sup> Wilkinson, R. and Pickett, K., *The Spirit Level: Why More Equal Societies Almost Always Do Better*, Allen Lane Penguin Group, 2009.

<sup>3</sup> *Ibid.*, p. 81.

<sup>4</sup> *Ibid.*, pp. 75-76.

<sup>5</sup> The World Bank, *World Development Report 2004: Making Services Work for Poor People*, The World Bank and Oxford University Press, 2003, p. 3; Gross, A. M., "The Right to Health in an Era of Privatization and Globalization: National and International Perspectives", in Barak-Erez, D. and Gross, A.M. (eds.), *Exploring Social Rights: Between Theory and Practice*, Hart Publishing, 2007, pp. 307-327 (which discusses the concept of tiered healthcare systems in the domestic contexts of Canada, South Africa and Israel).

<sup>6</sup> Fredman, S., "Engendering Socio-Economic Rights", *South African Journal of Human Rights*, Vol. 25(3), 2009, p. 1.

<sup>7</sup> See, for example, Porter, B., "Expectations of Equality", *Supreme Court Law Review*, 33 S.C.L.R. (2d), 2006 (which documents the debates on equality and social rights in the early 1980s in Canada).

<sup>8</sup> See, for example, Fredman, S., *Human Rights Transformed: Positive Rights and Positive Duties*, Oxford University Press, 2008 (which focuses in particular on India and South Africa); O'Connell, R. "From Equality before the Law to the Equal Benefit of the Law: Social and Economic Rights in the Irish Constitution", in Doyle, O. and Carolan E. (eds.), *The Irish Constitution: Governance and Values*, Round Hall Press, 2008 (which focuses on Ireland); Meyerson, D., "Equality Guarantees and Distributive Inequity", *Public Law Review*, Vol. 19, 2008, p. 32 (which focuses on Australia, Canada and the United Kingdom).

<sup>9</sup> UN Committee on Economic, Social and Cultural Rights, *General Comment 20: Non-discrimination in economic, social and cultural rights (Art. 2, Para 2)*, UN Doc. E/C. 12/GC/20, 2 July 2009, Para 1.

<sup>10</sup> Hunt, P., *Reclaiming Social Rights: International and Comparative Perspectives*, Dartmouth Publishing, 1996, p. 71 (in which Hunt states that "it is no coincidence that rights with special relevance to marginalized groups are also those which are juridically marginalized").

<sup>11</sup> The International Bill of Human Rights is composed of the Universal Declaration of Human Rights (UDHR), G.A. Res. 217A (III) (1948), the International Covenant on Civil and Political Rights (ICCPR), G.A. Res. 2200A (XXI) (1966), and the International Covenant on Economic, Social and Cultural Rights (ICESCR), G.A. Res. 2200A (XXI) (1966).

<sup>12</sup> See, for example, McKean, W., *Equality and Discrimination under International Law*, Clarendon Press, 1983, p. 285.

<sup>13</sup> Craven, M., *The International Covenant on Economic, Social and Cultural Rights: A Perspective on its Development*, Clarendon Press, 1995, p. 154.

<sup>14</sup> *Ibid.*

<sup>15</sup> See above, note 12, p. 285.

<sup>16</sup> International Convention on the Elimination of All Forms of Racial Discrimination, G.A. Res. 2106A (XX) (1965); Convention on the Elimination of All Forms of Discrimination Against Women, G.A. Res. 34/180 (1979).

<sup>17</sup> See above, note 11, ICCPR, Article 26.

<sup>18</sup> UN Committee on Economic, Social and Cultural Rights, *General Comment 9: The Domestic Application of the Covenant*, UN Doc E/C. 12/1998/24, 3 December 1998.

<sup>19</sup> WHO Commission on the Social Determinants of Health, *Closing the Gap in a Generation: Health Equity Through Action on the Social Determinants of Health*, World Health Organization, 2008, p. 26.

<sup>20</sup> *Ibid.*

<sup>21</sup> *Ibid.*, p. 29.

<sup>22</sup> Wilkinson, R., *The Impact of Inequality: How to Make Sick Societies Healthier*, Routledge, 2005, p. 15.

<sup>23</sup> *Ibid.*

<sup>24</sup> See above, note 19, p. 3.

<sup>25</sup> *Ibid.*

<sup>26</sup> *Ibid.*, p. 4.

<sup>27</sup> *Ibid.*, p. 5.

<sup>28</sup> *Ibid.*, p. 7.

<sup>29</sup> World Health Organization, *Health Systems Financing: The Path to Universal Coverage, The World Health Report 2010*, Chapter 1, p. 5.

<sup>30</sup> See above, note 19, pp. 202-206.

<sup>31</sup> See above, note 11, ICESCR Articles 6-14.

<sup>32</sup> See above, note 22, p. 103.

<sup>33</sup> *Ibid.*, p. 103-107.

<sup>34</sup> *Ibid.*, p. 105.

<sup>35</sup> *Ibid.*, p. 111.

<sup>36</sup> *Ibid.*, p. 110.

<sup>37</sup> *Ibid.*, p. 101.

<sup>38</sup> *Ibid.*, p. 18.

<sup>39</sup> *Ibid.*

<sup>40</sup> *Ibid.*

<sup>41</sup> *Ibid.*

<sup>42</sup> See, for example, Rae, D., *Equalities*, Harvard University Press, 1981, p. 21; Phillips, A. *Which Equalities Matter?*, Polity Press, 1999, p. 3.

<sup>43</sup> *Ibid.*, Rae, p.21; *Ibid.*, Phillips, p. 27.

<sup>44</sup> UN Human Rights Committee, *General Comment No. 25: The Right to Participate in Public Affairs, Voting Rights and the Right of Equal Access to Public Service (Art. 25)*, UN Doc. No. CCPR/C/21/Rev. 1/Add. 7, 1996, Para 21.

<sup>45</sup> See above, note 42, Rae, p. 21.

<sup>46</sup> *Ibid.*

<sup>47</sup> *Ibid.*, p. 41.

<sup>48</sup> *Ibid.*, p. 22.

<sup>49</sup> *Ibid.*, p. 32.

<sup>50</sup> *Ibid.*, p. 34-35.

<sup>51</sup> *Ibid.*, p. 35.

<sup>52</sup> *Ibid.*

<sup>53</sup> For example, see above, note 11, ICCPR, Article 2 (which prohibits “distinctions of any kind, such as race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status”).

<sup>54</sup> See above, note 42, Rae, p. 45.

<sup>55</sup> *Ibid.*, p. 47.

<sup>56</sup> *Ibid.*

<sup>57</sup> *Ibid.*

<sup>58</sup> *Ibid.*, p. 48.

<sup>59</sup> The term “discrimination”, in both common usage and in domestic law generally, refers to such suspect classifications or unreasonable status-based distinctions. See above, note 12, p. 10 (“The word ‘discriminate’ taken alone is now commonly used in the pejorative sense of an unfair, unreasonable, unjustifiable or arbitrary distinction, not only in English but in other languages.”).

<sup>60</sup> See above, note 8, Fredman, p. 176-177 (“Prohibiting differentiation according to socio-economic status would inevitably lead to a concept of equality with distributive connotations, bringing a positive duty in its wake.”); Fiss, O., “Foreword”, in Gargarella, R., Domingo, P. and Roux, T. (eds.), *Courts and Social Transformation in New Democracies: An Institutional Voice for the Poor?*, Ashgate Publishing 2006, p. xii (which argues that “economic status” or “poverty” should be “an independent and sufficient basis for corrective action”).

<sup>61</sup> See above, note 11, UDHR, Articles 2 (non-discrimination) and 7 (equality); ICCPR, Articles 2 (non-discrimination) and 26 (equal protection); ICESCR, Articles 2 (non-discrimination) and 3 (equality of men and women).

<sup>62</sup> Equality and non-discrimination are reiterated in many provisions of the UDHR. See for example UDHR Articles 1 (“All human beings are born free and equal in dignity and rights.”), 10 (“Everyone is entitled in full equality to a fair and public hearing.”), 16 (Men and women “are entitled to equal rights as to marriage”) and 23 (everyone “has the right to equal pay for equal work”).

<sup>63</sup> See above, note 11, UDHR, Article 2.

<sup>64</sup> UN Sub-Commission on the Prevention of Discrimination and the Protection of Minorities, First Session, UN Doc. No. E/C. 4/52, 6 December 1947, p. 4.

<sup>65</sup> Commission on Human Rights, Third Session, Summary Record of the Fifty-Second Meeting, UN Doc. No. E/CN. 4/SR. 52, 8 June 1948, p. 5.

<sup>66</sup> Morsink, J., *The Universal Declaration of Human Rights: Origins, Drafting and Intent*, University of Pennsylvania, 1999, p. 113; Skogly, S., “Article 2”, in Alfredson, G. and Eide, A. (eds.), *The Universal Declaration of Human Rights*, Kluwer Law International, 1999, p. 79; Nowak, M., *U.N. Covenant on Civil and Political Rights: CCPR Commentary*, N. P. Engel, Kehl, 1993, p. 52; but compare Craven, see above, note 13, p. 175 (in which it states that wealth “could hardly be considered ‘suspect’”).

<sup>67</sup> Additionally, Article 1 of the American Convention on Human Rights (1969) has the same list of prohibited grounds of discrimination as the UDHR, the ICCPR and the ICESCR, except that “property” is replaced by “economic status” in the English version. Article 1(1) of the Convention of the Rights of Migrant Workers and their Families (1990) lists both “economic position” and “property” as prohibited distinctions.

<sup>68</sup> See above, note 66, Morsink, pp. 113-114.

<sup>69</sup> See, for example, CESCR, *Concluding Observations of the Committee on Economic, Social and Cultural Rights: Canada*, UN Doc. No. E/C. 12.1/Add. 31, 1998, Para 51.

<sup>70</sup> See above, note 9, Paras 25 (property) and 35 (economic and social condition).

<sup>71</sup> Vandenhoe, W., *Non-Discrimination and Equality in the View of the UN Human Rights Treaty Bodies*, Intersentia, 2005, p. 134.

<sup>72</sup> See Fredman, S., “Positive Duties and Socio-Economic Disadvantage: Bringing Disadvantage into the Equality Agenda”, *European Human Rights Law Review*, Vol. 3, 2010, pp. 290-304 and specifically p. 292 (which discusses the importance of the Equality Act 2010 including a positive duty on public bodies in relation to socio-economic disadvantage).

<sup>73</sup> UDHR, Article 7, which provides in part: “All are equal before the law and are entitled without any discrimination to equal protection of the law.”

<sup>74</sup> Möller, J., “Article 7”, in Alfredson, G. and Eide, A. (eds.), *The Universal Declaration of Human Rights*, Kluwer Law International, 1999, p. 153.

<sup>75</sup> ICCPR, Article 26.

<sup>76</sup> Choudhury, T., “The Drafting of Article 26 of the International Covenant on Civil and Political Rights”, *European Human Rights Law Review*, Vol. 5, 2002, p. 591.

<sup>77</sup> See above, note 66, Nowak, p. 466.

<sup>78</sup> *Ibid.*

<sup>79</sup> *Ibid.*, p. 468.

<sup>80</sup> *Ibid.*, p. 459.

<sup>81</sup> See above, note 76, p. 598 (which states “equal protection of the law and non-discrimination were seen as fundamentally different notions”).

<sup>82</sup> ICCPR, Article 2(1), which states that any State Party to the ICCPR undertakes to respect and ensure “the rights recognized in the present Covenant, without distinction of any kind”.

<sup>83</sup> See above, note 66, Nowak, p. 465.

<sup>84</sup> UN Human Rights Committee, *General Comment 18: Non-discrimination*, U.N. Doc. No. HRI/GEN/1Rev. 6, 2003. The UN Human Rights Committee has also issued general comments on Article 3 (equal rights of men and women) and Article 14 (right to equality before the courts). The Committee on Economic, Social and Cultural Rights, responsible for monitoring the ICESCR, has issued general comments on Article 3 (equal rights of men and women) and Article 2(2) (non-discrimination).

<sup>85</sup> *Ibid.*, UN Human Rights Committee, *General Comment 18: Non-discrimination*, Para 7.

<sup>86</sup> See above, note 71, p. 86. (“None of the [human rights] Committees has paid much attention to a conceptual distinction between the principles of equality and non-discrimination.”)

<sup>87</sup> See above, note 84, UN Human Rights Committee, *General Comment 18: Non-discrimination*, Para 12.

<sup>88</sup> *Ibid.*

<sup>89</sup> UN Human Rights Committee, *Concluding Observations of the Human Rights Committee: United States of America*, UN Doc. No. CCPR/C/USA/CO/3/rev. 1, 2006, Para 22.

<sup>90</sup> UN Human Rights Committee, *Concluding Observations of the Human Rights Committee: Canada*, UN Doc. No. CCPR/C/CAN/CO/5, 20 April 2006, Para 24.

<sup>91</sup> UN Human Rights Committee, *Concluding Observations of the Human Rights Committee: New Zealand*, UN Doc. No. A/50/40, 3 October 1995, Para 182.

<sup>92</sup> UN Human Rights Committee, *Concluding Observations of the Human Rights Committee: Japan*, UN Doc. No. CCPR/C/JPN/CO/5, 2008, Para 29.

<sup>93</sup> Canadian Constitution Act 1982, Canadian Charter of Rights and Freedoms § 15(1).

<sup>94</sup> *Andrews v. Law Society of British Columbia* (1989), 1 S.C.R. 143.

<sup>95</sup> *Law v. Canada* (1999), 1 S.C.R. 497, Para 88 (which revisits *Andrews*).

<sup>96</sup> See above, note 94, Para 72, (see particularly the decision of La Forest J.).

<sup>97</sup> See above, note 7, p. 226. Bruce Porter explains that the first draft on the equality provision presented by the Trudeau government was labeled “non-discrimination rights”. In response to concerted lobbying over the next year, the provision was renamed “equality rights” and included – in addition to equality before the law, equal protection of the law and non-discrimination – two new provisions, equality under the law and equal benefit of the law. The broad wording adopted by Canada was considered the most expansive in the world.

<sup>98</sup> *The Declaration of Principles on Equality*, promulgated by The Equal Rights Trust, also presents, in Principle 1, a “right to equality” substantially broader than non-discrimination by including, in addition to non-discrimination, the rights to equality before the law, the right to equal protection of the law and the right to equal benefit of the law.

<sup>99</sup> Fredman, S., *Discrimination Law*, Oxford University Press, 2002, p. 70 (which documents the attempts of non-enumerated groups to define themselves as enumerated groups). See, for example, *Gosselin v. Quebec* (2002) 4 S.C.R. 429 (which proved a distinction on the enumerated basis of age, but failed to prove a distinction based on stereotype, prejudice or disadvantage).

<sup>100</sup> UDHR, Article 25; ICESCR, Article 12; Kinney, E. D. and Clark, B. A., “Provisions for Health and Healthcare in the Constitutions of the World”, *Cornell International Law Journal*, Volume 37(2), 2004, p. 287 (which states that 67.5 % of all countries have constitutional provisions on health or healthcare). The right to health is also recognised in the preamble to the Constitution of the World Health Organization, which states that “[t]he enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being without distinction of race, religion, political belief, economic or social condition”.

<sup>101</sup> UN Committee on Economic, Social and Cultural Rights, *General Comment 14: The right to highest attainable standard of health*, U.N. Doc. E/C. 12/200/4, 2000, Para 2.

<sup>102</sup> ICESCR, Article 12(1).

<sup>103</sup> *Ibid.*, Article 12(2).

<sup>104</sup> See above, note 101.

<sup>105</sup> *Ibid.*, Para 9.

<sup>106</sup> *Ibid.*, Para 11.

<sup>107</sup> *Ibid.*, Paras 19, 34-36.

<sup>108</sup> *Ibid.*, Para 12(b)(iii).

<sup>109</sup> *Ibid.*, Para 19.

<sup>110</sup> *Ibid.*, Para 30.

<sup>111</sup> *Ibid.*, Para 43(e).

<sup>112</sup> UN Committee on Economic, Social and Cultural Rights, *Concluding Observations of the Committee on Economic, Social and Cultural Rights: Colombia*, UN Doc. No. E/C. 12/1/Add. 74, 2001, Para 26.

<sup>113</sup> *Ibid.*, Para 47.

<sup>114</sup> UN Committee on Economic, Social and Cultural Rights, *Concluding Observations of the Committee on Economic, Social and Cultural Rights: Ecuador*, UN Doc. No. E/C. 12/1/Add. 100, 2004, Paras 34, 36 and 54.

<sup>115</sup> UN Committee on Economic, Social and Cultural Rights, *Concluding Observations of the Committee on Economic, Social and Cultural Rights: United Kingdom*, UN Doc. No. E/C. 12/GBR/CO/5, 2009, Para 32.

<sup>116</sup> *Ibid.*

<sup>117</sup> UN Committee on Economic, Social and Cultural Rights, *Concluding Observations of the Committee on Economic, Social and Cultural Rights: Brazil*, UN Doc. No. E/C. 12/BRA/CO/2, 2009, Para 11.

<sup>118</sup> UN Committee on Economic, Social and Cultural Rights, *Concluding Observations of the Committee on Economic, Social and Cultural Rights: Australia*, UN Doc. No. E/C. 12/AUS/CO/4, 2009, Para 28.

<sup>119</sup> See above, note 9, Para 29.

<sup>120</sup> *Ibid.*, Para 33.

<sup>121</sup> *Ibid.*, Para 34.

<sup>122</sup> *Ibid.*, Para 8.

<sup>123</sup> *Ibid.*, Para 27.

<sup>124</sup> Hunt, P., *UN Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health: Annual Report to the Human Rights Council*, UN Doc. No. A/HRC/7/11, 2008, Para 15.

<sup>125</sup> *Ibid.*, Para 42. The Special Rapporteur understands the health concept of “equity” – meaning equal access to healthcare according to need – to be akin to equality and non-discrimination in human rights law. (*Ibid.*, Para 43.)

<sup>126</sup> *Ibid.*, Para 42.

<sup>127</sup> McCoy, D., “Financing Health Care: for All, for Some, for Patients or for Profits?”, in The North-South Institute, *The Global Right to Health: Canadian Development Report 2007*, Ottawa: Renouf Publishing, 2006, pp. 59-83, 66.

<sup>128</sup> *Brown v. Board of Education*, 347 U.S. 483 (1954).

<sup>129</sup> See above, note 127, p. 66.

<sup>130</sup> Fundar – Centro de Análisis e Investigación, International Budget Project and International Human Rights Internship Program, *Dignity Counts: A guide to using budget analysis to advance human rights*, 2004, p. 10. The system is considerably more complicated than presented here. See *ibid.*, p. 12; See also González Rossetti, A., “Change Teams and Vested Interests: Social Security Reform in Mexico”, in Kaufman, R. and Nelson, J. (eds.), *Crucial Needs Weak Incentives: Social Sector Reform, Democratization and Globalization in Latin America*, Baltimore: John Hopkins University Press, 2004, pp. 70-71 (which identifies two additional tiers, private healthcare for the wealthy and a complete lack of healthcare for a rural population of mostly indigenous people).

<sup>131</sup> *Ibid.*, Fundar – Centro de Análisis e Investigación, pp. 10-11.

<sup>132</sup> *Ibid.*, pp. 50-51.

<sup>133</sup> See Frenk, J. and Gómez-Dantés, O., "Ideas and Ideals: ethical basis of health reform in Mexico", *The Lancet*, Vol. 373, Issue 9673, 2009, pp. 1406-1408 (which explains that the intent behind the second-tier healthcare system was to provide healthcare protection to 50 million people who had none).

<sup>134</sup> While the intent is entirely different than the intent in *Brown* or apartheid South Africa, under international human rights law prejudicial intent is not necessary to show status-based discrimination. Rather, any distinction that has the "purpose or effect" of impairing the enjoyment of rights by a protected group amounts to discrimination.

<sup>135</sup> See above, note 101, Para 43(f).

<sup>136</sup> *Corte Constitucional de la República de Colombia, Sala Segundo de Revisión* (2008) Constitutional Court of Colombia, Judgment No T-760/2008.

<sup>137</sup> Yamin, A. and Parra-Vera, O., "Judicial Protection of the Right to Health in Colombia: From Social Demands to Individual Claims to Public Debates", *Hastings International and Comparative Law Review*, Vol. 33(2), 2010, pp. 101-129.

<sup>138</sup> *Ibid.*, p. 105.

<sup>139</sup> See above, note 136, Para 2.2.3, p. 10.

<sup>140</sup> *Ibid.*, Para 3.4, pp. 36-37.

<sup>141</sup> *Ibid.*, Para 3.4.2.3, p. 38.

<sup>142</sup> *Ibid.*, Para 6.1.2.1.1, p.185 (two systems of healthcare violate the constitutional right to equality).

<sup>143</sup> See above, note 127, p. 70.

<sup>144</sup> *Ibid.*

<sup>145</sup> People's Health Movement, Medact and Global Equity Gauge Alliance, *Global Health Watch 2005-2006: an alternative world health report*, Zed Books, 2005, p. 63.

<sup>146</sup> *Ibid.*, pp. 64-65.

<sup>147</sup> See above, note 127, p. 71.

<sup>148</sup> See above, note 29, p.13.

<sup>149</sup> See above, note 42, Rae, p. 25.

<sup>150</sup> *Mashavha v. President of the Republic of South Africa* (2004) CCT 67/03.

<sup>151</sup> *Ibid.*, Para 51.

<sup>152</sup> *Ibid.*

<sup>153</sup> See Newdick, C., "Accountability for Rationing – Theory into Practice," *Journal of Law, Medicine and Ethics*, Vol. 33(4), 2005, p. 662; see also *Rogers v. Swindon Primary Care Trust* (2006) EWCA Civ. 392 (in which the plaintiff was denied Herceptin which was recommended by her doctor, even though the drug was funded for all those with a doctor's recommendation in other healthcare districts).

<sup>154</sup> *Ibid.*, Newdick, p. 662.

<sup>155</sup> *Ibid.*, p. 662.

<sup>156</sup> *Ibid.*, p. 667.

<sup>157</sup> *Ibid.*

<sup>158</sup> *Ibid.*

<sup>159</sup> Afonso da Silva, V. and Vargas Terrazas, F., "Claiming the Right to Health in Brazilian Courts: the exclusion of the already excluded", 2008, available at: [http://papers.ssrn.com/sol3/papers.cfm?abstract\\_id=1133620](http://papers.ssrn.com/sol3/papers.cfm?abstract_id=1133620); see also Hoffmann, F. F. and Bentes, F. R. N. M., "Accountability for Social and Economic Rights in Brazil", in Gauri, V. and Brinks, D. M. (eds.), *Courting Social Justice: Judicial Enforcement of Social Rights in the Developing World*, Cambridge University Press, 2008, pp. 142-143 (which states that the middle class has appreciably better access than the poorer class to courts because they are able to bring right-to-health claims via private counsel).

<sup>160</sup> See above, note 137, p. 114.

<sup>161</sup> *Ibid.*

<sup>162</sup> See above, note 5, Gross, pp. 337-339.

<sup>163</sup> *Soobramoney v. Minister of health, KwaZulu-Natal*, 1 South African Law Report 765 (1998).

<sup>164</sup> *Chaoulli v. Quebec Attorney General* (2005) 1 SCR 791.

<sup>165</sup> *Ibid.*, Para 6.

<sup>166</sup> *Ibid.*, Para 241 (translation of trial court decision in dissenting opinion of Binnie and LeBel, JJ.).

<sup>167</sup> *Ibid.*, Para 7.

<sup>168</sup> *Ibid.*, Paras 243-254.

<sup>169</sup> *Ibid.*, Para 45.

<sup>170</sup> *Ibid.*, Para 84.

<sup>171</sup> *Ibid.*, Para 242 (translation of trial court decision in dissenting opinion of Binnie and LeBel, JJ.).

<sup>172</sup> *Ibid.*

<sup>173</sup> *Ibid.*

<sup>174</sup> King, J., "Constitutional Rights and Social Welfare: A Comment on the Canadian *Chaoulli* Health Care Decision", *The Modern Law Review*, Vol. 69(4), 2006, p. 632 (which states that *Chaoulli* "may well be the most controversial case yet decided under the Charter").

<sup>175</sup> *Ibid.*, pp. 631-643.

<sup>176</sup> Jackman, M., "The Last Line of Defence for [Which] Citizens': Accountability, Equality, and the Right to Health in *Chaoulli*", *Osgoode Hall Law Journal*, Vol. 44, 2006, p. 359.

<sup>177</sup> *Ibid.*, p. 359.

<sup>178</sup> *Ibid.*

<sup>179</sup> *Ibid.*, pp. 360-361.

<sup>180</sup> *Ibid.*, p. 361.

<sup>181</sup> See above, note 174, p. 639.

# LAW AND “THE GOOD LIFE”: LEARNING DISABILITY, EQUALITY AND HEALTHCARE IN THE UK

Nick O’Brien<sup>1</sup>

## Introduction: the “Penalty of Disability”

Disabled people throughout the world fare badly against almost any measure of social deprivation. According to the United Nations (UN), they make up the world’s largest and most disadvantaged minority: an estimated 20% of the world’s poorest people are disabled; 98% of disabled children in developing countries do not attend school; an estimated 30% of the world’s street children are disabled; and the literacy rates for disabled people is as low as 3%, or in some countries 1% for disabled women.<sup>2</sup>

As the UN puts it:

“In every region in the world, in every country in the world, persons with disabilities often live on the margins of society, deprived of some of life’s fundamental experiences. They have little hope of going to school, getting a job, having their own home, creating a family and raising their children, enjoying a social life or voting. For the vast majority of the world’s persons with disabilities, shops, public facilities and transport, and even information are largely out of reach.”<sup>3</sup>

In some cases the degree of marginalisation can quite simply be a matter of life and death. In October 2010, the Council of Europe’s Human Rights Commissioner, Thomas Ham-

marberg, drew attention to the recent action of the Prosecutor-General in Bulgaria initiating criminal investigations into 166 deaths and 30 more cases of abuse of children living in state-run homes for young people with “mental disabilities”. As the Commissioner observed:

“In Europe today, thousands of people with disabilities are still kept in large, segregated and often remote institutions. In a number of cases they live in substandard conditions, suffering abject neglect and severe human rights abuses. In too many cases, premature deaths are not investigated or even reported.”<sup>4</sup>

In such circumstances, the objective of the State is quite blatantly one of isolation and control, with caged beds and other restraints regarded as entirely normal. Independent living and participation, for so long the goal of the worldwide disability movement, are in such circumstances an idle dream.

Yet, there are grounds for cautious optimism. In Albania, for example, results have been achieved by moving disabled people to community and family-based housing. In the Former Yugoslav Republic of Macedonia and in Serbia ambitious plans for similar reforms have been adopted<sup>5</sup>. As the UN points

out, in a few developed and developing countries more comprehensive law reform aimed at promoting and protecting the rights of disabled people has created the prospect of disabled people leading fulfilling and independent lives as students, workers, family members and citizens: “they are able to do so because society has removed the physical and cultural barriers that had previously hindered their full participation”.<sup>6</sup>

That society in some developed nations has taken these steps is in large measure due to the shift in perception of disability that at least in some quarters has occurred since the Second World War and more particularly in the last two decades. Whereas just a generation or two ago the disadvantage experienced by disabled people would have been greeted by a mixture of acquiescence and pity, the adoption of disability as a civil rights issue in the USA, albeit not as an explicit element of the Civil Rights Act 1964, created an environment in which such disadvantage is now more likely, and not just in the USA, to be greeted by a sense of indignation. At the same time, social theory has generated a way of thinking about disability that identifies “the problem” as residing in the arbitrary barriers to inclusion erected by society rather than in physical or mental impairment itself; and the law in turn has responded with anti-discrimination measures, such as the Americans with Disabilities Act 1990 (ADA) or, in Britain, the Disability Discrimination Act 1995, that have brought disability within the fold of equality legislation, alongside the more established “strands” of race and gender.<sup>7</sup>

Despite its relatively late emergence as a rights issue, disability can more recently claim a place in the vanguard of legislative reform designed to promote not just formal equality but substantive equality too. Critical

to these initiatives has been the concept of “reasonable accommodation” or “reasonable adjustment”, which has been described as inaugurating a “new paradigm” of equality law concerned not so much with equal treatment but with different treatment as a means of achieving equal participation in social, political and cultural life rather than simply equality of opportunity, diversity or non-discrimination.<sup>8</sup> From being the Cinderella at the equality ball, disability has quickly emerged to stake a claim to the glass slipper of progressive legislation. The first UN human rights convention of the 21<sup>st</sup> century, in turn incorporating the concept of reasonable accommodation, as well as a firm commitment to the principle of “participation”, is after all the Convention on the Rights of Persons with Disabilities (the UN Convention), described by the Council of Europe Human Rights Commissioner as both “landmark” and a “roadmap towards better treatment of people with disabilities”.<sup>9</sup>

The picture, even in those few developed countries that have embraced disability rights legislation, is not, however, one of unremitting progress. In the USA, for example, it has been noted that there has been something of a “backlash” since the ADA was passed in 1990.<sup>10</sup> In the UK, where the Disability Discrimination Act (DDA) was enacted in 1995, the most recent survey conducted by the Equality and Human Rights Commission suggests that disabled people remain seriously marginalised in employment, educational attainment, and income.<sup>11</sup> What Amartya Sen describes as “the penalty of disability” remains severe.<sup>12</sup>

This article considers one aspect of that “penalty”, namely disabled people’s experience of healthcare in the UK. It considers, in particular, how the legal framework, although not

a significant source of individual litigation in this area, has nevertheless played an important part as a catalyst for action by regulatory agencies and voluntary sector bodies. In doing so, it offers reflection on the, sometimes surprising, ways in which law can be mobilised to bring about systemic and cultural change.

### **1. Access to Healthcare in the UK: the Limits of Anti-discrimination Law**

In the last decade the experience of disabled people in the UK healthcare system has attracted particular and sustained attention. Despite its vicissitudes under governments of different political complexion, the National Health Service (NHS) remains for many a gold standard of the post-1945 welfare state. As an index of performance against equality measures, therefore, it carries special and symbolic significance.

Of particular interest has been the experience of those with learning difficulties or mental health problems, not least since estimates suggest that even among disabled people it is they who experience the highest levels of exclusion and are among the most vulnerable.<sup>13</sup> As the report of an independent inquiry put it in July 2008:

“The health and strength of a society can be measured by how well it cares for its most vulnerable members. For a variety of reasons, including the way society behaves towards them, adults and children with learning disabilities, especially those with severe disability and the most complex needs are some of the most vulnerable members of our society today.”<sup>14</sup>

As the evidence of the last decade has accumulated it has become increasingly clear that

if this is indeed a reliable measure, then the UK “cares” not very well at all. What has perhaps been especially disturbing is the extent to which, despite 15 years of anti-discrimination law and a decade of domestic human rights provision, the findings suggest that discrimination and prejudice have played a significant part in the pattern of deprivation.<sup>15</sup> The ability of the law to provide effective protection is to that extent called into doubt.

The DDA 1995, recently absorbed and amended by the Equality Act 2010, has since 1996 provided legislative protection against discrimination in the receipt of goods, facilities and services. In principle, it has since then been open to individual disabled people to bring discrimination claims against the providers of healthcare services, including since 1999 for breaches of the duty to make reasonable adjustments, for example, for failure to provide auxiliary aids and services where to do so would make an otherwise unreasonably difficult or impossible to use service accessible.<sup>16</sup> In fact, there is very little sign of anyone having brought such cases to challenge, for example, the failure to conduct accessible health checks, to adapt screening programmes, to communicate effectively and to provide training aimed at the distinctive needs of disabled people.<sup>17</sup>

There are several possible reasons. In general, the goods, facilities and services provisions have attracted relatively little litigation of any sort by comparison with the employment provisions of the DDA. For example, during the years 1996-2001, there were just 53 goods, facilities and services claims, as opposed to approximately 8,900 employment claims.<sup>18</sup> In part, this is no doubt due to the relative ease of bringing claims in the specialist employment tribunals; by compar-

ison, claims to the civil courts for breaches of the goods, facilities and services provisions are potentially expensive and technical. The employment tribunal also provides a more accessible appeals process, which leads to the regular reporting of appellate cases so that there has emerged a relatively sophisticated and well-known body of case law. In the civil courts, the likelihood and ease of appeal is much reduced, with the result that there have been scarcely a handful of reported higher court decisions on the goods, facilities and services provisions. Whatever the reasons, in a common law jurisdiction this lack of precedent is potentially fatal to the visibility and development of the law, at least as an instrument of individual litigation.

It should not be supposed, however, that potential causes of action did not exist. According to the Disability Rights Commission (DRC),<sup>19</sup> the number of potential goods, facilities and services cases referred to it between 2004 and 2007 numbered 25,117, compared to 35,534 employment cases. There are no figures to indicate how many such enquiries related to the provision of healthcare.<sup>20</sup> What is clear, however, is that the majority of the goods, facilities and services cases highlighted by the DRC as noteworthy at the end of its seven-year lifespan were almost exclusively about commercial consumer disputes in relation to shops, restaurants, bars and transport facilities. None related to learning disability and health services, notwithstanding the DRC's strategic commitment to treat people with learning disability as a priority for litigation support and the consistently damning reports on the overall provision of healthcare for people with learning disabilities that have emerged during the course of the decade.<sup>21</sup>

The closest the DRC came to touching upon health and social care issues in its conduct

of litigation was through the device of intervening as an interested third party in cases being brought under the Human Rights Act 1998. One such case involved a challenge to a local authority's manual handling policy in domestic social care settings, on the basis that it amounted to a 'no lifting' ban and was unlawful;<sup>22</sup> another case, more directly concerned with healthcare services, related to the circumstances in which artificial nutrition and hydration may be withdrawn from disabled patients.<sup>23</sup> Whilst it is significant that the ability to get close to health and social care issues entailed recourse to human rights legislation rather than anti-discrimination law, the cases themselves served rather to accentuate the general invisibility of healthcare services as the subject matter of anti-discrimination litigation. Despite the existence of relatively comprehensive laws in the UK, healthcare services have so far remained largely beyond the reach of individual disabled litigants.

## **2. A Different Approach: The DRC and "Equal Treatment: Closing the Gap"**

In 2006-2007, the final year of the DRC's existence, a new approach to implementing the law was inaugurated by the introduction of the Disability Equality Duty,<sup>24</sup> developing the approach to race equality that had been in place since 2001 following the Stephen Lawrence Inquiry and its popularisation of the concept of "institutional discrimination". The new duty placed the onus on public authorities to take positive steps to promote equality for disabled people in the delivery of their services and functions. In so doing it effectively turned disability rights law on its head, shifting attention from retrospective, individual litigation to prospective, collective action aimed at remedying systemic and structural defects in the provision of services to disabled people. This was an example of

what has been described as the fifth, “transformational” phase of equality legislation in the UK, which has recently been extended to all protected characteristics in the Equality Act 2010.<sup>25</sup>

It was partly in anticipation of the implementation of the Disability Equality Duty in December 2006 that the DRC commenced a formal inquiry into the health inequality experienced by people with learning disabilities or mental health problems. As the DRC’s chairman, Bert Massie, commented in the foreword to the inquiry report’s identification of serious deficiencies in the level of service provided by the NHS: “The implementation of the Disability Equality Duty provides the impetus to remedy this neglect through a strategic and proactive approach.”<sup>26</sup>

The implication was that the new duty would have the potential to penetrate into those areas of healthcare service that had in effect remained immune from individual litigation, despite the best intentions of the framers of the DDA, and indeed of the DRC, during its lifespan. In the meantime, the DRC had chosen to use its own investigative powers in a prospective and systemic way that anticipated to some extent the approach that would be made possible by the new duty.

The DRC’s investigation in fact proved to be an important piece in an emerging pattern of public audit and non-governmental organisation campaigns in the first decade of the 21<sup>st</sup> century. As the report explained, the inquiry had produced new evidence that “people with learning disabilities and people with mental health problems are more likely to experience major illnesses, to develop them younger and die of them sooner than other citizens”;<sup>27</sup> they are less likely to get the screening they need and they encounter significant barriers in gaining access to basic

health services. For people with learning disabilities, the risks in particular include obesity and respiratory disease; for people with mental health problems, obesity, smoking, heart disease, high blood pressure, respiratory disease, diabetes and stroke.<sup>28</sup>

Despite the higher risks experienced by these groups, the investigation revealed that they are actually less likely than other people to receive evidence-based checks and treatments. People with mental health problems receive standard cholesterol checks less often than others with heart disease, and breathing tests less often than others with respiratory problems. People with learning disabilities who have diabetes have fewer measurements of their body mass index, and those with stroke have fewer blood pressure checks; they also have very low cervical cancer screening rates. Both groups experience what is described as “diagnostic overshadowing”, that is, the interpretation of physical ill-health as an aspect of a known mental health condition or learning disability with the result that it is not investigated or treated properly.<sup>29</sup>

To illustrate the extent to which people with learning disabilities and people with mental health problems had eluded targeted government intervention, the DRC report pointed out that there are more obese people with learning disabilities or mental health problems in England than there are obese people in Birmingham and Coventry combined. To address the problem of obesity among these groups would therefore have a greater impact than to do so across those two large Midlands cities. As the report pointed out:

“A national programme to tackle health inequalities in England would not ignore whole cities like Birmingham or Coventry and yet people with learning disabilities

and/or mental health problems have, to date, been ignored in national health inequalities programmes.”<sup>30</sup>

More generally, the DRC concluded that the cause of health inequalities are “multiple and include deprivation, lifestyle, access to health assessments and treatments and side effects of anti-psychotic and mood stabiliser medication”.<sup>31</sup> Especially striking was the link to social deprivation:

“Recent data (...) suggest that around 20-33% of the increased risk of poor health faced by children with learning disabilities in the UK can be attributed to their increased risk of exposure to socio-economic disadvantage. The health problems experienced by people with learning disabilities and/or mental health problems are shaped by broader social inequalities, and tackling poverty must form a key part of any efforts to address those problems.”<sup>32</sup>

The DRC was specifically concerned, however, to focus on issues other than social deprivation and to identify the “disability penalty”.<sup>33</sup> That disability penalty was manifest, for example, in the fact that, even after accounting for social deprivation, people with schizophrenia and bipolar disorder who have major physical health problems are more likely to die sooner than other people with the same health problems. It was manifest also in the fact that someone with a learning disability or mental health problem might experience deprivation differently because of what the DRC called “compounding difficulties of social exclusion, discrimination and isolation”.<sup>34</sup> As the DRC put it, “[t]his is therefore rightly a matter of disability equality, to be addressed through the new Disability Equality Duty, which requires public sector organisations to work positively to promote equal outcomes for disabled people”.<sup>35</sup>

The promotion of “equal outcomes” rather than the “equal treatment” of the report’s title had by the end emerged as the proposed objective.

### 3. A Decade of “Indifference”

The DRC formal investigation reinforced and dovetailed with an earlier campaign launched in 2004 by Mencap, the leading learning disability non-governmental organisation. The campaign, *Treat me right!*, which went beyond primary healthcare to include acute care in hospital as well, also aimed to focus attention on the finding that people with learning disability have poorer health than the general population.<sup>36</sup> According to Mencap, this is partly because they develop conditions that are directly related to their impairment or because they are generally poor and are therefore more likely to have unhealthy lifestyles. To that extent, the prevalence of high rates of morbidity can be isolated from what might be regarded as “prejudice” or “discrimination”. However, Mencap also suggests that a significant factor is the poor standard of treatment afforded to people with learning disability by the NHS, very often as a direct result of what it describes as “ignorance and prejudice among healthcare professionals towards people with learning disability”.<sup>37</sup>

Mencap found that 75% of General Practitioners (GPs) said they had no training to help them treat people with a learning disability, and that 90% thought that a patient’s learning disability had made it more difficult for them to provide an accurate diagnosis. The lack of specific training increased the likelihood of diagnostic overshadowing and limited the ability of health professionals to understand the different ways that people with learning disabilities communicate.<sup>38</sup>

Mencap also found that care in hospital was particularly bad, often as a result of lack of understanding and training, or because of assumptions about the level of care that can be expected from family and care-home staff. In some instances, Mencap identified what it regarded as “blatant discrimination”, with healthcare staff seeming to make “arbitrary value judgments about people with a learning disability having less worth than people without a disability”.<sup>39</sup>

In a follow-up report entitled *Death by Indifference*, Mencap published its findings on the deaths of six people with learning disability in NHS hospitals. According to Mencap, these six “shocking and tragic” cases demonstrate that there is “institutional discrimination” within the NHS against people with a learning disability, leading to neglect and even premature death.<sup>40</sup> Mencap identified what it considered to be six contributory factors: people with learning disability are seen to be a low priority; many healthcare professionals do not understand much about learning disability; many healthcare professionals do not properly consult and involve the families and carers of people with a learning disability; many healthcare professionals do not understand the law around capacity and consent to treatment; health professionals rely inappropriately on their estimates of a person’s quality of life; and the complaints system within NHS services is often ineffective, time-consuming and inaccessible.<sup>41</sup>

Mencap’s conclusions reinforced the findings of two separate investigations conducted by the health service regulator, the Healthcare Commission, into the alleged abuse of people with learning disabilities in the care of Cornwall Partnership NHS Trust and Sutton and Merton Primary Care Trust, respectively. In those cases, the Healthcare Commission found evidence that abuse had occurred in

part because learning disability services were such a low priority and attracted poor levels of management: “institutional abuse” prevailed mainly as a result of “lack of awareness, lack of specialist knowledge, lack of training and lack of insight”.<sup>42</sup>

When the Health Service Ombudsman for England, Ann Abraham, investigated the six specific cases identified by Mencap, she too came to some stark conclusions.<sup>43</sup> The Ombudsman’s report illustrated “some significant and distressing failures in service across both health and social care, leading to situations in which people with learning disabilities experienced prolonged suffering and inappropriate care”.<sup>44</sup> The investigation found in some cases that there had been “maladministration and service failure for disability related reasons”, as a well as a failure “to live up to human rights principles, especially those of dignity and equality”.<sup>45</sup> The Ombudsman concluded that the death of one of the individuals concerned occurred as a consequence of the service failure and maladministration identified, and in another case that it was likely the death of the person could have been avoided if the care had not fallen so far below the acceptable standard. In one of those cases, the Ombudsman found that the individual concerned had not been fed for twenty-six days.<sup>46</sup>

The Ombudsman’s findings were consistent with the broader findings of the Independent Inquiry into Access to Healthcare for People with Learning Disabilities by Sir Jonathan Michael, published as *Healthcare for All* in 2008. That inquiry found “appalling examples of discrimination, abuse and neglect across the range of health services”, which it attributed to learning-disabled people being “not visible or identifiable” by health services; lack of awareness among staff; the needs of learning-disabled people not being a pri-

ority for the NHS; inadequate monitoring of compliance with the law; the tendency for learning-disabled people to slip through the regulatory and inspectorate net; insufficient knowledge and information on the part of staff to make reasonable adjustments; very limited training and education about learning disability for NHS staff; and ignorance and fear, negative attitudes and values.<sup>47</sup>

These findings present a uniformly dispiriting picture of the experience of people with learning disabilities within the NHS. It is all the more dispiriting since it is now thirty years since an influential report of The King's Fund, *An Ordinary Life*, spelt out in 1980 the aspiration to end generations of social exclusion.<sup>48</sup> That aspiration was finally translated into government policy in 2001 when a government White Paper, *Valuing People*, constructed its central objectives around the principles of independence, rights, choice and inclusion;<sup>49</sup> and in a 2007 consultation report the aspiration to enable people with learning disabilities to lead ordinary lives and do the things most people take for granted was reasserted, although the then Secretary of State for Health, Alan Johnson, conceded that, despite some progress, for many people with learning disabilities "little has changed".<sup>50</sup> The 2009 sequel, *Valuing People Now*, whilst placing its trust in the concept of "personalisation", in the sense of adherence to a framework of person-centred planning, individualised services and individually managed budgets, and measures to support access to paid work, could not fail to acknowledge the continuing difficulties of implementing real change.<sup>51</sup>

This rather bleak analysis offers little comfort to those on either side of the law and policy divide. On the one hand, the experience of people with learning disabilities, both in healthcare and beyond, has proved largely

impervious to government policy aimed at promoting independence, choice and inclusion; on the other hand, whether because of the inaccessibility of the court process or because of the unwillingness on other grounds of disabled people to make use of it, that experience has almost entirely eluded the reach of individual law enforcement and the protection of rights through the civil court structure. A reasonable response might fall somewhere between frustration and despair.

#### **4. Anti-discrimination Law as a Critical Resource**

As a counter to that counsel of despair it is possible to cite the most recent progress report compiled by the Department of Health, which indicates that the convergence of individual claims, referred in this instance to the Health Service Ombudsman, and a concerted critique of structural and systemic failings, is now producing tangible change on the ground. As the report indicates, there are now clear examples of health authorities taking innovative approaches, involving people with learning disabilities and their families in planning, assessing and delivering services, and so ensuring that their hospital ward, GP surgery or community service is fully accessible and actually working in the interests of disabled people. The report points also to improved leadership within the NHS to ensure the active engagement of disabled people and their families, especially through the strengthened role of Learning Disability Partnership Boards. In short, the report suggests that the abstractions of "empowerment" and "choice" are increasingly being made a practical reality.<sup>52</sup>

Moreover, an important contributor to those encouraging signs has been the legal framework, both in its role as the creative purveyor

of interpretive concepts, such as “discrimination” and “reasonable adjustment”, and as a focal point for enabling critical but mutually reinforcing processes to occur, such as, precisely, the DRC formal investigation and the investigation of individual grievances by the Health Service Ombudsman. To that extent, the experience of people with learning disabilities in the NHS warrants further reflection on how the anti-discrimination legal framework has played its part, notwithstanding its identified limitations. Such an exercise is especially valuable since the part played by the law is not that of straightforward enforcement most readily recognised by those, especially within a common law jurisdiction, who measure success by the number of cases brought to court, the achievement of court judgment in those cases, and whenever possible the appearance of those judgments in the law reports as properly promulgated legal precedent. In this instance, it has been more a question of mobilising or “giving force to” the law, by a variety of means, than of “enforcement” more strictly conceived.

First, throughout the various inquiries cited, the language of disability-rights law offers the primary vehicle for some of the most far-reaching conclusions and recommendations. It is not just the campaigning voice of Mencap that speaks in terms of “discrimination”. The official report of Sir Jonathan Michael and the investigation of the DRC speak quite explicitly of discrimination and prejudice being a significant factor. The Health Service Ombudsman adopted the language of the DDA when she identified maladministration and service-deficiency that had occurred for “disability-related reasons”. The use of the language of discrimination brings to these observations a sense of urgency and entitlement that would otherwise be missing. It also relates the experience of disabled people to the broader tradition of human rights

implementation in a way that makes the evasions of the past harder to sustain.

Secondly, these various reports take for granted something that apparently could not be taken for granted in the negotiations that led to the UN Convention, namely, that in the case of disability rights, the failure to make reasonable adjustments is itself an instance of discrimination and not merely the regrettable omission of an optional extra.<sup>53</sup> It is no exaggeration to say, in fact, that much of the substance of the various reports is directed towards realising in practice the full potential of the reasonable adjustment duty and of doing that in a context where the failure to make such adjustments carries with it a measure of opprobrium. The failure to make adequate provision for routine health checks, to adapt screening processes to ensure coverage of those who might otherwise not take advantage of them, to take additional steps to ensure adequate communication with patients whose media and styles of communication are unusual, to provide training targeted at the distinctive needs of disabled people – these steps, variously identified by the DRC, the Health Service Ombudsman and Sir Jonathan Michael, are all in their different ways examples of adjustments to standard policies and practices deemed necessary to ensure equal recognition for people with learning disabilities. In such instances, it is the legal concept of reasonable adjustment that lends cogency and immediacy to what might otherwise be seen as empty exhortation or counsel of perfection. In the case of disability rights, different treatment is quite simply the primary condition of equality.

Thirdly, and related in particular to the language of reasonable accommodation, there is the implicit recognition in all these reports that, as prescribed by the Disability Equality Duty (now the Equality Duty contained

in the Equality Act 2010, albeit subject to the potential relaxation of approach signalled by the draft regulations),<sup>54</sup> the onus, even in law, rests on the NHS not on individual and vulnerable disabled people. It is not just that the DRC's formal investigation anticipated and welcomed the imminent duty as an opportunity to reverse historic neglect. The very initiative of the various other reports and the tenor of their recommendations leave no room for the complacent assurance that in the absence of, and until, defeat in court, all can be assumed to be well. Notwithstanding the changes in the Equality Act 2010 and in the draft regulations, the very existence of a statutory duty, including the obligation to prepare and publish equality objectives, reinforces an approach to the legal framework that is more "positive" than the earlier reliance on retrospective individual litigation.

The Department of Health's own response to the Health Service Ombudsman's report indicates the range of positive initiatives in place: for example, the creation of the Health Self Assessment to improve collaboration between local people with learning disabilities, their carers and care professionals; the establishment of Learning Disability Partnership Boards to facilitate dialogue between health and social care decision makers; the nomination of Learning Disability Leads to demonstrate leadership and share good practice; and the identification of liaison and facilitation staff in acute and primary care to improve the patient experience of people with learning disabilities.<sup>55</sup> These steps can be seen as a response to the heightened expectations created by the new fifth generation duty. In practice, the signs are that the language of positive equality duty has begun to permeate the collective imagination, at least within the upper echelons of the NHS.

## 5. The Broader Legal Framework

Beyond the framework provided by the DDA as a piece of anti-discrimination law, two other legal instruments helped shape the critique of NHS practice in the process of public audit: the Mental Capacity Act and the Human Rights Act.

First, it is the Mental Capacity Act that reinforces the assumed capacity of disabled people to make decisions for themselves rather than the reverse, as in the past. As Mencap discovered, that change of mindset has yet to be achieved in full across the NHS. Even the Department of Health in its follow-up to the Health Services Ombudsman's report concedes that more needs to be done to improve the skills and understanding of mainstream staff in various ways, including in respect of mental capacity, consent and "best interest" decision-making.<sup>56</sup>

This is not just a technical legal issue but something that goes to the heart of how far disabled people are recognised as autonomous individuals with, as a matter of fundamental principle, as much entitlement to direct their own lives as anyone else. Family carers should not have to explain to hospital staff their obligations; nor should "Do Not Resuscitate" notices be placed in patients' records without any conversation with the individuals concerned or their families. One patient experience cited by the Department for Health graphically illustrates the potentially inhumane treatment that the law is intended to remedy and for which it creates a language of protest:

"My son has a severe learning disability and challenging behaviour. I arrived at the hospital where he needed tests. I was asked 'How many people should I get? Four

or five?’ It took a moment to realise the doctor meant the number of people required to hold my son down and force treatment on him. There was no question of speaking to him or me about the best way to explain the treatment or keeping him as calm as possible. I had to explain best interest decision making to her, and to her manager, before even the most basic principles of the law were followed.”<sup>57</sup>

Secondly, there is the language of human rights, given local flavour by the domestic Human Rights Act 1998 but in essence that of the European Convention on Human Rights, especially as articulated in Article 3, with its prohibition of inhuman and degrading treatment, and in Article 8, with its commitment to the value of private and domestic life.

Explicit, and implicit, in the public audit described is a deep suspicion that people with learning disabilities are simply not valued at all, or if they are, that the value placed upon their lives is less than that of other people. It is this underlying mentality that shapes quite explicitly the entire trail of policy development from The King’s Fund report of 1980 and through its explicit adoption in the *Valuing People* agenda of 2001. It is inherent too in the repeated suggestions that people with learning disabilities have not been credited with full personhood, that they have been invisible to health service construction and data collection, that they have simply not been a serious enough priority to warrant targeted prevention and screening programmes.

It is the human rights language of dignity or worth that animates these discussions and creates a framework within which a critique of accepted practice can be mounted. The Health Service Ombudsman speaks of

the human rights principles of dignity and equality; Mencap, of inappropriate “quality of life” assessments by health professionals; Sir Jonathan Michael, of ignorance, fear and negative attitudes. Underpinning the sense of indignation that permeates these various reactions is the realisation that those with learning disabilities have simply not been accorded fully human status; and at root it is that intuition that founds the basis of all indignation against inequality and disadvantage. Equality emerges in these reports as at root a human rights value, alongside fairness, respect, dignity and autonomy (the FREDA values, adopted by the Department of Health).<sup>58</sup>

## **6. Beyond Law: Dignity, Universalism and “the Good Life”**

This narrative of the experience of people with learning disabilities suggests three broad conclusions about the way in which a legal framework, based on the model of anti-discrimination law, can extend its reach beyond the conventional forum of individual court-based litigation. Firstly, even in a sphere such as healthcare, which does not readily lend itself, at least in the UK context, to individual anti-discrimination litigation, the legal framework, by creating expectations and creating a language in which those expectations can be articulated, can play a decisive part in constructing the critique of services that invites audit and investigation by non-litigious means. In that way, the legal framework emerges as a powerful, albeit indirect, resource for interpreting the experience of disadvantage and inequality, and as the conveyor of a sense of urgency and insistence that might otherwise be diminished.

Secondly, court action does not exhaust the process of invoking the legal framework. The

devices of audit and inquiry, especially when embedded in grass-roots non-governmental organisation action, can effectively invoke the law and create an environment in which the values underpinning the law are given expression. The role of ombudsman emerges also as a potentially important resource. Although frequently lacking enforcement powers and essentially quasi-judicial in character, ombudsmen, whether with general or specialist mandates, have the ability to provide ease of access to adjudicative processes, to the invocation of the law even if not to its strict application, and to the recommendation of a suite of remedies that exceeds the narrower range very often available to the civil courts.

Thirdly, it is important for anti-discrimination law to coalesce with other law, so that it becomes part of a broader legal framework based on common values and objectives. In the examples cited, the laws relating to mental capacity and domestic human rights law were invoked by protagonists to capture those experiences of disadvantage and degradation that largely eluded anti-discrimination law in the particular circumstances encountered by disabled individuals and their families. It was that coalition that lent breadth, depth and precision to the critique of services that all agreed were falling short of acceptable standards. It is, furthermore, a legacy that has wide application but, in a narrower UK context, is especially salient when government policy may yet have a regressive impact on the obligation actively to plan ahead rather than contemplate remedial action after the event.

The narrative of a decade's experience also invites three further reflections, of even broader application. The first concerns the nature of "dignity". A recurrent theme has

been the fact that people with learning disability are denied dignity by being ignored, undervalued and excluded from recognition in the ordinary conduct of daily life, on hospital wards and in GPs' surgeries. The recurrence of this sort of misrecognition is an indication that it is deeply rooted in the way in which equality and dignity itself are construed. As Martha Nussbaum has argued, the dominant tradition of thinking about human personhood has mistakenly taken its distinguishing characteristic to reside in rationality, as something quite separate from the needs that human beings share with each other. The practical extension of the equality principle to people with learning disabilities, however, compels the realisation that an approach to human dignity based exclusively on cognitive factors is inadequate to the task.<sup>59</sup>

Instead, what emerges is the need for the principle of equality to be rooted not solely or even primarily in cognitive attributes but very firmly in the bodily nature of the human person, in the fundamental capabilities that lie at the core of the good life for human beings. It is a realisation that reaffirms the status of the equality principle as one aspect of a broader framework of value that includes human rights but that does not deny the inevitability of human need, vulnerability and interdependence as a component of human dignity and source of human solidarity. In the end, the language of duty and restraint gives way to more positive language and to a notion of shared human dignity broadly conceived.<sup>60</sup> It is a language, too, that invites the reasonable accommodation of different need as a means of reaching beyond concerns about formal equality and process to something more substantive, to a model of liberalism grounded "very much on judgments about what makes a good life".<sup>61</sup>

The second reflection concerns the status of disabled people as a minority group. The translation from the deontological to the teleological, i.e. from notions of duty to notions of the good life, forces the recognition that, although disability has made ground in recent years as a minority group issue, in reality it is scarcely a minority group issue at all. As one commentator has remarked:

“While anti-discriminatory legislation is central to the response, for example, to discrimination on the basis of race or gender, it need not be for discrimination on the grounds of disability (...) the universalising thesis, in which disability is treated as part of the normal, is both the most intellectually satisfactory and the most effective, and (...) has the consequence that anti-discrimination legislation might not always be the most effective legal response to disability discrimination.”<sup>62</sup>

That recognition is especially acute in the context of healthcare. The experience of healthcare for those who are disabled and for those who are not is invariably an encounter with need, vulnerability and dependence. Moreover, the components of good healthcare will be the same in both cases: the sort of “personalisation” that can facilitate good care and dignity for disabled people is the sort of care to which non-disabled people also aspire.

The experience of healthcare, conceived as more than just another consumer service and instead as a basic public response to shared human need, highlights the fact that disability is a continuum, a difference of degree not of kind, extending across various levels of ability and impairment, mediated by social circumstance and environment, and fluctuating in degree through every individual life, from

cradle to grave.<sup>63</sup> The emergence of disability as a rights issue, although at first in the guise of a minority group concern and therefore as an aspect of identity politics, in fact suggests that a unified approach to equality will look beyond the language of minority groups and local identity to a form of universalism that unites rather than divides.

Thirdly, and finally, the experience of healthcare afforded to people with learning disabilities makes it clear that, as well as saying something about entitlement, a comprehensive equality principle must say something about the human qualities needed to overcome inequality in practice. Yet another recurrent theme has been the perceived absence of the personal and professional characteristics required to enable healthcare staff to provide the level of care needed by those with learning disabilities. Basic, everyday human qualities such as kindness, insight and practical know-how have repeatedly been in short supply.

Part of the response has been to recommend better training and more intrusive regulation. It is likely, however, that something more fundamental is also required, both the cultivation of personal “virtue” and the collective building up of those institutions and environments that can internalise such virtuous dispositions, making them natural and apparently effortless, rather than the outcome of a constant straining to meet some externally imposed standard of behaviour. It is, in other words, likely to be as much a matter of self-realisation as of external regulation, of the shared long-term development of character and virtuous disposition as the isolated absorption of occasional guidance and training.<sup>64</sup>

When asked what would make a real difference, the families of people with learning disabilities have reported that the key attribute of staff is their ability to establish “warm, respectful and caring” relationships.<sup>65</sup> As one mother put it:

“Often – not always, but sometimes – the best people have been people who have come with the right values and attitudes and with no experience whatsoever. (...) That’s why it is so important that the person understands and has that ability to build a relationship, to see the person as a person. You can teach all the rest.”<sup>66</sup>

This ethical and political language, rooted more in those traditions of thought associated with Aristotle than with Kant, has

not always been an obvious resource for an equality tradition that is more at home with notions of merit and desert, “the right” rather than “the good”.<sup>67</sup> It is, however, one aspect of the “new paradigm” created by inclusion of disability in the equality fold that such language should be part of a unified perspective on equality and human rights. The challenge posed by the experience of disability is not simply that of finding legal forms that will transcend the boundaries of equal opportunity, non-discrimination and identity. It is also the challenge of finding the language that will root those legal forms in a more comprehensive and positive set of values that can speak of the good life and of the good society, and of the part played by the equality principle in achieving both.

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<sup>2</sup>United Nations, *From Exclusion to Equality: Realizing the rights of persons with disabilities – Handbook for Parliamentarians on the Convention on the Rights of Persons with Disabilities and its Optional Protocol*, Geneva, 2007, available at: <http://www.ohchr.org/Documents/Publications/training14en.pdf>.

<sup>3</sup>*Ibid.*, p.1.

<sup>4</sup>Hammarberg, T., *Inhuman treatment of persons with disabilities in institutions*, 2010, available at: [http://commissioner.cws.coe.int/tiki-print\\_blog\\_post.php?postId=93](http://commissioner.cws.coe.int/tiki-print_blog_post.php?postId=93).

<sup>5</sup>*Ibid.*

<sup>6</sup>See above, note 2.

<sup>7</sup>Gooding, C., *Disabling Laws, Enabling Acts: Disability Rights in Britain and America*, Pluto Press, 1994. On Europe, see Waddington, L., *From Rome to Nice in a Wheelchair: The Development of a European Disability Policy*, Europa Law Publishing, 2006.

<sup>8</sup>See Fredman, S., “Disability Equality: A Challenge to the Existing Anti-Discrimination Paradigm”, in Lawson A. and Gooding, C., Hart (eds.), *Disability Rights in Europe: From Theory to Practice*, Hart Publishing, 2005, pp. 199-218.

<sup>9</sup>See above, note 4.

<sup>10</sup> Hamilton Krieger, L. (ed.), *Backlash Against the ADA: Reinterpreting Disability Rights*, The University of Michigan Press, 2003.

<sup>11</sup> Equality and Human Rights Commission, *Triennial Review 2010: How Fair is Britain? Equality, Human Rights and Good Relations in 2010*, 2010, available at: [http://www.equalityhumanrights.com/uploaded\\_files/triennial\\_review/how\\_fair\\_is\\_britain\\_-\\_complete\\_report.pdf](http://www.equalityhumanrights.com/uploaded_files/triennial_review/how_fair_is_britain_-_complete_report.pdf).

<sup>12</sup> Sen, A., *The Idea of Justice*, Penguin, 2009, p. 259.

<sup>13</sup> See, for example, Disability Rights Commission, *Equal Treatment: Closing the Gap*, 2006, and the research justifying investigation cited at Appendix 3, pp. 109-111.

<sup>14</sup> Michael, Sir J., *Healthcare for All: Report of the Independent Inquiry into Access to Healthcare for People with Learning Disabilities*, 2008, p. 7.

<sup>15</sup> *Ibid.* See also Parliamentary and Health Service Ombudsman, *Six Lives: the provision of public services to people with learning disabilities*, 2009.

<sup>16</sup> See Disability Discrimination Act 1995, s. 21 for the duty as originally conceived.

<sup>17</sup> Any such cases commenced in the county court would routinely go unreported, and there are no reported cases in the higher or appellate courts. Neither the Equality and Human Rights Commission nor the predecessor commission, the Disability Rights Commission, has drawn attention to any such cases. See, for example, Disability Rights Commission, *DRC Legal Achievements: 2000-2007*, 2007.

<sup>18</sup> Leverton, S., *Monitoring the DDA 1995, Phase 2*, 2002, available at: <http://research.dwp.gov.uk/asd/asd5/IH91.pdf>.

<sup>19</sup> The Disability Rights Commission was a statutory body in Britain, established in 2000 and dissolved in 2007 when it became merged within the Equality and Human Rights Commission.

<sup>20</sup> Disability Rights Commission, *DRC Legal Achievements: 2000-2007*, 2007, p. 142.

<sup>21</sup> *Ibid.*, pp. 123-5.

<sup>22</sup> *R. v East Sussex County Council ex parte A, B, X and Y* [2003] CO/4843/2001 High Court.

<sup>23</sup> *R. (on the application of Burke) v General Medical Council* [2005] EWCA Civ 1003 CA.

<sup>24</sup> Disability Discrimination Act 1995, Section 49A (as amended by Disability Discrimination Act 2005).

<sup>25</sup> Hepple, B., "The New Single Equality Act in Britain", *Equal Rights Review*, Vol. 5, 2010, pp. 11-24; cf. McCruden, C., "Foreword", in Blanck, P. (ed.), *Disability Rights*, Ashgate, 2005, pp. xiv-xv. Note now, however, that the new general and specific duties in s. 149 of the Equality Act 2010, which comes into force in April 2011, and the UK Government's draft regulations, contained in The Equality Act 2010 (Statutory Duties) Regulations 2011, mark a potential retreat from the more anticipatory and proactive aspects of the earlier disability duty.

<sup>26</sup> Disability Rights Commission, *Equal Treatment: Closing the Gap*, 2006, p. 2.

<sup>27</sup> *Ibid.*, p. 1.

<sup>28</sup> *Ibid.*, pp. 4-7.

<sup>29</sup> *Ibid.*

<sup>30</sup> *Ibid.*, p. 7.

<sup>31</sup> *Ibid.*, p. 41.

<sup>32</sup> *Ibid.*

<sup>33</sup> *Ibid.*, p. 42.

<sup>34</sup> *Ibid.*

<sup>35</sup> *Ibid.*

<sup>36</sup> Mencap, *Treat me right!*, 2004.

<sup>37</sup> Mencap, *Death by Indifference*, 2007, Appendix pp. 29-31.

<sup>38</sup> *Ibid.*, p. 29.

<sup>39</sup> *Ibid.*

<sup>40</sup> *Ibid.*, p. 1.

<sup>41</sup> *Ibid.*, pp. 18-24.

<sup>42</sup> *Ibid.*, p. 19.

<sup>43</sup> Parliamentary and Health Service Ombudsman, see above, note 15.

<sup>44</sup> *Ibid.*, Part One, p. 3.

<sup>45</sup> *Ibid.*

<sup>46</sup> *Ibid.*, pp. 22-24, 59.

<sup>47</sup> See above, note 14, pp. 7-8.

<sup>48</sup> The King's Fund, *An Ordinary Life*, 1980.

<sup>49</sup> Department of Health, *Valuing People: A new strategy for learning disability for the 21st century*, 2001.

<sup>50</sup> Department of Health, *Valuing people now: Consultation Report*, 2007.

<sup>51</sup> Department of Health, *Valuing people now*, 2009.

<sup>52</sup> Department of Health, *Six Lives – Progress Report*, 2010.

<sup>53</sup> On the UN negotiations, see Quinn, G. and Gombos, G., "Promoting a Paradigm Shift", *Equal Rights Review*, Vol. 2, 2008, pp. 83-93, especially p. 83.

<sup>54</sup> See above, note 25.

<sup>55</sup> Department of Health, *Six Lives Progress Report*, 2010.

<sup>56</sup> *Ibid.*, p. 36.

<sup>57</sup> *Ibid.*, p. 39.

<sup>58</sup> Department of Health, *Human Rights in Healthcare – A Framework for Local Action*, 2007, p. 3.

<sup>59</sup> Nussbaum, M., *Frontiers of Justice: Disability, Nationality, Species Membership*, Harvard, 2006.

<sup>60</sup> *Ibid.* See also Johnson, K. and Walmsley, J. with Wolfe, M., *People with Intellectual Disabilities: Towards a Good Life*, The Policy Press, 2010; and Burchardt, T., "Capabilities and disability: the capabilities framework and the social model of disability", *Disability and Society*, Vol. 19(7), 2004, pp. 735-51.

<sup>61</sup> Taylor, C., "The politics of recognition", in Guttman, A. (ed.), *Multiculturalism: Examining the Politics of Recognition*, Princeton University Press, 1994, p. 61.

<sup>62</sup> Alldridge, P., "Locating Disability Law", *Current Legal Problems*, Vol. 59(1), 2006, pp. 289-318, at p. 318. See also Bickenbach, J. E., "Minority Rights or Universal Participation: The Politics of Disablement", in Jones, M. and Basser Marks L. A. (eds.), *Disability, Divers-ability and Legal Change*, Kluwer Law International, 1999, pp. 101-116.

<sup>63</sup> See above, note 59, esp. Chapter 3. See also Nussbaum, M., *Hiding from Humanity: Disgust, Shame and the Law*, Princeton University Press, 2004, pp. 305-319 and Chapter 7.

<sup>64</sup> MacIntyre, A., *Dependent Rational Animals: Why Human Beings Need the Virtues*, Duckworth, 1999; Phillips A. and Taylor, B., *On Kindness*, Penguin, 2009.

<sup>65</sup> Mansell, J., *Raising our sights: services for adults with profound intellectual and multiple disabilities*, 2010, p. 12.

<sup>66</sup> *Ibid.*

<sup>67</sup> Eagleton, T., "The Right and the Good: Postmodernism and the Liberal State", *Textual Practice*, 1994, pp. 1-10, reprinted in Regan, S. (ed.), *The Eagleton Reader*, 1998, pp. 294-303.

# THE MENTAL HEALTH GAP IN SOUTH AFRICA – A HUMAN RIGHTS ISSUE

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## Introduction

On 30 March 2007, South Africa became a signatory to the United Nations Convention on the Rights of Persons with Disabilities (CRPD) and its Optional Protocol.<sup>2</sup> This was ratified several months later on 30 November 2007. The CRPD was negotiated during eight sessions of an Ad Hoc Committee of the General Assembly from 2002 to 2006 and adopted on 13 December 2006. To date, there have been 140 signatories to the CRPD (with 59 ratifications) and 83 signatories to the Optional Protocol (with 37 ratifications). The CRPD is intended as a human rights instrument with an explicit social development dimension and constitutes a significant global commitment to a human rights framework in which issues of achieving substantive equality and the full and unfettered rights of persons with disabilities are placed at centre-stage.

In aligning itself to this international human rights treaty, the South Africa Government committed itself to a radical new approach to persons with disabilities of all kinds, based on the fundamental premise that such persons are “subjects” with rights, who are capable of claiming those rights and making decisions for their lives based on their free and informed consent as well as being active members of society. Importantly, mental health conditions are conceptualised as disabilities within the CRPD.<sup>3</sup> This political act by the South Africa Government has profound implications for both the health and

social development agenda. Furthermore, the establishment of the international Committee on the Rights of Persons with Disabilities, which has oversight and monitoring functions, means that citizens of signatory states, including South Africa, have a means of reporting local violations and obtaining redress.

Despite the significance of this major step towards achieving human rights for disabled persons, it seems that there is widespread ignorance, both within and outside the public health sector, of the CRPD and its expectations. Similarly, members of the general public, whom the treaty is intended to protect, are likely to have little or no knowledge of its existence and its implications for their lives. By all accounts, the South Africa Government is not carrying out its obligations and responsibilities as a signatory to the CRPD. As is the case in many low- and middle-income countries (LAMICs), health and social services for the mentally disabled remain grossly inadequate, under-developed and under-funded.<sup>4</sup> The rights of such persons as outlined in the CRPD are routinely violated, and mentally disabled people generally remain isolated, stigmatised and in many cases disenfranchised 16 years after the end of apartheid.

South Africa’s commitment to this international treaty followed an earlier domestic commitment to human rights for people with mental disabilities in the form of new

mental health legislation. The Mental Health Care Act 2002 (MHCA) was implemented in 2004 and was generally hailed as one of the most progressive pieces of mental health legislation in the world.<sup>5</sup> An entire chapter was dedicated to human rights for those with mental disabilities. Furthermore, the MHCA contained articles addressing compulsory admission, protection of patients' property, rights to appeal, the reporting of abuses and the formation of independent review boards with ombuds functions. It also highlighted several important principles including: the use of the minimum possible compulsion; the importance of not just treatment but also rehabilitation and reintegration; the decentralisation of mental health care from large psychiatric institutions into district and community-based health services; and the integration of mental health into primary health care.<sup>6</sup>

Unfortunately, the MHCA was an unfunded mandate. Very little preparation occurred – training was not provided, facilities were not developed at district and primary care levels, and no budget was allocated by the government for implementation of such a potentially transformative piece of legislation. The result is that now, six years later, a host of chronic problems are encountered throughout health services nationwide in relation to the care, treatment and rehabilitation of those with mental disabilities.<sup>7</sup>

This paper describes the “mental health gap” that exists between current resources for mental health care in South Africa and the huge “burden” of suffering and disability due to mental illness and disability.<sup>8</sup> It identifies the multiple inequities that exist between resources and opportunities for the physically ill and those for the mentally ill.<sup>9</sup> Finally, this paper considers the CRPD, its implications for the conceptualisation and understand-

ing of mental disability, and the challenge it represents for transforming South Africa's health and social systems as well as its society from its current situation of gross inequity and discrimination against those with mental disabilities towards a situation where the mentally disabled enjoy full parity and human rights.

## **1. The Global “Mental Health Gap”**

### **1.1 The Global Mental Health Burden**

Globally, mental and neurological disorders are responsible for approximately 14% of the global burden of disease, while over 30% of disability-adjusted life-years (DALYs) are attributable to these disorders.<sup>10</sup> This is expected to increase over the next decades. Currently, neuropsychiatric disease surpasses both cardiovascular disease and cancer as the leading cause of disability due to non-communicable disorders. In addition, mental disorders are commonly co-morbid with physical disorders such as heart disease, cancer and metabolic diseases.<sup>11</sup> This is particularly relevant to LAMIC contexts within Sub-Saharan Africa where the HIV/AIDS pandemic has added considerably to the burden of neuropsychiatric disease and disability.<sup>12</sup> Mental disorders are responsible: for increased mortality due to suicide and reduced life expectancy; for considerable individual and collective suffering; for significant loss of social and occupational functioning and productivity; for extensive disability; and for a major burden on caregivers and families. The impact of mental disability is felt most keenly in LAMIC contexts.<sup>13</sup> For example, approximately 86% of the 800,000 annual suicides globally occur in LAMICs and this may be an underestimate as surveillance and reporting systems are often inadequate within these contexts.<sup>14</sup> There is evidence that maternal and perinatal mental

disorders are more common in LAMICs<sup>15</sup> and further evidence supports an association between perinatal and maternal mental illness and a number of negative infant outcomes (including low birth weight, under-nutrition, poor growth, diarrheal disease and impaired motor and cognitive development).<sup>16</sup> Mental illness and disability is both a cause and outcome of traumatic injuries and accidents.<sup>17</sup> Finally, substance use disorders commonly co-occur with mental illnesses and are associated with multiple negative health and social effects.<sup>18</sup>

## 1.2 Global Mental Health Resources

Despite these alarming facts, services for mental illness and disability are almost universally inadequate. Furthermore, while advances have been made in general health promotion and prevention, the same cannot be said for mental disability. Ignorance, prejudice and stigma are widespread. This situation is undoubtedly worse in LAMIC contexts. Analysis of data from the World Health Organisation's Atlas Project on mental health shows "widespread, systematic and long-term neglect of resources for mental health care in low-income and middle-income countries".<sup>19</sup> Essential community-based mental health care services exist in only half of LAMICs, while only 60% of countries worldwide have facilities to train primary health workers in mental health care. Within Africa and Asia there is a gross inadequacy of beds for those requiring hospitalisation for mental illness. The median number of beds in African countries is 0.34 per 10,000 population and 73% of these are in psychiatric hospitals. In Asia the situation is worse with only 0.33 beds per 10,000 population and 83% of these located in psychiatric hospitals.<sup>20</sup> By contrast, Europe has a median of 8 beds per 10,000 population and, with the exception of some LAMIC countries in Cen-

tral and Eastern Europe, most of these beds are in community-based hospitals.<sup>21</sup> Many psychiatric hospitals remain unsuitable for rehabilitation and reintegration of individuals admitted with severe mental disorders. Similarly, there is major inequity between high-income countries (HICs) and LAMICs in terms of trained mental health professionals. The average number of psychiatrists in HICs, for example, is 10.5 per 100,000 population, as opposed to low-income countries (LICs), where the average number is 0.05 per 100,000 population.<sup>22</sup> Globally, mental health receives a disproportionately small proportion of health budgets and mental health services are therefore funded from general health budgets where they receive low priority. This is especially the case in countries dealing with other major health problems such as HIV/AIDS, tuberculosis and malnutrition. In terms of mental health legislation and policy, LAMIC regions fare especially poorly. Globally, approximately a third of countries have no such regulations, while in Africa only half do. Of those countries that do have mental health legislation, a large proportion have not revised their legislation for decades, leaving persons with mental illness without legal protection.<sup>23</sup>

## 2. The "Mental Health Gap" in South Africa

### 2.1 The Mental Health Burden in South Africa

South Africa is a middle-income country with a population of 47 million characterised by multiple societal-level socioeconomic risk factors for mental illness and disability (see Table 1). It ranks 13<sup>th</sup> highest in the world in terms of the proportion of the population living under the poverty line (50%); is second highest in terms of income inequality (GINI coefficient is 65); has the 19<sup>th</sup> highest unem-

ployment rate (24%); and has a high rate of urbanisation, lying 41<sup>st</sup> with a rate of 1.4%.<sup>24</sup> In addition, South Africa has extraordinarily high rates of crime and violence, one of the highest road accident death rates in the world, and lies 99<sup>th</sup> out of 121 countries in a 2007 *Economist* rating using a "Global Peace Index".<sup>25</sup> It has the 4<sup>th</sup> highest rate of drug offences and, according to the United Nations Office on Drugs and Crime (UNODC), South Africa now ranks within the top 30% of countries in terms of rates of opiate addiction.<sup>26</sup> South Africa is also located at the epicentre of the HIV/AIDS pandemic in Sub-Saharan Africa with the 4<sup>th</sup> highest prevalence rate (18%) and the greatest number of people liv-

ing with HIV/AIDS worldwide.<sup>27</sup> HIV/AIDS is associated with a significantly increased burden of neuropsychiatric disease and disability including depression, anxiety, psychosis and dementia.<sup>28</sup> Furthermore, the mortality due to AIDS impacts on children, hundreds of thousands of whom have been orphaned. Child-headed households are now a common phenomenon in South Africa. There is now substantial evidence that poverty, inequality, urbanisation, unemployment, trauma and violence and substance abuse are major environmental risk factors for mental illness and therefore increase the burden of mental illness and disability within a society.<sup>29</sup>

Indicator		Ranked in the world (total no of countries)
Proportion of the population living under the poverty line	50%	13 <sup>th</sup> highest (100)
Index of income inequality (GINI coefficient)	65	2 <sup>nd</sup> highest (134)
Unemployment rate	24%	19 <sup>th</sup> highest (131)
Urbanisation rate	1.4%	41 <sup>st</sup> highest (63)
Murder rate (per 100,000 population)	47.5	3 <sup>rd</sup> highest (121)
Rapes (per 100,000 population)	1.2	1 <sup>st</sup> highest (65)
Assaults (per 100,000 population)	12.1	1 <sup>st</sup> highest (57)
Burglaries (per 100,000 population)	8.9	10 <sup>th</sup> highest (54)
Total crimes (per 100,000 population)	77.2	10 <sup>th</sup> highest (60)
Drug related offences (per 100,000 population)	53.8	4 <sup>th</sup> highest (60)
Incarceration rate (per 100,000 population)	335	18 <sup>th</sup> highest (155)
Road traffic deaths (per 100,000 population)	33.2	24 <sup>th</sup> highest (178)
Opiate drug abuse (per 100,000 population)	0.38	47 <sup>th</sup> highest (133)
Global Peace Index	2.4	22 <sup>nd</sup> lowest (121)
HIV prevalence	18%	4 <sup>th</sup> highest in world

Indicator		Ranked in the world (total no of countries)
Number of people living with HIV/AIDS	5.7 million	1 <sup>st</sup> highest in world
HIV/AIDS deaths per year	350,000	1 <sup>st</sup> highest in world
Tuberculosis incidence (per 100,000 population)	600	9 <sup>th</sup> highest (200)
Life expectancy at birth (years)	48.9	16 <sup>th</sup> lowest (221)
Death rate (per 1,000 population)	17	12 <sup>th</sup> highest (220)
Infant mortality rate (per 1,000 live births)	44.4	59 <sup>th</sup> highest (221)
Suicide rate – total (per 100,000 population)	15.4	22 <sup>nd</sup> highest (106)
Suicide rate – male (per 100,000 population)	25.3	17 <sup>th</sup> highest (103)
Suicide rate – female (per 100,000 population)	5.6	26 <sup>th</sup> highest (103)
Physicians (per 1,000 population)	0.77	119 <sup>th</sup> highest (201)
Psychiatrists (per 100,000 population)	0.28	
Psychologists (per 100,000 population)	0.32	
Social workers in mental health (per 100,000 population)	0.4	
Occupational therapists in mental health (per 100,000 population)	0.13	
Nurses in mental health (per 100,000 population)	10	
Psychiatric beds in mental health facilities (per 100,000 population)	24	

Table 1: Socioeconomic and health indicators for South Africa

Until quite recently, there was little in the way of epidemiological data on mental illness in South Africa. However, the South Stress and Health Study (SASH), which was part of the WHO World Mental Health (WMH) Survey Initiative conducted between 2002 and 2004, reported results of a population-based survey of 4351 adults.<sup>30</sup> The 12-month prevalence of any DSM-IV/CIDI disorder<sup>31</sup>

was 16.5%, with the most common disorders being agoraphobia (4.8 %), major depressive disorder (4.9%) and alcohol abuse or dependence (4.5 %). The authors of the SASH study note that prevalence rates of common mental disorders are significantly higher in South Africa than in another WMH African country, Nigeria, and are in fact more similar to the rates reported from Colombia

and Lebanon. Interestingly, both of these countries have a number of socioeconomic features in common with South Africa and likewise have experienced chronic conflict.<sup>32</sup> The SASH study authors also observe that the estimated prevalence of substance abuse in South Africa (5.8%) was at least about twice as high as that in other WMH countries, with the exception of Ukraine. With a national suicide rate of 15.4 per 100,000 population, South Africa is ranked 22<sup>nd</sup> in the world.<sup>33</sup>

## 2.2 Mental Health Resources in South Africa

Despite South Africa's progressive mental health legislation (i.e. MCHA), multiple barriers to the financing and development of mental health services exist, which result in: (i) psychiatric hospitals remaining outdated, falling into disrepair, and often unfit for human use; (ii) serious shortages of mental health professionals; (iii) an inability to develop vitally important tertiary level psychiatric services (such as child and adolescent services, psychogeriatric services, neuropsychiatric services, etc.); and (iv) community mental health and psychosocial rehabilitation services remaining undeveloped, so that patients end up institutionalised, without hope of rehabilitation back into their communities. This state of affairs remains unchanged despite the legislated commitments to reform mental health care in the MHCA.

While legislation exists and a mental health policy was approved in 1997, to date this policy has not been widely published or implemented together with guidelines.<sup>34</sup> This is due to both administrative and capacity issues and to the low priority given to mental health by provincial health departments.<sup>35</sup> In addition, there is no national mental health plan and, at a provincial level, only one of nine provinces has a specific mental health

plan.<sup>36</sup> There is no specific budget for mental health either at national or provincial level and therefore mental health services are funded out of general health budgets where they inevitably end up at the bottom of a pile of pressing needs when money is allocated. In a recent survey of all nine provinces, Lund and colleagues found that only 3 provinces could report data on mental health expenditure – these reported 1%, 5% and 8% respectively.<sup>37</sup> While this range is about average for most middle-income countries, it reflects the disproportionately low allocation made to mental health (given the high prevalence of mental disorders and the fact that over 30% of disability-adjusted life-years (DALYs) are attributable to these disorders).<sup>38</sup>

Research conducted in KwaZulu-Natal Province reveals gross inequity in the allocation of provincial health budgets to psychiatric facilities.<sup>39</sup> Budget increases to six psychiatric hospitals over the 5-year period (2006-2010) ranged from 8% to 25% with a mean 5-year increase of 19% and a mean annual increase of 3.8%. This contrasted with budget increases to seven general hospitals over the same 5-year period, which ranged from 29% to 64% with a mean 5-year increase of 51% and a mean annual increase of 10.2%. The median cumulative budget increase for psychiatric hospitals was significantly lower than that of general hospitals, clearly illustrating a pattern of inequitable treatment of psychiatric hospitals in relation to general hospitals. Furthermore, this analysis showed that four of the six psychiatric hospitals surveyed experienced an actual year-to-year drop in budget allocations at some point during the 5-year period. None of the general hospitals experienced a drop in budget during the period. This highlights the impression that the government does not value psychiatric services and is prepared to sacrifice the

expansion of psychiatric services in order to maintain general hospital services.

The MHCA made law the introduction of Mental Health Review Boards (MHRBs) in every region of the country. The establishment of such boards is the responsibility of provincial departments of health. These boards have “ombuds” functions, representing the interests of patients, reviewing compulsory treatment, hearing appeals and investigating allegations of abuse. While MHRBs have been set up in most regions, their efficiency and effectiveness varies considerably. A recent review conducted in KwaZulu-Natal Province, for example, reported that the MHRB had visited only 7 of the 36 hospitals in the region in the preceding 6 months, while 10 hospitals had either never been visited or had not been visited for more than 2 years.<sup>40</sup> The authors observe that operational inefficiencies limit substantially “the capacity of the Review Board or judiciary to intervene timeously in the event of a violation of the Act”.

In terms of hospital resources for psychiatry, South Africa is not too badly off compared with other African countries with 2.1 beds per 10,000 population, but fares badly in comparison with the European median of 8 beds per 10,000 population. Of these 2.1 beds, 1.8 are in psychiatric hospitals and 0.3 in general hospitals.<sup>41</sup> This figure represents just over 60% of the beds required to comply with norms established by the South African National Department of Health.<sup>42</sup> Availability of beds for psychiatric care varies substantially from province to province – for example, KwaZulu-Natal has only 25% of the number of acute beds required to comply with norms.<sup>43</sup>

Community-based services are worse off: there are only 80 day treatment facilities

available in the country (for a population of 47 million) and half of these are provided and run by a non-governmental organisation (the South African Federation of Mental Health (SAFMH)). In addition, there are 0.36 beds per 10,000 population located within 63 community residential facilities nationwide and, again, half of these are provided by the SAFMH.

Resources specifically structured for the treatment of children and adolescents are grossly inadequate. Only 1.4% of outpatient facilities, 3.8% of acute beds in general hospitals and 1% of beds in psychiatric hospitals are for children and adolescents.<sup>44</sup> Information is not available for the total number of child and adolescent psychiatrists in South Africa (and the number varies considerably from region to region) but in general there are very few. For example, in KwaZulu-Natal Province (which has a population of 10 million) there are only two such specialists within the public health system.

Human resources for mental health care in South Africa are desperately inadequate. A recent national survey revealed that, per 100,000 population, the country has only 0.28 psychiatrists, 0.32 psychologists, 0.4 social workers, 0.13 occupational therapists and 10 nurses.<sup>45</sup> Thus, as far as psychiatrists are concerned, South Africa has less than 30% of the number required to comply with national norms of 1 per 100,000 population. Furthermore, this figure (0.28 per 100,000 population) falls far below the average for other middle-income countries (which is approximately 5 per 100,000 population) and even further below the average for high-income countries (which is approximately 15 per 100,000 population).<sup>46</sup> Furthermore, most mental health professionals tend to be located within urban centres, leaving large

rural regions of the country without such services. For example, of the 32 psychiatrists working in the public health sector in KwaZulu-Natal Province, only 6 are located outside of the major cities.

Thus it is clear that resources for mental health care are seriously inadequate in South Africa and, given the large burden of disease which is undoubtedly increased by socio-economic conditions of poverty, inequality, violence and infectious diseases, there is a considerable gap between needs and services. This is borne out by recent research. In the SASH study, only 28% of adults with a severe or moderately severe disorder and only 24.4% of those with mild cases received treatment.<sup>47</sup> Other research in KwaZulu-Natal shows that a large proportion of the population relies on informal services in the community for mental health treatment.<sup>48</sup> In a sample of patients with first-episode psychosis (FEP), Burns and colleagues reported that 38.5% had consulted a traditional healer for the incipient psychotic illness prior to making contact with formal psychiatric services.<sup>49</sup> This compares with rates reported in FEP patients in other LAMIC contexts – a third in Zambia, 24% in Singapore and 23% in Iran.<sup>50</sup> Consultation with traditional healers may delay access to care for people with early mental illness and this in turn may impact negatively on the course and outcome of the illness.<sup>51</sup> Traditional healers are more geographically accessible and more culturally accessible to many citizens, particularly in the largely rural province of KwaZulu-Natal. There is good evidence that a significant proportion of individuals experiencing mental health problems in this region consult traditional healers as their first port of call despite the fact that the services of traditional healers are often more expensive than public health services.<sup>52</sup> In addition to geographical

and financial barriers, another major factor leading individuals to traditional healers is societal stigma associated with the use of formal mental health services.<sup>53</sup> Thus South Africa, like most other LAMICs, is characterised not just by inadequacies in the availability of resources for mental health care but also by numerous barriers to access to mental health services.<sup>54</sup>

### **3. The Mental Health Gap Is a Human Rights Issue**

The gap that exists between the burden of mental illness and disability and the relative lack of mental health resources in South Africa is a human rights issue. The state has an obligation to provide services for the health needs of its people; and it is clear that services for those with mental illness and disability are woefully inadequate and, for many people, inaccessible in that nation. South Africa is by no means the only country characterised by a mental health gap – indeed most countries fall short of meeting the mental health needs of their citizens.<sup>55</sup> However, South Africa is a nation that has publically declared its commitment to upholding the rights of the mentally ill and disabled – both in enacting one of the most progressive pieces of mental health legislation in the world<sup>56</sup> and through signing and ratifying the CRPD. In making these commitments, the government of South Africa has affirmed its belief that all members of the society have a fundamental constitutional right to care. Emerging from decades (if not centuries) of racism and discrimination based on ethnicity, the new regime has been both passionate and vocal in addressing the rights of minority and previously discriminated groups in society. The South African Constitution guarantees these rights and it is clear that discrimination on the basis of race, gender, sexual orientation

or physical disability is punished severely within the new dispensation.<sup>57</sup>

This is not the case however regarding those with mental illness or disability. As is still the case in many countries around the world, people with mental disabilities face multiple forms of inequity and discrimination in their daily lives.<sup>58</sup> Both outside and within the health system, patients encounter discrimination and prejudice – in the form of reduced work opportunities and social opportunities, disenfranchisement and restriction of civil liberties, inferior treatment of co-morbid physical illnesses, and in the form of social stigma. This is reflected, as we have seen, in the state’s failure to close the mental health gap through the provision of resources. This means that people with mental disabilities experience a fundamental violation of their basic right to care by the state. This calls for a human rights approach to the mental health gap in South Africa as well as in other nations.

#### **4. A Human Rights Approach to Inequity in Mental Health Care**

The CRPD sets out a framework for a rights-based approach to disability and in doing so “calls for changes that go beyond quality of care to include both legal and services reforms” and “demands that we develop policies and take actions to end discrimination in the overall society that has a direct effect on the health and well-being of the [mentally] disabled”.<sup>59</sup> The CRPD sets out a number of guiding principles:

- a) Respect for inherent dignity, individual autonomy including the freedom to make one’s own choices, and independence of persons;
- b) Non-discrimination;

c) Full and effective participation and inclusion in society;

d) Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity;

e) Equality of opportunity;

f) Accessibility;

g) Equality between men and women; and

h) Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities.<sup>60</sup>

In addition to these principles, the CRPD highlights the importance of a number of related rights. These include:

- 1) Equal recognition before the law, access to justice, and legislative reform to abolish discrimination in society;
- 2) Awareness-raising to educate society, combat prejudices and promote awareness of the capabilities of persons with disabilities;
- 3) The right to life, liberty and security of person including freedom from degrading treatment, abuse, exploitation and violence;
- 4) The right to movement, mobility, independent living and full inclusion within the community including full access to and participation in cultural life, recreation, leisure and sport;
- 5) Freedom of expression and opinion, access to information and full participation in political and public life;

- 6) Respect for privacy, for the home and the family, including the freedom to make decisions related to marriage and parenthood;
- 7) The right to equal education, work and employment including the full accommodation of individual requirements;
- 8) The right to health, habilitation and rehabilitation; and
- 9) The right to an adequate standard of living, suitable accommodation and social protection.<sup>61</sup>

With respect to mental illness, how does this framework inform our response to the inequities and discrimination present in society and mental health care? Specifically, if we take these principles and rights and apply them to the South African context, what actions are required to transform that society so that persons with mental disabilities experience full equality, an end to discrimination, and full recognition of their personhood? An action plan at national as well as local levels would include:

*1. The development of a strong advocacy movement, led by persons with mental disabilities.* Repeatedly it has been shown that “user-led” advocacy around issues of legal reform, services development, and societal transformation has been most effective in ending discrimination and stigmatisation and achieving human rights for specific minority communities.<sup>62</sup>

*2. Legislative reform to abolish discrimination, outlaw abuse and exploitation, and protect personal freedom, dignity, and autonomy.* Civil commitment laws that deprive individuals of their freedom “must provide for minimum substantive and procedural protections that

protect mentally ill individuals’ fundamental agency”.<sup>63</sup> In addition, such laws should guarantee the rights to counsel, appeal, and review in relation to involuntary commitment as well as redress for violations. As mentally disabled persons may not be in a position to safeguard their personal rights while unwell, there should be a mechanism for active monitoring and enforcement of such rights. The MHRBs legislated in the MHCA are a good start and are intended to fulfil an ombuds function.<sup>64</sup> However, as discussed earlier, the functioning and actual power of these boards has so far been inadequate. If this is to be more than just a gesture then the state needs to act urgently to implement this important structure as an effective guardian of human rights for the mentally disabled.

*3. Legislative reform to enforce equality of opportunity, access, and participation in all aspects of life.* While health-related legislative reform is important, this must be accompanied by legal measures aimed at rectifying inequalities and discrimination that exist in respect of the mentally disabled in social, economic, and political facets of society. Substantive equality requires attention to the social context that contributes to the origin of mental disabilities as well as to the use of mental health services by individuals.

*4. Inclusion of mental disability on the agenda of development programs and targets such as the Millennium Development Goals.* At the international, national, and regional levels, mental disability rights and “needs” must be included in programs aimed at achieving development targets and alleviating poverty and inequality.

*5. Mental health and social services reform with equitable funding for resources, infrastructure, and programmes development.*

Along with other governments, the South African government should be pressured to heed growing calls for the up-scaling of health and social services relevant to mental disability as well as increased budget allocations for mental health.<sup>65</sup> Signatories to the CRPD and its Optional Protocol must be held to account in terms of their domestic planning. The establishment of the Committee on the Rights of Persons with Disabilities as a monitoring organ means that citizens of States Parties to the CRPD have a means of reporting local violations of the CRPD and obtaining redress.<sup>66</sup>

*6. Removal of barriers to access to health services encountered by persons with mental disabilities.* Legal reforms are required to remove financial barriers to access for those with mental disabilities. Legislation is also required to enforce equality and outlaw discrimination based on ethnicity, race, gender, and age within health services. Finally, education campaigns and programs on mental disability and the rights of mentally disabled persons should be conducted on an ongoing basis within the health service.

*7. Removal of barriers to access to social, family-related, accommodation, educational, occupational and recreational opportunities, and full participation for persons with mental disabilities.* Legislative reforms, as well as public and institutional education campaigns and programmes, should be implemented at national and local levels to remove these barriers to access, eradicate stigma, and ensure the full participation of persons with mental disabilities. Suitable accommodation is a fundamental right as enshrined in the CRPD, and domestic policies, planning, and legal reform need to be informed by an acknowledgement of this right.

*8. Service systems reform to move away from institutional care toward providing treatment, care, rehabilitation, and reintegration within the community.* As Alicia Yamin and Eric Rosenthal state:

“From a human rights perspective, people are entitled to live in and receive care in the community not because it is more efficient, but because all human beings develop their identities within social contexts, and have rights to work and study, as well as be with family and friends.”<sup>67</sup>

Furthermore, planning and decision-making power related to care in the community needs to be transferred to “the individuals and communities that the health system is supposed to serve”.<sup>68</sup> This means the integration of “users” and family members into both national and local decision-making structures.

## Conclusion

South Africa has “nailed its colours to the mast” through enacting legislation and signing international treaties aimed at upholding and ensuring the human rights of people with mental disability. Despite this, that nation continues to fall far short of meeting the needs of its citizens affected by mental illness. The mental health gap is considerable in South Africa, despite a progressive regime that has championed the rights of other disadvantaged groups in society. While laudable, South Africa’s efforts to achieve formal equality should not stand alone, without similar advocacy focused on the achievement of substantive equality for persons with mental disabilities. Real life factors such as poverty, illiteracy, income inequality, homelessness, war and displacement, discrimination based

on ethnicity, race, and gender, social exclusion, stigma, and abuse all impact the mentally ill individual's ability to access services and realise full personhood within their communities. A rights-based approach to mental disability means domesticating such treaties

as the CRPD. Using the framework of this convention and others like it, it is possible to formulate an active plan of response to the multiple inequalities and discrimination that exist in relation to mental disability, both in South Africa and in other nations.

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<sup>2</sup> The Convention on the Rights of Persons with Disabilities and its Optional Protocol were adopted on 13 December 2006. The Convention was opened for signature on 30 March 2007 and entered into force on 3 May 2008. The UN Enable website was established to report all aspects of the treaty and contains information on the guiding principles, entry into force, signatories, and monitoring of the Convention, as well as full-text versions of the Convention and its Optional Protocol in a number of languages. The UN Enable website is available at: <http://www.un.org/disabilities/default.asp?navid=12&pid=150>.

<sup>3</sup> Convention on the Rights of Persons with Disabilities, Article 1.

<sup>4</sup> See, for example, Kohn, R., Saxena, S., Levav, I. and Saraceno, B., "The treatment gap in mental health care", *Bulletin of the World Health Organization*, Vol. 82, 2004, pp. 858–866.

<sup>5</sup> Mental Health Care Act, 2002, available at: [www.acts.co.za/mental\\_health\\_care\\_act\\_2002.htm](http://www.acts.co.za/mental_health_care_act_2002.htm).

<sup>6</sup> The principle of integration of mental health into primary health care is central to global mental health efforts. For example, WHO and the World Organization of Family Doctors co-sponsored an investigation into the progress made in integrating mental health into primary health care. For the report in full, see World Health Organization and World Organization of Family Doctors, *Integrating mental health into primary care: A global perspective*, Geneva, 2008.

<sup>7</sup> See Burns, J. K., "Implementation of the Mental Health Care Act (2002) at District Hospitals in South Africa: Translating Principles into Practice", *South African Medical Journal*, Vol. 98, No. 1, 2008, pp. 46-51; and Ramlall, S., Chipps, J. and Mars, M., "Impact of the South African Mental Health Care Act No. 17 of 2002 on regional and district hospitals designated for mental health care in KwaZulu-Natal", *South African Medical Journal*, Vol. 100, No. 10, pp. 667-670.

<sup>8</sup> Regarding the "mental health gap", see The WHO World Mental Health Survey Consortium, "Prevalence, Severity, and Unmet Need for Treatment of Mental Disorders in the World Health Organization World Mental Health Surveys", *Journal of the American Medical Association*, Vol. 291(21), 2004, pp. 2581–2590. Note also that the use of the term "burden" here requires clarification. The term is not used in the sense of individuals being "burdensome" or a cause of hardship for others. The term is used to describe the added social and economic responsibilities and costs associated with either living with a mental disability or being in a care-giving role in relation to a person with a mental disability.

<sup>9</sup> For a comprehensive overview of the inequities and inequalities that characterise mental health care, see Burns J. K., "Mental health and inequity: a human rights approach to inequality, discrimination and mental disability", *Health and Human Rights: An International Journal*, Vol. 11, No. 2, 2009, pp. 19-31.

<sup>10</sup> Prince, M., Patel, V., Saxena, S., Maj, M., Maselko, J., Phillips, M. R. and Rahman, A., "No health without mental health", *The Lancet*, Vol. 370, Issue 9590, 2007, pp. 859-877.

<sup>11</sup> For a review of co-morbid mental disability and physical illness, see above, note 10. See also De Hert, M., Dekker, J. M., Wood, D., Kahl, K. G., Holt, R. I. and Möller, H. J., "Cardiovascular disease and diabetes in people with severe mental illness: Position statement from the European Psychiatric Association (EPA), supported by the European Association for the Study of Diabetes (EASD) and the European Society of Cardiology (ESC)", *European Psychiatry*, Vol. 24, Issue 6, 2009, pp. 412-424. For a discussion of co-morbid mental disability and substance abuse, with particular emphasis on developing LAMICs, see Srinivasa Murthy, R., "Psychiatric comorbidity presents special challenges in developing countries", *World Psychiatry*, Vol. 3(1), 2004, pp. 28–30.

<sup>12</sup> Jonsson, G. and Joska, J. A., "Assessment and treatment of psychosis in people living with HIV/AIDS", *South African Journal of HIV Medicine*, Vol. 10, No. 3, 2009, pp. 20-27.

<sup>13</sup> See *The Lancet*, Vol. 370, Issue 9590, 2007, which contained a series of six papers documenting the current evidence for global mental health, with a focus on LAMICs.

<sup>14</sup> See above, note 10.

<sup>15</sup> Cooper, P. J., Tomlinson, M., Swartz, L., Woolgar, M., Murray, L. and Molteno, C., "Post-partum depression and the mother-infant relationship in a South African peri-urban settlement", *British Journal of Psychiatry*, Vol. 175, 1999, pp. 554-558; and Patel, V., DeSouza, N. and Rodrigues, M., "Postnatal depression and infant growth and development in low income countries: a cohort study from Goa, India", *Archives of Disease in Childhood*, Vol. 88, 2003, pp. 34-37.

<sup>16</sup> Nilsson, E., Lichtenstein, P., Cnattingius, S., Murray, R. M. and Hultman, C. M., "Women with schizophrenia: pregnancy outcome and infant death among their offspring", *Schizophrenia Research*, Vol. 58, 2002, pp. 221-29; Benned- sen, B. E., Mortensen, P. B., Olesen, A. V. and Henriksen, T. B., "Preterm birth and intra-uterine growth retardation among children of women with schizophrenia", *British Journal of Psychiatry*, Vol. 175, pp. 239-245; Webb, R., Abel, K., Pickles, A. and Appleby, L., "Mortality in offspring of parents with psychotic disorders: a critical review and meta-analysis", *American Journal of Psychiatry*, Vol. 162, 2005, pp. 1045-1056.

<sup>17</sup> O'Connor, T. G., Davies, L., Dunn, J. and Golding, J., "Distribution of accidents, injuries, and illnesses by family type. ALSPAC Study Team. Avon Longitudinal Study of Pregnancy and Childhood", *Pediatrics*, Vol. 106, 2000, e68; Leifer- man, J., "The effect of maternal depressive symptomatology on maternal behaviors associated with child health", *Health Education and Behavior*, Vol. 29, 2002, pp. 596-607; De Jong, J. T., Komproe, I. H. and Van Ommeren, M., "Common mental disorders in postconflict settings", *The Lancet*, Vol. 361, 2003, pp. 2128-2130.

<sup>18</sup> Srinivasa Murthy, R., see above, note 11.

<sup>19</sup> Saxena, S., Thornicroft, G., Knapp, M. and Whiteford, H., "Resources for mental health: scarcity, inequity, and inefficiency", *The Lancet*, Vol. 370, Issue 9590, 2007, pp. 878-889.

<sup>20</sup> World Health Organisation, *Mental Health Atlas 2005*, 2005, available at: [http://www.who.int/mental\\_health/evidence/atlas/global\\_results.pdf](http://www.who.int/mental_health/evidence/atlas/global_results.pdf).

<sup>21</sup> Saraceno, B. and Saxena, S., "Mental health services in Central and Eastern Europe: current state and continuing concerns", *Epidemiol Psychiatr Soc*, Vol. 14(1), 2005, pp. 44-48.

<sup>22</sup> Shah, A. A. and Beinecke, R. H., "Global mental health needs, services, barriers and challenges", *International Journal of Mental Health*, Vol. 38(1), 2009, pp. 14-29.

<sup>23</sup> See above, note 10.

<sup>24</sup> See Central Intelligence Agency, *The World Factbook*, 2010, available at: <https://www.cia.gov/library/publications/the-world-factbook/>; United Nations Development Programme, *Human Development Report 2007/2008: Fighting climate change: Human solidarity in a divided world*, 2007, available at: [http://hdr.undp.org/en/media/HDR\\_20072008\\_EN\\_Complete.pdf](http://hdr.undp.org/en/media/HDR_20072008_EN_Complete.pdf); South African Institute of Race Relations, *Unemployment and Poverty*, 28 November 2008, available at: [http://sareporter.com/index2.php?option=com\\_content&do\\_pdf=1&id=269](http://sareporter.com/index2.php?option=com_content&do_pdf=1&id=269); and Human Sciences Research Council, *Fact sheet: Poverty in South Africa*, 2004, available at: [http://www.sarpn.org.za/documents/d0000990/P1096-Fact\\_Sheet\\_No\\_1\\_Poverty.pdf](http://www.sarpn.org.za/documents/d0000990/P1096-Fact_Sheet_No_1_Poverty.pdf).

<sup>25</sup> See Institute for Security Studies, *Murder in the RSA for April to March 2003/2004 to 2008/2009*; World Health Organisation, *Global Status Report on Road Safety*, 2009, available at: [http://whqlibdoc.who.int/publications/2009/9789241563840\\_eng.pdf](http://whqlibdoc.who.int/publications/2009/9789241563840_eng.pdf); and Institute for Economics and Peace and Economist Intelligence Unit, *Global Peace Index*, 2010, available at: <http://www.visionofhumanity.org/gpi-data/#/2010/scor>.

<sup>26</sup> See United Nations Office on Drugs and Crime, *The Eighth United Nations Survey on Crime Trends and the Operations of Criminal Justice Systems*, 2005, available at: <http://www.unodc.org/unodc/en/data-and-analysis/Eighth-United-Nations-Survey-on-Crime-Trends-and-the-Operations-of-Criminal-Justice-Systems.html>; and United Nations Office on Drugs and Crime, *Opiate Drug Consumption – Country Rankings*, available at: [http://www.photius.com/rankings/opiate\\_drug\\_consumption\\_country\\_ranks.html](http://www.photius.com/rankings/opiate_drug_consumption_country_ranks.html).

<sup>27</sup> See Index Mundi, *HIV/AIDS – adult prevalence rate*, available at: <http://www.indexmundi.com/g/r.aspx?t=50&v=32>; and Human Sciences Research Council, *South African national HIV prevalence, incidence, behaviour and communication survey 2008: A turning tide among teenagers?*, 2009, Cape Town: HSRC Press, available at: <http://www.mrc.ac.za/pressreleases/2009/sanat.pdf>.

<sup>28</sup> Vlassova, N., Angelino, A. F., and Treisman, G. J., "Update on mental health issues in patients with HIV infection",

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<sup>29</sup> See Patel, V. and Kleinman, A., "Poverty and common mental disorders in developing countries", *Bulletin of the World Health Organization*, Vol. 81(8), 2003, pp. 609-615; Weich, S., Lewis, G. and Jenkins, S. P., "Income inequality and the prevalence of common mental disorders in Britain", *British Journal of Psychiatry*, Vol. 178(3), 2001, pp. 222-227; Marwaha, S. and Johnson, S., "Schizophrenia and employment", *Social Psychiatry and Psychiatric Epidemiology*, Vol. 39(5), 2004, pp. 337-349; and Ribeiro, W. S., Andreoli, S. B., Ferri, C. P., Prince, M. and Mari, J. J., "Exposure to violence and mental health problems in low and middle-income countries: a literature review", *Rev Bras Psiquiatr*, Vol. 31, Suppl. 2, 2009, pp. S49-57.

<sup>30</sup> Williams, D. R., Herman, A., Stein, D. J., Heeringa, S. G., Jackson, P. B., Moomal, H. and Kessler, R. C., "Twelve-month mental disorders in South Africa: prevalence, service use and demographic correlates in the population-based South African Stress and Health Study", *Psychological Medicine*, Vol. 38(2), 2008, pp. 211-220.

<sup>31</sup> DSM-IV (Diagnostic and Statistical Manual, 4th Ed) is published by the American Psychiatric Association and is one of the major diagnostic systems used in psychiatric research. The CIDI (Composite International Diagnostic Interview) is a comprehensive, fully-structured interview designed to be used by trained lay interviewers for the assessment of mental disorders according to the definitions and criteria of ICD-10 [the International Classification of Diseases, 10th Ed] and DSM-IV. It is intended for use in epidemiological and cross-cultural studies as well as for clinical and research purposes. The diagnostic section of the interview is based on the World Health Organisation's Composite International Diagnostic Interview (WHO CIDI, 1990).

<sup>32</sup> Colombia is rated 13<sup>th</sup> highest in terms of income inequality (GINI coefficient 53.8), 14<sup>th</sup> highest in terms of population living under the poverty line (49.2%), has the highest murder rate in the world (63 per 100,000 population) and is rated 116<sup>th</sup> out of 121 countries in terms of the Global Peace Index. Lebanon has a GINI coefficient of 45 (ranked 38<sup>th</sup>), has 28% of its population below the poverty line (ranked 49<sup>th</sup>) and is ranked 114<sup>th</sup> out of 121 on the Global Peace Index. See Central Intelligence Agency, *The World Factbook 2010*, above note 24; United Nations Development Programme, above note 24; and Institute for Economics and Peace and Economist Intelligence Unit, above note 25.

<sup>33</sup> Burrows, S. and Laflamme, L., "Suicide mortality in South Africa: A city-level comparison across socio-demographic groups", *Social Psychiatry and Psychiatric Epidemiology*, Vol. 41(2), 2006, pp. 108-114.

<sup>34</sup> Lund, C., Kleintjes, S., Kakuma, R., Flisher A. J. and MHaPP Research Programme Consortium, "Public sector mental health systems in South Africa: inter-provincial comparisons and policy implications", *Social Psychiatry and Psychiatric Epidemiology*, Vol. 45(3), 2010, pp. 393-404.

<sup>35</sup> Lund, C., Kleintjes, S., Campbell-Hall, V., Mjadu, S., Petersen, I., Bhana, A., Kakuma, R., Mlanjeni, B., Bird, P., Drew, N., Faydi, E., Funk, M., Green, A., Omar, M. and Flisher, A. J., *Mental health policy development and implementation in South Africa. Phase 1 Country Report*, Mental Health and Poverty Project, University of Cape Town, Cape Town, 2008, available at: [http://www.who.int/mental\\_health/policy/development/SA%20Country%20Report%20-%20Final%20Draft%20Jan%202008.pdf](http://www.who.int/mental_health/policy/development/SA%20Country%20Report%20-%20Final%20Draft%20Jan%202008.pdf).

<sup>36</sup> KwaZulu-Natal Province.

<sup>37</sup> See above, note 34. The three provinces are Northern Cape Province, Northwest Province and Mpumalanga Province.

<sup>38</sup> See above, note 10.

<sup>39</sup> Burns, J. K., "Mental health services funding and development in KwaZulu-Natal Province: A tale of inequity and neglect", *South African Medical Journal*, Vol. 100(10), 2010, pp. 662-666.

<sup>40</sup> See Ramlall et al, above, note 7.

<sup>41</sup> See above, note 34.

<sup>42</sup> National Department of Health: Pretoria, *Norms Manual for Severe Psychiatric Conditions*, 2003.

<sup>43</sup> See above, note 39.

<sup>44</sup> Kleintjes, S., Lund, C., Flisher A. J. and MHaPP Research Programme Consortium, "A situational analysis of child and adolescent mental health services in Ghana, Uganda, South Africa and Zambia", *African Journal of Psychiatry*, Vol. 13, 2010, pp. 132-139.

<sup>45</sup> See above, note 34.

<sup>46</sup> Data obtained from the World Health Organisation database, *Atlas: Country profiles on mental health resources*, 2005, available at: [http://www.who.int/mental\\_health/evidence/atlas/](http://www.who.int/mental_health/evidence/atlas/).

<sup>47</sup> See above, note 30.

<sup>48</sup> Burns, J. K., Jhazbhay, K. and Emsley, R. A., "Causal attributions, pathway to care and first-episode psychosis: a South African perspective", *International Journal of Social Psychiatry*, 2010, doi:10.1177/0020764010390199.

<sup>49</sup> *Ibid.*

<sup>50</sup> See Mbewe, E., Haworth, A., Welham, J., Mubanga, D., Chazulwa, R., Zulu, M. M., Mayeya, J. and McGrath, J., "Clinical and demographic features of treated first-episode psychotic disorders: a Zambian study", *Schizophrenia Research*, Vol. 86(1), 2006, pp. 202-207; Chong, S. A., Mythily, S., Lum, A., Chan, Y. H. and McGorry, P., "Determinants of duration of untreated psychosis and the pathway to care in Singapore", *International Journal of Social Psychiatry*, Vol. 51(1), 2005, pp. 55-62; and Sharifi, V., Kermani-Ranjbar, T., Amini, H., Alaghband-rad, J., Salesian, N. and Seddigh, A., "Duration of untreated psychosis and pathways to care in patients with first-episode psychosis in Iran", *Early Intervention in Psychiatry*, Vol. 3(2), 2009, pp. 131-136.

<sup>51</sup> See above, note 48.

<sup>52</sup> Mkize, L. P. and Uys, L. R., "Pathways to mental health care in KwaZulu-Natal", *Curationis*, Vol. 27(3), 1994, pp. 62-71.

<sup>53</sup> See Thornicroft, G., "Stigma and discrimination limit access to mental health care", *Epidemiologia e Psichiatria Sociale*, Vol. 17(1), 2008, pp. 14-19.

<sup>54</sup> Saraceno, B., van Ommeren, M., Batniji, R., Cohen, A., Gureje, O., Mahoney, J., Sridhar, D. and Underhill, C., "Barriers to improvement of mental health services in low-income and middle-income countries", *The Lancet*, Vol. 370, Issue 9593, 2007, pp. 1164-1174.

<sup>55</sup> See above, note 4.

<sup>56</sup> McCrea, N. L., "An analysis of South Africa's mental health legislation", *The National Law Review*, 2010, available at: <http://www.natlawreview.com/article/analysis-south-africa-s-mental-health-legislation>.

<sup>57</sup> Constitution of the Republic of South Africa, Chapter 2: 9.3, available at: <http://www.info.gov.za/documents/constitution/1996/96cons2.htm#9>.

<sup>58</sup> See above, note 9.

<sup>59</sup> Yamin, A. E. and Rosenthal, E., "Out of the shadows: Using human rights approaches to secure dignity and well-being for people with mental disabilities", *PLOS Medicine*, Vol. 2(4), 2005, pp. 296-298.

<sup>60</sup> See above, note 2.

<sup>61</sup> *Ibid.*

<sup>62</sup> Goodley, D., "Empowerment, self-advocacy and resilience", *Journal of Intellectual Disability*, Vol. 9(4), 2005, pp. 333-343.

<sup>63</sup> See above, note 59.

<sup>64</sup> See above, note 5.

<sup>65</sup> Lancet Global Mental Health Group, "Scale up services for mental disorders: A call for action", *The Lancet*, Vol. 370, Issue 9594, 2007, pp. 1241-1252.

<sup>66</sup> For example, mental health is notably absent from the Millennium Development Goals (MDGs.) For a critique, see Miranda, J. J. and Patel, V., "Achieving the millennium development goals: Does mental health play a role?", *Public Library of Science Medicine*, Vol. 2(10), 2005, pp. 962-965. Miranda and Patel have pointed out that, even though mental disability impacts both directly and indirectly on many areas of social and economic life, mental health is completely absent from the MDGs. They provide evidence linking mental health directly to three of the MDGs — the eradication of extreme poverty and hunger; the reduction of child mortality; and the improvement of maternal health. However, if one considers the numerous effects of mental disability on social and economic development at the individual and community level, then it is apparent that combating mental disabilities and reducing the morbidity associated with them must contribute to the realisation of almost all the MDGs. The omission of mental health from the MDG agenda is a good example of the inequality and discrimination that exists within the health and development discourse itself.

<sup>67</sup> See above, note 59.

<sup>68</sup> *Ibid.*



# TESTIMONY

*"In 2005, the government issued a regulation which allowed them to demolish a house without asking or telling the people living in it.*

*Since then, they have been constantly demolishing houses all around the unrecognised villages. They come in the morning when the husband is away so that only the women and the youngest children are in the house."*

*Khadra Elsana*



## The Women of the Negev: Testimony from Representatives of a Bedouin Women's Organisation



Photo credit: Sidreh-Lakiya

The Bedouins of the Negev desert are one of the most disadvantaged minorities within Israel. Numbering between 160,000 and 180,000 people, they are systematically excluded from Israeli society and denied the rights and standard of living enjoyed by the majority population. Approximately half of the Bedouin population lives in “unrecognised” villages (approximately 45),

while the remainder lives in the 7 government-planned villages that have been established since 1968<sup>1</sup> and the 9 villages which have been “recognised” by the government since 1999.<sup>2</sup> Prior to that, their land was confiscated by the Israeli state and they had been displaced from their homes. They have Israeli citizenship, but those living in the “unrecognised” villages have no address registration, which can lead to problems with accessing services. Living conditions in the “unrecognised” villages are poor: there is no electricity, running water or transportation. Services in the “recognised” villages are also severely substandard, with only elementary schools and basic healthcare facilities.<sup>3</sup> Most worryingly, homes in the “unrecognised” villages are under constant threat of demolition, with the Israeli state recently having adopted more restrictive regulations and undertaken a large-scale campaign of clearing entire villages, leaving their inhabitants homeless.<sup>4</sup>

The unemployment level among the Bedouin is higher than among any other community in Israel. Among women, this level is extremely high, with less than

10% of women participating in the labour force at all.<sup>5</sup> This is combined with very low levels of literacy (approximately 90% of Bedouin women are illiterate), a high prevalence of traditional practices such as polygamy, and a high incidence of diseases, especially stress-related ones like hypertension.<sup>6</sup> Most girls do not continue their education beyond elementary school.<sup>7</sup> Bedouin women suffer multiple discrimination on the bases of both gender and ethnicity. The Israeli media portray them as primitive and backward. Levels of political participation are extremely low.



Photo credit: Sidreh-Lakiya

Sidreh is an organisation of Bedouin women from the Negev desert in Israel.<sup>8</sup> Based in the village of Lakiya, it was founded twelve years ago with the aim of empowering Bedouin women through educational and rights-based initiatives. The organisation's activities centre around economic development, awareness-raising and advocacy, social empowerment, and education. Sidreh works with a number of other organisations both within Israel and the Occupied Palestinian Territories,



Photo credit: Sidreh-Lakiya



Photo credit: Sidreh-Lakiya

and abroad. Its educational programme, which is recognised by the Ministry of Education, has resulted in major improvements in literacy and educational attainment among participating women. Part of the organisation is a social enterprise, centred around the Lakiya Negev Weaving Project, which enables over 70 women to use their traditional weaving and em-

**broidery skills to produce high-quality products for sale on the domestic and international markets. Importantly, it gives Bedouin women a social life and a source of income, and enables them to gain a range of skills, including IT, accounting, administration and driving.**

**On behalf of The Equal Rights Trust, Vania Kaneva met with two women who manage Sidreh - Khadra Elsana and Hala Abu Shareb - and obtained from them the following testimony, presented here in their own words.**

My name is Khadra, I have four children and I live in Lakiya, a village in the north of the Negev desert in Israel. I work at Sidreh. Our organisation is named after a tree that grows up in the desert. We chose this name because it represents the women of our community, who are strong like the tree despite the situ-

ations we find ourselves dealing with. The organisation works on different levels: economic development, education, health, and housing. We established our organisation in 1997 with a small group of women from all around the Negev. We wanted to make a change in our community, to make women more involved, to encourage them to participate in community life, and to give women the skills to do this. The first things we did were all about empowering women and teaching them skills that would enable them to ask for their rights, both within the community and from the government.

We have different projects. The weaving project, which is on the economic development side, was the first project in all the Negev and all of Israel that was based on a social enterprise model and the idea that simple skills like weaving can be used to empower women. Participating in a project like



Photo credit: Sidreh-Lakiya

this gives the women independence and confidence, and empowers them on all levels – personally, economically and socially. Today the project supports 70 women all around the Negev.



Half of the Bedouin population in the Negev live in unrecognised villages and the situation in them is bad. They do not have even basic services such as electricity, running water, roads, transportation and high schools. Not even health clinics – only some unrecognised villages have one, but these are not open all the time. They have only one general doctor for the whole village and no specialist doctors for women and children. Since there is no electricity, they are powered by electrical generators for a couple of hours a day, so the clinics do not store most medicines and vaccinations.

More than 80% of Bedouin women aged 30 and above are illiterate, especially in the

unrecognised villages. The first high school that was built in the Negev was built in 1979, and not all women went – it was very new for them. 77% of Bedouin girls in the unrecognised villages drop out after elementary school and do not go on to complete their education beyond the sixth grade. The main reason is that in the unrecognised villages there are no high schools, so they have to go to the nearest of the seven recognised villages. The parents are afraid to take this risk and send their daughters to a different family, especially since the schools are often named after a local family or tribe, which can cause problems. The level of teaching in these high schools is in any case very low and the classes and schools are overcrowded. Less than 10% of Bedouin pupils who graduate from them – boys and girls – continue to higher education. They are not well prepared to take the entrance exams for university.

Our work on education started 10 years ago and so far we have reached 1400 women, who can now read and write in Arabic, and also 1600 women who completed their secondary school through our project in the unrecognised villages. What our organisation does is provide classes for illiterate women in the unrecognised villages, in both Hebrew and Arabic. All the services in Israel are in Hebrew – hospitals, banks, post offices – and the women want to learn it. We also have a group for those willing to complete their education. We teach especially young girls who have dropped out from school but want to complete their high school education and continue on to higher education. There is no curriculum for this kind of teaching. We are the first and only organisation that created this curriculum which fits exactly with the needs and worries of the Bedouin women, and which is relevant to them. According to a number of theories, the best way to teach

is to deal with the issues and problems relevant to the people you are teaching and the things they deal with on a daily basis. The organisation also provides training for the teachers, who are usually academic Bedouin girls who need continuous learning in order to develop their skills. When we enter a village, it is not just for teaching. We also organise lectures on various topics, including human rights. We have brought in lawyers, doctors and other professionals to give talks. Sometimes the women themselves ask for a particular topic.

We give women the tools to develop their own committees - women's committees in each village - through which they can claim their rights. In one case, after a lecture given by us, the women gathered together and decided to write a letter to the Ministry because there were no garbage bins in their village. They wrote it on their own initiative, but the main thing was that they knew how to ask, where to ask, and they knew their rights and entitlements. The government didn't provide garbage bins - they told them that they would have to buy them, and of course these women do not have money for this. But the fact that they did something, that they already know how to ask, is important.

Another big problem in the unrecognised villages is home demolitions. In 2005, the government issued a regulation which allowed them to demolish a house without asking or telling the people living in it. Since then, they have been constantly demolishing houses all around the unrecognised villages. They come in the morning when the husband is away so that only the women and the youngest children are in the house. Most of them cannot speak Hebrew, and even if they could, it would not help. The government officials come with a big crew of more than 30-40

units - army, police, everything. They bring down the house and then they send the bill for their "work" to the people to pay. There is no stated purpose of this. The only reason they give is that the villages are unrecognised, and that this land does not belong to the owners but to the State of Israel. They are trying to move the Bedouin to settlements that the government itself makes. The Bedouin right now sit on less than 2% of their original lands - and on this 2%, the government is carrying out demolitions. The experience is extremely traumatic for the people involved. They are not given any option, no other accommodation and they are left literally on the street. In the last Ramadan, they stepped it up and were carrying out demolitions almost every day. They destroyed one entire village. We arranged a protest after this. Our women went to Jerusalem one day to protest against the demolitions next to the Knesset.<sup>9</sup> This was the first time Bedouin women have participated in this kind of civil protest. Politics is generally considered men's business, but when it comes to their houses, the women can stand up as well. There were a large number of women at the protest, and it was very amazing to see.

In our community in the Negev, speaking of politics is often taboo. It is considered a man's job. Last year we decided that enough was enough - we must involve women in politics. In the recognised villages, there are Councils and it is essential that women become more involved in these and use them to claim their rights. We organised the first conference, we brought the first Arab woman who was elected to the Knesset and the first Bedouin in the government, and we spoke about women's involvement and these women leaders' roles in increasing women's participation. It was the first time we spoke of this in public. It was agreed that we must encour-

age more women to participate in communal life. We established the first women's committee, which will be responsible for voicing women's demands. This is small politics, on the local level, but this is the way to start. Now they have the first community centre, which they built together with men, and it has been agreed that the women will have use of it in the morning, the children in the afternoon and the men in the evening. This is the first time women have been involved in the planning and physical development of their village – the first time women's needs have been considered in this regard. It is not much that they need – most people want a simple life, to be able to work their lands and their animals in peace. But there are younger people as well who want a more modern life and a modern village. So on one side there is a contradiction between the generations, young and old, which is normal and exists in most communities, while on another side there are contradictions between men and women. With our organisation, men have been supportive because we have a strategy about dealing with problems. The organisation's staff know how to address men – when we enter a village we go to the men first and we do a lot of work to convince them that men and women need to work together, and the benefits of what we do and women's participation. The Israeli government has said to us that the problem is with our men, that they do not want us to be more involved, but we said to them that they need to provide services and leave us to sort out our internal problems. You cannot punish an entire community. The government needs to do its job.

The situation in the Negev is such that no one feels safe and each family becomes more closed and isolated as a result. Forty years ago, all the families were united and it was easy to find men and women and people

from different families working together. This is no longer the case. People are becoming internally divided into clans and families, men and women. People are afraid of each other and have no sense of security. Many men do not want their women to work outside the home. Men still feel responsible for providing for their wives and children, but they are no longer able to do so due to high unemployment and lack of work opportunities. This makes them frustrated and they are more protective of women.

We carry out lobbying both inside and outside Israel. We have petitioned the Knesset about many things: employment, health, housing and rights. We are also using the domestic courts but this has not brought about any improvement. First and foremost we need recognition, and a solution to the land problem. If this gets solved, the rest of the problems will be much more easily solved. There is little that community organisations like ours can do about the wider peace process, but we are trying to create awareness of our culture and people among Jewish Israelis and foreigners who come to visit us. Israelis hear about the Bedouin from the media and they have created wrong stereotypes about us, which we are trying to break. We have many ideas about how to overcome this and bring people together. One of the ways we spread awareness is through our newspaper. It is only in Arabic at present, but we want to issue it in Hebrew as well, so that the Jewish people may know about who we are. Our newspaper reaches some of the non-Bedouin Arabs in Israel, and they have expressed surprise. They also have stereotypes about us and see us as simpler people. Our newspaper tries to inform them about us. The difference in development between us and other Palestinians, in the West Bank and within Israel, is up to 50 years.

The primary challenge for our organisation, and generally for civil society in the Negev, is funding. We have our road and our vision. We know where we want to go. We have a strategy about how to work within our com-

munities, with the government and with the international community, but we need support. We learn from everything we do, from our experiences, but we have to go to great lengths to secure funding.




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<sup>1</sup> The seven government -planned villages are al-Shba, Rahat, Laqiya, Ar'ara al-Naqab, Qseifa, Houra, and Shqueb al-Salam (Segev-Shalom).

<sup>2</sup> The nine "recognised" villages are Um-Batin, Gassar al-Ser, Al-Grain, Um-Matnan (Abu Krinat), Bir Hadaj, Makhul, Wadi Gowein (Mulada), Tarabin and Drijat.

<sup>3</sup> The Negev Coexistence Forum for Civil Equality, *The Arab-Bedouin in the Negev-Naqab Desert in Israel: Response to the Report of the State of Israel on Implementing the Covenant on Economic, Social and Cultural Rights (ICESCR)*, October 2010, available at: [http://www.phr.org.il/uploaded/Final\\_Shadow\\_report\\_ESCR\\_1Nov\\_10.pdf](http://www.phr.org.il/uploaded/Final_Shadow_report_ESCR_1Nov_10.pdf).

<sup>4</sup> Human Rights Watch, *Off the Map: Land and Housing Rights Violations in Israel's Unrecognized Bedouin Villages*, 30 March 2008, available at: <http://www.hrw.org/en/reports/2008/03/30/map>; "Israel police raze 'illegal' Bedouin village in Negev", *BBC News*, 27 July 2010, available at: <http://www.bbc.co.uk/news/world-middle-east-10777040>.

<sup>5</sup> Sinai, R., "66% of Negev Bedouin Live below Poverty Line", *Haaretz*, 15 January 2007, available at: <http://www.haaretz.com/print-edition/news/66-of-negev-bedouin-live-below-poverty-line-1.210067>.

<sup>6</sup> Sidreh, *Data on the Bedouin Women of the Negev*, available at: <http://www.lakiya.org/121194/Data-on-the-Bedouin-Women-of-the-Negev>.

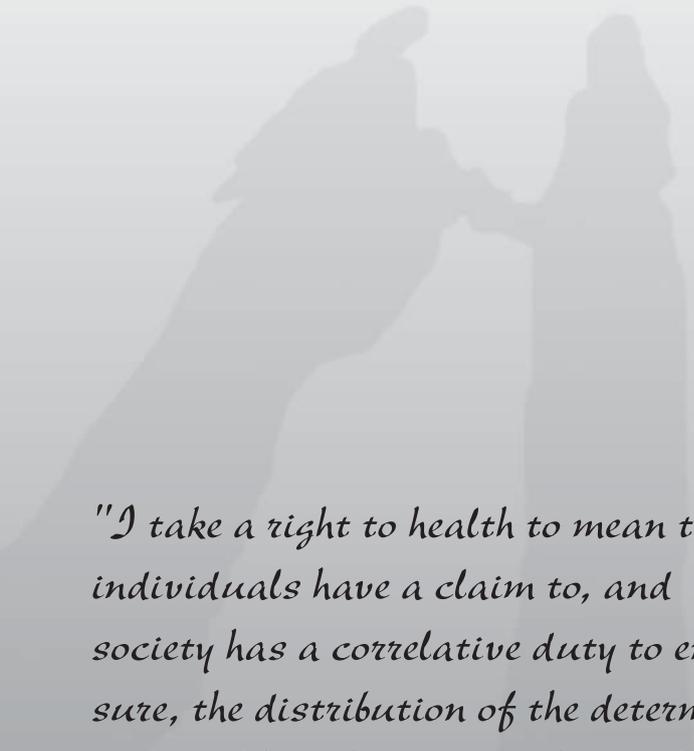
<sup>7</sup> *Ibid.*

<sup>8</sup> For further information, see the Sidreh website: <http://www.lakiya.org/>.

<sup>9</sup> The Knesset is the Parliament of Israel.



# INTERVIEW



*"I take a right to health to mean that individuals have a claim to, and society has a correlative duty to ensure, the distribution of the determinants of health in a way that is fair to all people."*

*Norman Daniels*

*"At the core of the right to health is an equitable, integrated, responsive, effective health system that is accessible to all and of good quality."*

*Paul Hunt*



## Health Justice, Equality and Fairness: Perspectives from Health Policy and Human Rights Law

*One has the strange impression of switching between parallel worlds when reading the main human rights and health policy works on the issues of health justice. Different contexts, intellectual traditions, conceptual frameworks and arguments, while running their own course, seem to be driven by similar fundamental concerns about what it is that a society ought to do regarding people's health needs. Instead of crossing over from one discourse to the other, it is desirable to have the two "talk" to each other.*

*ERT spoke with Norman Daniels, Professor of Ethics and Population Health at the Department of Global Health and Population, Harvard School of Public Health, Harvard University, and Paul Hunt, Professor at the Department of Law/Human Rights Centre, University of Essex, and former United Nations Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health (August 2002-July 2008). We spoke with Professor Daniels on the phone, and recorded and transcribed his replies. Professor Paul Hunt provided us with his written answers to a few related questions. Each has seen the replies of the other, although they have not had the chance for a real live dialogue. But each word below is their own, and each question is presented exactly as asked. Still, this notional double interview is a "fabrication" which, while it cannot create a dialogue between international human rights lawyers and health policy experts, can at least demonstrate the need.*

**ERT: Professor Daniels, you are one of the leading authorities on health justice and health equity. How did you become interested in this area?**



**Norman Daniels:** Through my initial interest in my own work in political philosophy, I became interested in examining theories of justice to see which had the best support. It seemed to me at the time that there was more agreement about how to distribute health-care than a number of other social goods, so it gave better answers about how we should carry out such distribution. I later came to see that this was a bit naïve, but nevertheless, that was what initially got me thinking about justice and healthcare. So my route to this area of interest was through more theoretical concerns. My interest in health and healthcare has subsequently grown as a separate focus of interest.

**ERT: Professor Hunt, you are one of the leading experts on the right to the highest attainable standard of health (or "the**

**right to health" for short). Can you tell us what led you to become involved in this area and why you consider it to be an important area of research and action?**



**Paul Hunt:** For some years I focussed on classic civil and political rights, but, in the early 1990s, I shifted my attention to economic, social and cultural rights. At that time economic, social and cultural rights were grossly neglected by virtually everyone – the UN, courts, national human rights institutions, established human rights non-governmental organisations, and so on. As for professionals working in the domains of economic, social and cultural rights - health workers, educationalists, or nutritionists - for the most part they had not even heard of the rights to health, education or food. And how could they? Almost nobody was talking about them! Yet economic, social and cultural rights are a central feature of the international code of human rights, as well as numerous national constitutions. It seemed to me that it was wrong for the human rights community to privilege civil and political

rights and neglect economic, social and cultural rights. Of course it was no coincidence that these much-neglected economic, social and cultural rights were especially important to much-neglected communities, especially the disadvantaged and impoverished. The first economic, social and cultural right that I wrote about was the right to the highest attainable standard of health, because its implementation is a matter of (literally) life and preventable death for billions around the world.

**ERT: Given that your mandate as UN Special Rapporteur was extensive and complex and your resources extremely limited, how did you organise your work?**

**Paul Hunt:** Before identifying my objectives as Rapporteur, I consulted widely and finally settled on three main goals. One, to raise the profile of the right to health as a fundamental human right; two, to clarify the legal obligations arising from the right to health; and three, to search for ways to operationalise this fundamental human right. Additionally, I decided to focus on two themes: poverty and the right to health; and discrimination and inequality and the right to health. Over six years, these goals and twin themes shaped my thirty-or-so UN reports. They reflect what I saw as the main challenges in 2002 – and these remain pretty much the main challenges today.

I wrote right-to-health reports on the countries I visited, prepared thematic right-to-health reports, such as on maternal mortality, and took up with governments numerous complaints I received from ordinary people alleging that their right to health had been violated<sup>1</sup>.

**ERT: In your reports, how did you address the issues of fairness, equality and equity in health?**

**Paul Hunt:** My twin themes of poverty and non-discrimination were designed to ensure that the issues of fairness, equality and equity were always central to my work.

These issues led to particular thematic reports, such as the UN General Assembly report on mental disability and the UN Commission on Human Rights report on sexual and reproductive health. They also led to particular country reports, such as the report on neglected diseases in Uganda - neglected diseases are those mainly suffered by the poorest people in the poorest countries. Fairness, equality and equity also led to reports on undocumented people in Sweden and indigenous peoples in Peru. Of course, when I wrote on other issues, such as access to medicines, I looked at fairness, equality and equity because they are key elements of the right to the highest attainable standard of health. In 2008, I submitted to the UN General Assembly *Human Rights Guidelines for Pharmaceutical Companies in relation to Access to Medicines* that include provisions on disadvantaged individuals, communities and populations; these provisions are explicitly based on the human rights concepts of equality and non-discrimination. The following year, I applied these concepts to the specific policies and programmes of GlaxoSmithKline when examining the right-to-health responsibilities of this major pharmaceutical company.

My reports remind states, and others, that they have a legal obligation to provide access to health-related services without discrimination and this means that they must have in place out-reach programmes for disadvan-

tagged individuals and communities that are sensitive to, for example, gender and cultural context.

**ERT: When promoting fairness, equality and equity, what were among the main obstacles you encountered?**

**Paul Hunt:** Many governments do not have in place effective health information systems enabling them to know the health status of individuals and populations in their jurisdictions. In many cases, the absence of reliable health information extends throughout the country, including to the dominant population groups. But the data problem is even more acute in relation to disadvantaged populations, such as ethnic minorities, indigenous peoples, the rural and urban poor, migrant workers and so on. Even if available, very often, the data are not routinely and reliably disaggregated by sex, ethnicity, rural/urban, age, socio-economic group and so forth. Of course, this makes it difficult to formulate and implement the most effective health policies, programmes and projects that will reach these disadvantaged groups.

Despite these data limitations, much more could be done, in all the countries that I looked at, to put in place health-related out-reach programmes for the disadvantaged and impoverished. Of course, better health information would help to make these programmes sharper and more effective. But most governments have enough information to establish more effective out-reach programmes than they presently have in place.

Also, although governments have legally binding obligations to enhance access to health-related services for all, rarely are these obligations either considered in the relevant policy-making processes or argued

before the courts and other adjudicative mechanisms.

**ERT: Professor Daniels, what do you consider to be the main challenges to equality and fairness in healthcare, in the United States and internationally?**

**Norman Daniels:** The United States is, in my view, a somewhat different problem to that in many other OECD countries, as well as some of the middle and low-income countries. In the United States, we have less commitment to distributing healthcare more equally than we do other goods. In most European and Commonwealth countries, there are long-standing forms of systems that deliver universal coverage to their populations. In the United States, however, this has been a big issue. Just recently, on 19<sup>th</sup> January 2011, there was a vote by the Republicans, who have regained control of the House of Representatives, through which they tried to repeal the Obama health reform, which had partially closed the insurance gap but did not even do that universally. In general, in the United States, we have strong vested interests that are more concerned about making money out of healthcare than they are about equity in healthcare, and those interests stand in opposition to universal coverage in the United States. The politicisation of this issue in a partisan way is a great misfortune, but it really does reflect a longstanding disagreement between the conservatives, the liberals and the centre in the United States. There ought to be a state role in delivering healthcare to the population. So in the United States, I see this as an ongoing and rather serious problem.

In many other wealthy countries, I think there are in place better efforts at health systems, which are more equitable in the dis-

tribution of healthcare. In the last 30 years, we have learnt from social epidemiology that the distribution of health in a population is not simply the result of the distribution of healthcare. There are significant health inequalities in all countries, whether or not they have universal coverage. For example, the distribution of education, jobs, residential housing, and political opportunity, including political participation, can all have a significant impact on the distribution of health in a population. So the health inequalities that exist in many wealthy countries reflect some of those inequalities, despite there being a system of universal health coverage. I think there remain a lot of problems in other countries. But in many of them where there is at least universal health coverage for medical services, there is some growing awareness of the other relevant factors which I have identified, which means there may be efforts to make policies more equitable regarding health.

**ERT: Is there a country at present that is the best in terms of healthcare fairness? How do you assess the other wealthy countries, especially in Western Europe, as well as Australia, Canada, New Zealand? Do you have a favourite?**

**Norman Daniels:** No I don't have one favourite country. There are different efforts in different countries. There are several countries that take reasonably good approaches. For example, Norwegian and Swedish efforts impress me. There is also a lot of concern in the UK about equitable distribution of healthcare and the result is better there than elsewhere. There are several countries which I think do a reasonably good job at promoting equality in health.

**ERT: You have in the past been recognised for your conception of healthcare justice based on fair equality of opportunity. As the concept of fair equality of opportunity has no universally agreed definition, could you explain how, if at all, this principle should be translated into making rationing decisions in healthcare? What does it mean to make a choice in healthcare rationing such that the choice advances fair equality of opportunity?**

**Norman Daniels:** I must firstly question the assumption behind your question. It is true that I do indeed argue that a general principle of protecting opportunity and, perhaps, the Rawlsian principle of fair equality of opportunity is an appropriate one, and such a general principle gives you a general picture of the grounds for our obligation to protect health in a population. I am very clear, however, that I do not think that this principle can answer a whole range of important resource-allocation and rationing questions. For that reason, I have argued that one has to supplement this principled account of fair equality of opportunity with a fair deliberative process. There is reasonable disagreement about how to promote equality of opportunity through healthcare provision in a population, so one needs to have a mechanism for resolving those disagreements. In my earlier book, *Just Health Care*,<sup>2</sup> I did believe that the equal opportunity principle could answer a lot of rationing questions, but I no longer believe that and argued against that over the last decade.<sup>3</sup>

**ERT: In view of the fact that you do not consider that the principle of fair equality of opportunity can provide sufficient guidance in rationing decisions, do you believe it is possible and indeed desirable to find a set of substantive princi-**

**ples according to which such decisions can be made?**

**Norman Daniels:** I am not sure it is possible to agree on something that would look like a set of principles, because although there are considerations that we can take to be very important in making resource allocation decisions – such as, for example, the seriousness of the condition, the prevalence of the condition, and the amount of benefit we can do through intervention, such considerations interact and trade-off against each other in complicated ways. People reasonably disagree about how to trade such considerations off against each other, so although I think it would be nice to be able to develop a set of principles, I do not think that we are in a position to do that. I think that what we need is a lot more practice at making decisions about more specific types of trade-offs in specific contexts. Maybe out of that we can accumulate commitments as to how to trade these principles off against each other, which could form a basis for further rationing decisions over time. This could emerge as our commitment to a fair system of rationing, but I do not think we are in a position ahead of time to agree on how to do that. That is why we need to focus on achieving a fair deliberative process.

**ERT: Turning to your advocacy of a fair deliberative process, how can we be sure that we do not reproduce and entrench the power relationships in society in such a process of deliberation? How can a deliberative process transcend the basic structures of domination and power in society? Does deliberation not legitimise the status quo rather than transcending an unequal and unjust society?**

**Norman Daniels:** I do not think that there can be any guarantees that any kind of deliberative process will transcend power rela-

tions in society. Any straightforwardly democratic process could reflect those relations. Such a deliberation will always risk being biased. But what's the alternative? A group of experts sitting and making these decisions by themselves, without the constraints that come from hearing a range of stakeholders from within society? We all know that those experts themselves may reflect some of the same power relationships within that society. The question is whether this is a reasonable, if not fool-proof, way of arriving at some way of enhancing legitimacy and arriving at fairness. I think it improves on any of the alternatives that might be available to us. There are certainly a lot of questions about how one develops a process and manages it so as to prevent, for example, charismatic people from being able to sway others and thereby hold undue power within the process. It could be that if one had commissions set up that were stacked by the powers that be, then this might serve to replicate the existing power structure in trying to co-opt the deliberative democratic process. There is no procedural guarantee.

On the other hand, we might experiment with different mechanisms to see which of them produces better results. But this raises a hard question: how do you measure what counts as a better result? And how can we gather evidence about which democratic procedures work better? If we knew what counted as a fair outcome, we would not need to find a procedure for arriving at it, unless it was a way to enhance legitimacy, or reassure us that we were coming up with an appropriate solution to a problem where we had agreed upon criteria. It is because we do not agree on the criteria for what counts as a fair outcome of a process, or a fair distribution of resources, that we need a process that everyone can agree is fair. And of course, that presupposes that we can agree on what

counts as a fair process. That is an empirical question and I am not sure how we set about doing that, although we do rely on such procedures all the time, to the extent that there is disagreement.

**ERT: Professor Hunt, in your view, given finite budgets, how should a Minister of Health choose between one possible health intervention and another? What does the right to health contribute to the issue of prioritisation?**

**Paul Hunt:** It is sometimes suggested that international human rights law does not permit prioritisation and, some ten or fifteen years ago, that was probably the prevailing orthodoxy. But thinking on economic, social and cultural rights has evolved in recent years. For example, when invited by the UN to prepare guidelines on a human rights approach to poverty reduction, Siddiq Osmani, Manfred Nowak and I came to the more nuanced view that international human rights law permits prioritisation, while imposing certain conditions on the process and outcomes of prioritisation.<sup>4</sup>

Certainly, the right to health remains work-in-progress and one of the areas where much more human rights work is needed is around prioritisation of health interventions. Health economists and ethicists have given a lot of attention to prioritising and rationing health interventions, using principles like cost-effectiveness and equity. Although they have not solved the dilemmas (far from it), they have given the issues considerable attention from which the human rights community must learn. Human rights practitioners have yet to get to grips with these difficult issues, even though prioritisation often privileges the health needs of wealthy, urban populations over the entitlements of the rural poor. In practice, prioritisation often marginalizes

the health entitlements of women, people with disabilities and other disadvantaged groups. This mirroring and deepening of patterns of inclusion and exclusion is offensive to the right to the highest attainable standard of health.

In a UN General Assembly report of 2007, I made some preliminary observations on prioritisation and the right to health. One key point is that human rights sometimes require prioritisation of particular substantive health interventions (e.g. those arising from core obligations), but they also demand a range of procedural considerations (e.g. participation, monitoring and accountability) that must be taken into account when setting priorities. Also, priority-setting must give regard to improving the situation of individuals, communities and populations that are especially disadvantaged, including those living in poverty. Further, while human rights have a constructive contribution to make to prioritisation, they are unlikely to provide neat answers to highly complex issues, any more than do ethics, economics or general theories of justice. Human rights are likely to rule out some processes and some choices, leaving a number of options, all of which are legitimate.

Even though we still await a refined and comprehensive human rights approach to health priority-setting, it is clear, when we look at what is happening on the ground, that most states are not doing anywhere near enough to meet their legally binding obligation to establish health-related out-reach programmes for the disadvantaged and impoverished. And for this, governments must be held accountable.

**ERT: Professor Daniels, in international human rights law, there is a recognised right to the highest attainable standard of**

**health but there is very little dialogue between lawyers, policy-makers and intellectuals in the area of healthcare justice as to what such a right involves. What do you think the right to the highest attainable standard of health consists of? And do you think it is a useful concept?**

**Norman Daniels:** I do think there is a way of talking about a right to health and a right to healthcare that makes sense. First of all, a right to health is not a right that ensures that your health is going to be good regardless of what is done for you. Nobody can guarantee that, and it would be ridiculous to suggest that this is what one means by a right to health. I take a right to health to mean that individuals have a claim to, and society has a correlative duty to ensure, the distribution of the determinants of health in a way that is fair to all people. So one needs some prior notion of social justice in order to clarify what that distribution is.

For example, we all know that there is a socio-economic status (SES) gradient of health. The higher on that SES hierarchy you are, the longer and healthier your life, and that is true in every country. The question, therefore, is which SES differences constitute a fair distribution of the components of SES, for example income, education, or more broadly opportunity. Reasonable people are going to disagree about what counts as fair distribution. How much better off should the best off people be allowed to be? A strict or radical egalitarian approach is a rare bird, and there is no country that is strictly egalitarian in that way. So if one takes that as evidence that nobody really considers this to be a manageable view, then we need to establish which inequalities are acceptable.

Is any inequality that generates a health inequality unjust? If the answer to that ques-

tion is “yes”, then health is the tail that wags the dog of justice and that is problematic, as there are many other social goods besides health which should be taken into consideration. There are many other things that people think are important and that they might, in fact, want to trade health for. We all trade health in our lives for some other kind of goods. We may choose to live far away from our place of work because we like the rural setting, but we may then have to commute longer with the resulting additional risks of death on the highway. Therefore, we all make such trade-offs in our own lives. To suggest that we would never trade health for anything else presents a complication in deciding which other inequalities are allowable if we do not want to let health be the determinant of all of them. If health, however, is just one among many other goods, we need to establish a theory about how to distribute all of such goods. Unfortunately, very few theories give us clear answers to all such questions. So my position is that inequality is an important issue. The question of which inequalities are allowed within a right to health becomes something that we need a more general answer to.

In answer to your question about what I think about the right to health and healthcare, I think of it as implying entitlements that individuals have to a socially relative array of services (in the case of healthcare) that is the outcome of a process of fair deliberation under reasonable resource-constraints. Now historically, the health benefits packages which exist in most health systems are not the result of any such deliberative process. They are historically determined by social practices in medicine and elsewhere. They include many services that are less important than others we might add or substitute for them and since every society faces some level of resource restrictions - as health is

not the only important social good - then reasonable decisions have to be made about which health services are more important to deliver to a population than others. So I see entitlement to healthcare services as a contingent claim that individuals with specific conditions have to services that are part of a reasonable array of services; society decides what that array is through appropriate deliberative procedures. Where we lack those procedures, and we do in most countries, then there is still a body of socially relative decisions that have been made and they may become a background against which one has to make further decisions. But some societies are now in the position where they realise that some process needs to be put in place for making more reasonable decisions about allocation of resources. In the United Kingdom, until the current government came in, the National Institute for Health and Clinical Excellence (NICE) was supposed to help to make recommendations. There are processes in Norway and Sweden for doing that. In Germany, the story is somewhat different. They do not want to impose constraints on anything that counts as efficacious unless there are cost-considerations about the pricing of what is covered. So the mechanism that has been put into place to look at efficiency frontiers for new drugs is an effort to set up price guidelines so the government can negotiate, based on a decision that if something falls below a threshold, then we don't cover it.

In the United States, we are in a much worse situation because nobody wants to address the problem in an honest way. I fear also that something similar is currently taking place in the United Kingdom, given that there was no discussion in the election regarding the decisions now being made in relation to the National Health Service. All of this was a big surprise that was not part of the election campaign and there was no public discussion.

The decisions have been made following the appointment of a new health minister by the new government, and this was not part of a public agenda that has any mandate behind it. It is not transparent in many dimensions and it was never part of any kind of election campaign, although, in my view, inclusion of a discussion in an election campaign does not tell you what the right thing to do is in all cases. This is still to be favoured, however, in a world that respects democratic process.

The current situation in the United Kingdom is a case where something that was not discussed is now being made part of the policy agenda of the government. Whatever criticisms one had of NICE, and I have some, and others have more, it at least was concerned to find out what public attitudes were through its Council and its statements on social values. In my view, it was morally questioning an adherence to a strong cost-effectiveness threshold in light of important arguments that people made that one ought to be flexible about how you use that, and this was a slow ten-year progress. I see that as evidence that there was a deliberative process going on, and people were listening to each other. Now that is going to be buried in the lack of transparency in the new system.

**ERT: Professor Hunt, in international human rights law, what are the main elements of the right to the highest attainable standard of health?**

**Paul Hunt:** In 2000, the UN Committee on Economic, Social and Cultural Rights set out in some detail what it understands the right to health to mean. Of course, the Committee emphasises that the "right to health is not to be understood as a right to be healthy".<sup>5</sup> Briefly, this fundamental human right encompasses medical care, as well as access to safe water, adequate sanitation, a safe working

environment, access to health-related information and education, and other critical pre-conditions of good health. Crucially, it places an obligation on governments to address discrimination and inequality. The right to health requires governments to enhance access for disadvantaged individuals, communities and populations; in other words, it has a social justice component. It also requires governments to put in place arrangements that facilitate the active and informed participation of those affected by health-related policies, programmes and practices. The right to the highest attainable standard of health is subject to progressive realisation, i.e. no government is expected to realise it overnight – or even in ten years – but to progressively work towards its realisation. This means we need indicators and benchmarks to measure whether or not progress is being made. However, the right to health is subject to resource availability, in other words, more is demanded of Canada than Chad. Monitoring and accountability are vital elements of the right to the highest attainable standard of health. Accountability must not be understood to mean only judicial accountability; it also includes non-judicial mechanisms, such as public enquiries established by national human rights institutions, which can be much more accessible to the disadvantaged and impoverished than courts of law. At the core of the right to health is an equitable, integrated, responsive, effective health system that is accessible to all and of good quality.

Plainly, the right to health is extensive and complex. Although subject to progressive realization, some elements of the right (known as “core obligations”) are of immediate effect, such as the requirement of non-discrimination. The challenge is to apply the elements of the right to health - non-discrimination, equality, progressive realization, core obligations, participation, accountabil-

ity, and so on - to specific health issues, like medicines, water and sanitation, sexual and reproductive health, the skills drain, and so on. Addressing this huge challenge remains work-in-progress but, thanks to the efforts of countless individuals and organizations, we are gradually identifying the main right-to-health obligations of states, as well as other actors.

**ERT: Professor Daniels, in general terms, how do you envisage the role of human rights lawyers in promoting healthcare justice?**

**Norman Daniels:** I think that it is not the role of lawyers or courts to make specific decisions about coverage. I think what lawyers should be pushing for is to ensure that there is an appropriate process in place elsewhere in the health system, and that the decisions that emerge from it are recognisably the results of that kind of process, with reasons generated as grounds for its policy. I think of the role of human rights lawyers as one of enforcing a fair process in decision-making about healthcare coverage, not in making very specific decisions about coverage themselves.

There is a certain kind of bias within law which is namely that it is largely focused on individuals who have the standing to bring suits, and that raises a question of who is actually identified as a “victim”. The legal process tends to favour somebody who has standing to bring a suit, and might, therefore, have the power and authority to do that as a result, for example, of their wealth. Such individuals with the necessary power and authority stand in opposition to a group of people who might be affected by making resources available to that individual, or individuals like that individual, in favour of others.

I particularly have in mind the mess that exists in Colombia which I see as highly problematic. They have the system of *tutelas* there, through which individual claims based on constitutional rights to life and dignity are brought. These suits focus on healthcare needs that claimants argue threaten life with dignity. The Ministry of Social Protection in Colombia lacks an appropriate form of process for making decisions about coverage. This is a longstanding problem in Colombia as in many other countries. There are often plausible grounds for the courts to say that nobody knows why a particular benefit is part of a benefits package over another benefit, and when it appears to be as important for a life with dignity as something else, there is no reason not to include it. It is unlikely, however, that the courts actually have the resources and adequate information to make such decisions, so I see this as a longstanding dilemma.

Despite Keith Syrett's view in his book on the role of the courts<sup>6</sup>, in which he takes Jim Sabin and I to task having overstated our view on the issue, I think that there is a lot of agreement between his view and mine, which is that the role of the courts in decision-making is to try to make sure that the state puts in place mechanisms for making the decisions in a reasonable way rather than being in the position to decide which particular health programme is more important than another.

One further point I would like to make in relation to the relationship between human rights and priority-setting in health is one which I made in an article which I co-authored with Sophie Gruskin in 2008<sup>7</sup>. Our argument is that there is a very important problem of priority-setting that lurks behind the international framework for human rights. Right claims themselves within that framework do not have priority over each other, and even

claimants to the same right cannot be ranked in order of priority. Therefore, for example, when you undertake an effort to improve a progressive realisation of the right to health in a particular setting, you have many choices which are not determined by priorities that come from within that international legal framework. Our argument was that the approach to priority-setting which Jim Sabin and I were developing might make a contribution in the field of human rights in that it has a lot of points of overlap with it. We are not arguing for a hierarchy of rights, but rather acknowledging that the international human rights framework does not allow us to prioritise. The question is, when decisions such as those regarding what governments should do for the progressive realisation of health are made, why are those decisions made rather than alternatives? This really goes to the problem of legitimacy and the different question of fairness. Such decisions can be unfair to people. Our view is that the human rights approach needs supplementation in order to enhance transparency of the reasons for such choices, and this is an important objective shared by the human rights approach and concerns about justice.

**ERT: Professor Hunt, are the health and human rights communities working together to enhance fairness, equality and equity?**

**Paul Hunt:** They have begun to, but there is a long way to go. Both communities could and should be doing much more to reach out to the other. There is no chance of implementing the right to health without the experience and expertise of health professionals, and so the human rights community has to do a much better job listening to and learning from a wide-range of health professionals. This means that human rights advocates have to become familiar with health

concepts and language. For example, some human rights advocates misunderstand the health term 'equity', while some health professionals misunderstand the human rights term 'equality'. In my experience, most health professionals have not yet grasped that legally binding human rights law can help them achieve their professional objectives, including fairness, equality and equity. Regrettably, many health policy makers are

using the right-to-health analysis neither to understand the health realities in their countries, nor to shape robust, sustainable and equitable health policies that are meaningful to the disadvantaged. In other words, a key challenge is for the human rights and health communities to work together more closely, collaboratively and respectfully, with a view to tackling discrimination and delivering equality and equity.

**Interviewers on behalf of ERT:  
Dimitrina Petrova and  
Libby Clarke**

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<sup>1</sup> For these UN reports, and other publications on the right to health by Paul Hunt, see the Human Rights Centre, University of Essex: [http://www.essex.ac.uk/human\\_rights\\_centre/research/rth/index.aspx](http://www.essex.ac.uk/human_rights_centre/research/rth/index.aspx). (Editor's note)

<sup>2</sup> Daniels, N., *Just Health Care*, Cambridge University Press, 1985. (Editor's note)

<sup>3</sup> See Daniels, N. and Sabin, J., "Limits to Health Care: Fair Procedures, Democratic Deliberation, and the Legitimacy Problem for Insurers", *Philosophy and Public Affairs*, October 1997, Vol. 26, Issue 4, pp. 303-350; Daniels, N. and Sabin, J., *Setting Limits Fairly: Can We Learn to Share Medical Resources?*, Oxford, 2002, and 2nd ed. 2008. (Editor's note)

<sup>4</sup> *Human Rights and Poverty Reduction: A Conceptual Framework*, OHCHR, 2004. See also Guideline 4 in *Principles and Guidelines for a Human Rights Approach to Poverty Reduction Strategies*, OHCHR, 2006.

<sup>5</sup> General Comment No.14, *The right to the highest attainable standard of health*, E/C.12/2000/4, Para 8.

<sup>6</sup> Syrett, K. J., *Law, Legitimacy and the Rationing of Healthcare: A Contextual and Comparative Perspective*, Cambridge University Press, 2007. (Editor's note)

<sup>7</sup> Gruskin, S. and Daniels, N., "Process is the Point: Justice and Human Rights: Priority Setting and Fair Deliberative Process", *American Journal of Public Health*, 2008, 98(9):1573-7; See also Daniels, N., *Just Health: Meeting Health Needs Fairly*, Cambridge University Press, 2008. (Editor's note)

# ACTIVITIES

- **The Equal Rights Trust Advocacy**
- **Update on Current ERT Projects**
- **ERT Work Itinerary: July-December 2010**



## The Equal Rights Trust Advocacy

*In the period since the publication of ERR Volume 5 (August 2010), ERT has been continuing with its work to expose patterns of discrimination globally and to combat inequality and discrimination both at the national and international level. Below is a brief summary of some of the most important ERT advocacy actions.*

### **ERT Launches *Unravelling Anomaly: Detention, Discrimination and the Protection Needs of Stateless Persons***

On 19 July 2010, ERT launched its report *Unravelling Anomaly: Detention, Discrimination and the Protection Needs of Stateless Persons*.<sup>1</sup> The report, which is the result of two years of research, reflection and debate, is ERT's contribution to a growing body of expertise on statelessness. Stateless persons are those who have no nationality, or whose nationality is ineffective. The report approaches the subject through the prism of detention - a crucial issue which offers unique insight into the broader challenge of statelessness.

The report finds that inequality and discrimination lie at the heart of the statelessness problem, as does the eternal tug-of-war between universal human rights and national sovereignty. It also finds that many persons who are held in long term immigration detention "awaiting removal" are in reality stateless, and therefore cannot be removed.

The report argues that statelessness should primarily be seen as a human rights issue, that the UNHCR and human rights treaty bodies should work in partnership to address the challenge, that all countries should

implement statelessness determination procedures and that authoritative guidelines should be developed to regulate the detention of stateless persons.

### **ERT Challenges French Authorities over Illegal Deportation of Roma Immigrants**

On 9 September 2010, ERT called on the government of France to adhere to a European Parliament Resolution and immediately halt a process of "voluntary deportation" of Roma immigrants residing in the country. ERT - also concerned by the news that the Italian authorities too had resumed dismantling Roma camps - called on the European Commission to adopt a Roma strategy which would ensure equal rights for the Roma in a manner which respects them as European citizens.

On 19 August 2010, the French authorities commenced a wave of deportations and within two weeks, approximately 1000 Roma had been deported and 128 Roma camps dismantled. ERT's statement condemned this discriminatory action by the French authorities which is in clear contravention of France's obligations under international and European law.

The statement highlighted a number of ways in which France's actions breached its obligations under International law.

- **Racial Discrimination** - The statement cited Article 18 of the Treaty on the Functioning of the European Union which enshrines the right to non-discrimination on grounds of nationality and Directive 2004/38/EC (Freedom of Movement

Directive)<sup>2</sup> which protects the freedom of movement and the right of migrant European Union citizens to reside in other EU member states. ERT argued that a law or policy which singles out one ethnic group within a European nationality for less favourable treatment – in this case, citizens of Romania and Bulgaria of Romani ethnic origin residing in France – is strongly prohibited and constitutes a clear case of race discrimination in violation of Articles 2(1) and 26 of the International Covenant on Civil and Political Rights, Article 2(1) of the International Convention on the Elimination of all forms of Racial Discrimination, Article 19 of the Treaty on the Functioning of the European Union and Directive 2000/43/EC4 (Race Equality Directive)<sup>3</sup>.

- **Collective Expulsion** – ERT argued that the actions of the French authorities violated the legal prohibition on collective expulsion under Article 4 of Protocol 4 to the European Convention on Human Rights. This provision has been interpreted by the European Court of Human Rights as “any measure compelling aliens, as a group, to leave a country, except where such a measure is taken on the basis of a reasonable and objective examination of the particular case of each individual alien of the group” (*Conka v. Belgium*, Application no. 51564/99, Para 59). Consequently, collective expulsions are prohibited under European law, including in cases where such measures are targeted solely against those who have overstayed the three month residency period allowed under the Freedom of Movement Directive and have failed to register with local authorities.

- **Alleged “Voluntary” Nature of Deportations** - ERT also questioned the “voluntary” nature of the deportations. ERT argued that a cash incentive of 300 Euro for each adult and 100 Euro for each child deported

“voluntarily” did not mask instances of rough policing, destruction of Roma homes and the confiscation of identity papers by those managing the deportation process and that such treatment cast severe doubt upon the “voluntary” nature of the deportations.

ERT’s statement expressed concern that the French deportations were merely one extreme manifestation of a wider xenophobic and discriminatory trend in French policy. The deportations followed a proposal made by President Nicolas Sarkozy on 30 July 2010 to strip “French citizens of foreign origin” of their nationality as punishment for violent crimes committed against law enforcement officers.<sup>4</sup> If passed into law, this proposal would violate Article 1 of the French Constitution as well as France’s obligations under European and international law, and may also contravene France’s treaty obligation to prevent statelessness.

#### **ERT Urges India to Reform Visa Policy which Discriminates on Grounds of Race**

On 14 September 2010, ERT wrote to the Prime Minister of India and the Indian External Affairs Minister to urge a change to the country’s visa and immigration policy, which discriminates against UK citizens of Pakistani origin. ERT’s letter referred to guidance on application processing time provided on the Indian High Commission’s visa application website for the United Kingdom. The guidance indicated that processing time for UK citizens of Pakistani origin was a minimum of 7-8 weeks, compared to a suggested minimum processing time of 5-7 days for all other UK citizens. This policy has affected a number of UK nationals, including students.

ERT research indicates that in addition to discriminating against UK citizens of Pakistani ethnic origin, the practice of imposing

different processing times on former nationals of Pakistan and a number of other countries is evident in Indian Embassies and High Commissions elsewhere. In particular, in Australia “former nationals” of Pakistan as well as Afghanistan, China, North Korea, Iran or Sri Lanka are subjected to longer waiting times while their application is processed.

ERT argued that these practices constitute racial discrimination against the affected group. The letter cited India’s obligations under the International Convention on the Elimination of All Forms of Racial Discrimination and the Covenants on Civil and Political and Economic, Social and Cultural Rights and draws attention to the recommendations of the Committee on the Elimination of Racial Discrimination in its General Comment 30 related to non-citizens, as well as to relevant case law.

### **Leading Experts Discuss ERT's Report *Unravelling Anomaly***

On 29 September 2010, ERT and the International Commission of Jurists co-hosted a side-event to the 15th Session of the UN Human Rights Council on Statelessness, Discrimination and Human Rights, which was informed by the findings of *Unravelling Anomaly: Detention, Discrimination and the Protection Needs of Stateless Persons*. Speakers included Volker Türk, Director of International Protection at the UNHCR; Jan Borgen, Deputy Secretary General of the International Commission of Jurists, and Tamas Molnar, Legal Advisor at the Ministry of the Interior of Hungary, who played a key role in developing that country’s statelessness determination procedure.

Amal de Chickera, Head of Statelessness and Nationality Projects for ERT, spoke of the four fundamental challenges – legal, po-

litical, institutional and equality – which face the human rights community in addressing the statelessness problem. He said that the legal challenge arises from the difficulties in promoting a right to a nationality for all people, while also ensuring that lack of effective nationality does not result in other human rights abuses. This reflects the tension between balancing interests of national sovereignty with the universality of human rights. At the national level, De Chickera said, the difficulties for stateless people in coming together and identifying visible spokespersons to raise their plight presented a major challenge in raising awareness of the discrimination and ill-treatment they face. At an institutional level, challenges arise because though statelessness falls within the mandate of many international human rights and humanitarian bodies, to date many of these institutions have failed to see the impact of statelessness on their particular area of focus. Turning to equality, De Chickera said that stateless people face inequalities and discrimination both within their countries of residence and as migrants, and that further, within the stateless community the *de facto* stateless (those with ineffective nationality) do not receive the same level of protection as *de jure* stateless persons, creating a further layer of inequality.

### **ERT Contributes to OSCE Review Conference on Tolerance and Non-discrimination**

On 8 October 2010, Dr Dimitrina Petrova, Executive Director of ERT delivered the introductory speech at the session on Intolerance against Migrants at the Organisation of Security and Cooperation in Europe (OSCE) Review Conference in Warsaw. ERT also submitted two written statements to the Review Conference: on tolerance and non-discrimination and on problems pertaining to statelessness.

**Intolerance against Migrants:** Dr Petrova presented an overview of issues of hate crime against migrants and intolerant anti-immigration discourses in the OSCE area from the perspective of equality and human rights. She further set out the various ways in which migrant rights have been restricted recently at all stages of the migration cycle, including in access to the destination country, admission processes, integration into the host society, and removal procedures. Dr Petrova also highlighted the situation of a number of migrant groups which are particularly vulnerable to discrimination, including Roma, stateless persons, children, and persons with mental health problems. Finally, she made recommendations to OSCE Participating states related to combating discrimination and intolerance against migrants.

**Tolerance and Non-discrimination Legislation:** ERT's written submission called on participating states to address issues of intolerance and discrimination by ensuring the full implementation of the right to equality in domestic legislation and ensuring that all essential elements of equality law are enshrined in national law. The submission focused on some of the basic elements of national equality law, relying on the principles contained in international human rights law, the authoritative interpretations of UN treaty bodies and the Declaration of Principles on Equality.<sup>5</sup>

**Problems Pertaining to Statelessness:** ERT's submission sought to highlight five particular problems of statelessness and urged OSCE Participating states to come together to find a common and sustainable solution to statelessness. The statement discussed: (i) present inequalities between the treatment of *de jure* and *de facto* stateless persons; (ii) the failure of the majority of the OSCE participating states to implement statelessness

determination procedures; (iii) the failure of immigration detention regimes to recognise and respond to the specific challenge posed by statelessness, and to ensure that immigration detention practices and policies do not discriminate against stateless persons; (iv) the failure of security detention regimes to recognise the impact that security detention may have in creating and exacerbating statelessness; and (v) specific challenges which emerge from protracted cases of statelessness, focusing on the Latvian case.

### **ERT Submits Shadow Report to the Universal Periodic Review for Sierra Leone**

On 1 November 2010, ERT submitted a shadow report to the Universal Periodic Review of Sierra Leone. In the submission, ERT highlighted some of the most significant challenges and problems facing the government of Sierra Leone in fulfilling its obligations to promote equality and combat discrimination.

The submission recommended that the government: (i) undertake a comprehensive review of domestic legislation to identify discriminatory laws and take immediate steps to amend or repeal such laws to ensure compliance with its international obligations; and (ii) take steps to develop and adopt comprehensive anti-discrimination legislation and policies providing protection from discrimination on all relevant grounds, in all areas of life governed by law, and making provision for the establishment of a national institution to ensure effective implementation and enforcement of the law.

### **ERT Recognises Human Rights Defenders Who Are Fighting Discrimination**

On 10 December 2010, International Human Rights Day, ERT recognised human rights

defenders who act to end discrimination by highlighting the work of three remarkable individuals with whom it works, who fight against discrimination despite the constant threat to their security.

**Asha el Karib** is the Executive Director of the Sudanese Organisation for Research and Development (SORD), an organisation established in 2007 by a group of Sudanese activists to build the capacity of Sudanese civil society organisations (CSOs). In recent years, repeated crackdowns on human rights defenders have had a crippling effect on the ability of civil society to organise themselves and to monitor human rights violations in Sudan. In 2009, in the immediate aftermath of a decision by the Prosecutor of The International Criminal Court (ICC) to issue an international arrest warrant against Sudanese President Omar Al Bashir, three national human rights organisations were closed down. Despite the difficulties facing civil society organisations in the country, SORD continues to operate in Sudan, challenging the government through advocacy for reform of discriminatory family laws and leading an awareness campaign on voter registration in advance of the referendum on independence for South Sudan in 2011.

**David Kuria**, the Chairman of the Gay and Lesbian Coalition of Kenya (GALCK), is a human rights activist fighting against the discrimination and ill-treatment of lesbian, gay, bisexual, transsexual and intersex persons. GALCK – established in 2006 as an umbrella body for organisations working to protect and promote the rights of LGBTI persons – provides capacity-building functions and coordinates awareness raising and advocacy activities. As the most prominent voice of the LGBTI community in Kenya – where male homosexual conduct is illegal and widespread discrimination against sexual minorities is

the norm – David Kuria and GALCK’s other staff face a range of personal difficulties and remain at risk of their organisation being closed down or their activities restricted by the government.

**Wan Yan Hai** - Wan Yan Hai is the founder and former director of the Beijing Aizhixing Institute, the first organisation working on issues of AIDS and HIV in China, which was founded in 1994. In the last few years, Aizhixing has regularly experienced government interference, including “investigations” by the local Taxation Bureau and the interruption of foreign donations when its bank refused to receive them on their behalf. In recent years, Wan has routinely faced denials of his rights and freedoms, censorship in the press, interruption during speeches, arbitrary detention and constant police monitoring outside his family home. Under increasing pressure from the Chinese authorities, Wan left China in April 2010.

#### **ERT Submits Parallel Report on Belarus to the 48th Session of the Committee on the Elimination of Discrimination against Women (CEDAW)**

On 4 January 2010, ERT submitted a parallel report on Belarus to the 48<sup>th</sup> session of CEDAW. The report assessed the adequacy and effectiveness of legal provisions designed to protect women in Belarus from discrimination in light of Belarus’ obligations under the Convention on the Elimination of All Forms of Discrimination Against Women (the Convention). ERT expressed concern about the inadequacy of the Belarus government’s legislative response to discrimination faced by women in a number of situations.

ERT submitted that anti-discrimination legislation in Belarus is inadequate in addressing the discrimination and disadvantages

faced by women. Despite significant positive developments in the law, legislative protections are still weak and inconsistent. In some fields the discriminatory application of laws is not effectively prohibited. There is no specific anti-discrimination law providing legal definitions of key concepts, general standards of protection or effective remedies and sanctions.

In its submission, ERT urged CEDAW to recommend that Belarus adopts comprehensive anti-discrimination legislation which prohibits, *inter alia*, all forms of gender-based discrimination and which: a) includes a comprehensive legal definition of discrimination; b) covers direct and indirect discrimination, multiple discrimination, discrimination by association or perception, segregation and harassment; c) creates protection against victimisation; and d) provides a basis for applying temporary special measures.

In addition, ERT also urged CEDAW to: (i) Recommend that the Belarus Government takes steps, including through well-resourced judicial training, to capacitate and improve understanding by the judiciary and other stakeholders of the concept of discrimination and the legal remedies that should be available to victims of discrimination; (ii) Recommend that the Belarus Government implements policy and resource mechanisms to ensure the equal engagement of women in all areas of political and public life, and adopts measures to ensure the equal participation of women at the highest levels of government; (iii) Recommend policy responses designed to reduce the gender pay gap and to enforce the principle of equal remuneration for work of equal value; (iv) Recommend that Belarus ratify the International Labour Organisation Convention concerning Equal Opportunities and Equal Treatment for Men and Women Workers: Workers with Family Responsibili-

ties (ILO Convention 156); (v) Recommend that the Belarus Government adopts measures to overcome the differences in pension entitlement between men and women; and to (vi) Recommend that the Belarus Government takes immediate legislative action to protect women from domestic, sexual and gender-based violence.

#### **ERT Submits Parallel Report on Kenya to the 48th Session of the Committee on the Elimination of Discrimination against Women (CEDAW)**

On 4 January 2010, ERT submitted a parallel report on Kenya to the 48<sup>th</sup> session of CEDAW. The report assessed the adequacy and effectiveness of legal provisions designed to protect women in Kenya from discrimination in the light of Kenya's obligations under the Convention. In so doing, it commented directly on the report of the Kenya Government to CEDAW and also used ERT's own research and evidence to raise issues of concern which were not addressed in the government's report.

ERT submitted that despite significant positive developments in the law – particularly as a result of the adoption of a new Constitution – anti-discrimination law in Kenya is inadequate in providing redress to women experiencing discrimination. In some fields, discriminatory laws remain in place, while the discriminatory application of other laws is not effectively prohibited. In a number of significant areas, including healthcare, education and criminal law, legislation does not prohibit discrimination or place a duty on public sector bodies to promote greater equality. There is no specific anti-discrimination law providing definitions of key concepts, general standards of protection or effective remedies and sanctions.

ERT urged CEDAW to recommend that Kenya adopts comprehensive anti-discrimination legislation which: a) covers direct and indirect discrimination, multiple discrimination, discrimination by association or perception, segregation, and harassment, and also outlaws victimisation; b) includes sexual orientation, gender identity and genetic inheritance as specified grounds of discrimination in addition to those specified in the Constitution and incorporates a test for the admission of new grounds in cases judged to be analogous to those listed; and c) provides protection from discrimination in all areas of life including education. In addition, ERT also substantiated nine further recommendations to CEDAW, including: (i) Recommend that the Kenya Government extends its much wel-

comed National Legal Aid Programme pilot scheme to cover anti-discrimination law and also extends the Programme's geographical scope; (ii) Recommend that the Kenya Government brings forward legislation which establishes the mandate, functions and powers of the Kenya National Human Rights and Equality Commission (KNHREC) and sets out the principles and content of comprehensive anti-discrimination law; (iii) Recommend the amendment of the Kenyan Employment Act to remove section 3(5) which excludes the country's Export Processing Zones from the scope of the Act, along with the adoption of comprehensive anti-discrimination law extending protection from discrimination in employment to cover those working in the Export Processing Zones.

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<sup>1</sup> The Equal Rights Trust, *Unravelling Anomaly: Detention, Discrimination and the Protection of Stateless Persons*, July 2010, available at: <http://www.equalrightstrust.org/view-subdocument/index.htm?id=748>.

<sup>2</sup> European Parliament and Council Directive 2004/38/EC of 29 April 2004.

<sup>3</sup> Council Directive 2000/43/EC of 29 June 2000 implementing the principle of equal treatment between persons irrespective of racial or ethnic origin.

<sup>4</sup> "Sarkozy crackdown on foreign-born criminals", *BBC News*, 30 July 2010, available at: <http://www.bbc.co.uk/news/world-europe-10820457>.

<sup>5</sup> The Equal Rights Trust, *Declaration of Principles on Equality*, October 2008, available at: <http://www.equalrightstrust.org/endorse/index.htm>.

# Protecting the Human Rights of Stateless Persons

Event Report, Geneva, 29 September 2010

Amal De Chickera and Jim Fitzgerald<sup>1</sup>

On 29 September 2010, The Equal Rights Trust (ERT) and the International Commission of Jurists (ICJ) co-hosted a side event to the 15<sup>th</sup> Session of the Human Rights Council on Statelessness, Discrimination and Human Rights. The event, which was held at the Palais des Nations, was chaired by ERT's Executive Director, Dimitrina Petrova. The speakers at the event were: (1) Volker Türk (Director of International Protection, United Nations High Commissioner for Refugees (UNHCR)); (2) Jan Borgen (Deputy Secretary General, International Commission of Jurists (ICJ)); (3) Tamás Molnár (Senior Legal Advisor, Ministry of Interior of the Republic of Hungary); and (4) Amal De Chickera (ERT's Head of Statelessness and Nationality projects), ERT's Advocacy and Communications Officer, Jim Fitzgerald, was the event rapporteur.

The discussion at this event was informed by the findings of ERT's recent report, *Unravelling Anomaly*.<sup>2</sup> The event began with the screening of a short video produced by ERT and entitled *No Place To Go*, in which two stateless people based in the UK shared their views and experiences with ERT.

**Volker Türk** spoke of the UNHCR mandate and perspective on statelessness, and stressed the importance of getting more organisations to prioritise the issue and build-

ing momentum in this regard. The key points which he made are as follows:

(1) It is very good to have a dialogue on statelessness from a human rights perspective. *Unravelling Anomaly* puts forward many interesting and challenging ideas which need to be explored and addressed.

(2) Of the estimated 12 million stateless people in the world, only 6 million are currently identified and accounted for in country-level statistics. Identification of stateless people is a complex issue and one which is often viewed as a political issue by states.

(3) There are two specific instruments governing statelessness – the 1954 Convention Relating to the Status of Stateless Persons (the 1954 Convention) and the 1961 Convention on the Reduction of Statelessness. However, there has been a low level of ratification of these Conventions. In addition, there are international human rights law and regional legal instruments – in particular in the Council of Europe – and other international legal instruments on nationality issues. However, national and international standards in this area are not consolidated and gaps do exist.

(4) It is not sufficiently widely known that UNHCR has a statelessness mandate. Indeed,



Photo credit: Massimo Frigo

From left: Tamás Molnár, Volker Türk, Dimitrina Petrova, Jan Borgen and Amal De Chickera at side event on statelessness, Geneva, 29 September 2010

the issue of statelessness is itself not widely publicised or well-known. However, UNHCR is increasing its work on behalf of stateless people around the world and is encouraged to see the rise in the attention paid to the issue.

(5) The dual anniversaries of the 1961 Convention on the Reduction of Statelessness and the 1951 Convention relating to the Status of Refugees provide an opportunity for advocacy on the question of statelessness, including on accession to the Conventions, reform of nationality laws and progress to reduce statelessness. UNHCR will be conducting many activities around this anniversary.

Volker Türk concluded his talk by calling for more civil society actors to get involved in work on statelessness, and also calling for more states to take action on statelessness. He commended the Government of Hungary on progressive steps taken, including accession to both statelessness conventions and the implementation of its statelessness determination procedure.

**Amal De Chickera** gave a brief background of ERTs work on statelessness before drawing attention to the (i) legal; (ii) political; (iii) institutional; and (iv) equality challenges which face the human rights community when addressing the statelessness problem.

The **legal challenge** pertaining to statelessness is the challenge of promoting the right of every individual human being to have a nationality, while ensuring that the lack of a nationality does not have a negative impact on the enjoyment of other human rights. The tension between national sovereignty and universal human rights goes to the heart of this challenge.

The 1954 Convention is an important document because it introduced an obligation to recognise statelessness, and to provide documentation to stateless people. But it has its limitations. Primarily, being a pre-human rights document, the Convention falls short of obligating states to promote and protect the human rights of stateless persons. Thus, it is ERT's view that while civil society ac-

tors must continue to lobby for ratification of the 1954 Convention, the Convention must be complemented by international human rights norms. Furthermore, regardless of whether or not states have ratified the 1954 Convention, they must fulfil their human rights obligations in respect to everyone (including stateless persons) within their jurisdiction. Implicit to the 1954 Convention is the necessity for states to identify stateless persons within their territories. Consequently, it is essential that all states have in place fair procedures for the determination of statelessness.

On the subject of detention – when a stateless person is detained in an immigration context, removal becomes very difficult. Therefore, in the absence of maximum time limits and strong protections, stateless persons can experience indefinite detention. International human rights standards including those pertaining to arbitrary detention, cruel, inhuman and degrading treatment, proportionality, necessity, and the right of review must be applied in the context of the detention of stateless persons as well. The more one examines the situation of stateless persons – particularly in detention – the more it becomes apparent that many legal standards we take for granted are ignored.

The stateless are **politically** voiceless. They do not form a political constituency, and therefore they cannot enter into the political discourse. In fact, the political discourse in many countries is alarmingly turning anti-immigrant, leaving the stateless in an even more vulnerable position. The human rights community must find a way to bring the issue of statelessness to the forefront of politics. This is a massive challenge, to which there are no easy answers.

Amal De Chickera then analysed the **institutional challenge** related to statelessness. Statelessness is a human rights problem. It is also an immigration and refugee problem. It falls squarely within the mandates of human rights, refugee and immigration organisations, but very few have prioritised the issue. Neither the human rights world, nor the refugee world has done enough. At an institutional level, more organisations need to prioritise the issue. They need to be aware of the implications of statelessness on their area of expertise – be it detention, women's rights, child rights or asylum services. It is also important to enhance cooperation amongst organisations that work on the issue. We need to find new ways of working together, sharing our expertise and collectively moving forward.

As to the **equality challenge**, it has three elements:

*i) Discrimination affecting the stateless in their own country*, both in respect of citizenship rights and in other areas. The situation faced by the Rohingya in Burma is the most striking example in this regard.

*ii) Discrimination affecting stateless migrants*, many of whom are in the developed world, who often face unfair restrictions on the right to work and access to social welfare, and are arbitrarily detained pending removal.

*iii) Inequalities within the treatment of statelessness*. These inequalities arise as a result of the distinction which is made between *de jure* stateless persons (those with no legal nationality) and *de facto* stateless persons (those with a nationality which is completely ineffective). The 1954 Convention only obligates protection of the *de jure* stateless, thus creating a hierarchy within the stateless

community and marginalising the *de facto* stateless.

We are left with the question: how to address this hierarchy? There are a number of possible approaches:

- a. Expand the definition of *de jure* statelessness to include persons who have traditionally been categorised as *de facto* stateless.
- b. Lobby governments to provide equal protection to the *de facto* stateless as recommended in the final acts to the Statelessness Conventions.
- c. Approach the problem from a protection perspective, collapse the distinction between *de jure* and *de facto* statelessness and equally protect all persons who have protection needs arising from their ineffective nationality.

This third approach is ERTs preferred approach to the problem, but it is very much a long term goal. In the short term, maximum protection for the stateless must be pursued through the first two approaches.

**Tamás Molnár** has played a key role in developing Hungary's statelessness determination procedure. He spoke about the most important provisions of the procedure. In 2007 the re-drafting of Hungarian immigration law and two other instruments required the development of a new statelessness determination procedure. The three legal instruments were as follows: (i) **Act No. II of 2007** on the entry and stay of third-country nationals, chapter VIII, Articles 76-86; (ii) **Government Decree No. 114/2007**, Articles 159-169 (more detailed implementing rules); and (iii) **Ministerial Decree No. 28/2007**.

Pursuant to the Act and the two decrees, a new procedure was developed, which has been applicable since 1 July 2007. The procedure is only open to stateless persons who are **legally staying** in the country. The procedure is by **application** (orally or in writing) and is free of charge, including at the judicial phase. Throughout the process, applicants are provided with free legal assistance and access to an interpreter. At the heart of the procedure is the realisation by the drafters that establishing that a person has no nationality in relation to all states is impractical given the evidentiary challenges. As such, the requirement is that the applicant shall **prove** or **substantiate** that he/she is stateless in relation to "countries of interest", which are:

- a) State of the place of birth;
- b) State of the previous place of residence/stay; and
- c) State of nationality of the family members.

Regional Directorates and the UNHCR are required to provide administrative assistance in support of **evidence collection**. Less formality is required in respect of documentation, in acknowledgement of the difficulties of securing relevant documents. The authority itself also collects information on citizenship laws, via Hungarian diplomatic missions, UNHCR, etc. Thus, there is a **shared burden of proof**.

**Decisions** are required to be made within 45 working days. In case of **recognition**, a residence permit for humanitarian purpose (1 year renewable each year) and identity documentation or a bilingual travel document (1 year + 6 months, costing 18 Euros) will be issued. In case of **refusal**, a judicial

review application can be made to the Metropolitan Court in Budapest which has exclusive competence in such cases. A personal hearing will follow, after which a decision will be made within 90 days which may alter the administrative decision. The UNHCR can take part in the proceedings, in any phase. It may: (i) attend the hearings; (ii) provide administrative assistance; (iii) look into the files and make copies; and (iv) receive copies of the administrative and judicial decisions.

**Jan Borgen** drew some conclusions from the previous presentations and spoke of the challenge for everyone to raise awareness of the issue of statelessness. He pointed out that Hungary is an exception in terms of its statelessness determination procedure. Few other countries even recognise the problem. Therefore, there is a lot which needs to be done to better protect stateless persons.

The discussion on how to contend with the challenges of statelessness should continue. Mr Borgen said that statelessness is an old problem, but the ERT report draws attention to the human rights element and casts it in a new light: statelessness is a human rights problem, not just a humanitarian problem.

We should ask how best to build a coalition to push for greater protection of stateless people. In this regard, human rights organisations must do more. The UNHCR should explore what more it could do on behalf of the stateless, particularly in the context of lobbying governments to accede to the statelessness conventions.

The Universal Periodic Review (UPR) provides an avenue through which countries which discriminate against and abuse the human rights of stateless persons can be held accountable. Civil society must use the UPR to raise the statelessness issue. Treaty bodies have been slow in recognising the statelessness problem. They should be challenged to prioritise the statelessness issue. Similarly, Special Rapporteurs who have a mandate relevant to statelessness have an important role to play.

Following the four panel presentations, participants engaged in a lively discussion. They raising some sensitive and difficult issues, including a number of questions related to specific groups of stateless persons, such as Bihari, Palestinian, Rohingya and Somali communities in different countries.

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<sup>1</sup> Amal De Chickera is Head of Statelessness and Nationality Projects at The Equal Rights Trust. Jim Fitzgerald is ERT's Advocacy and Communications Officer.

<sup>2</sup> The Equal Rights Trust, *Unravelling Anomaly: Detention, Discrimination and the Protection Needs of Stateless Persons*, 2010, available at: <http://www.equalrightstrust.org/view-subdocument/index.htm?id=748>

## Update on Current ERT Projects

### **Law Enforcement Discrimination and Death in Custody**

Launched in December 2007, this project has three main objectives: (i) to systematise the existing knowledge on the relationship between deaths in custody and discriminatory policy or conduct by law enforcement bodies; (ii) to enhance the global understanding of the nexus between deaths in custody and discrimination; and (iii) to develop and promote new advocacy tools to complement existing investigation techniques and standards. ERT works with researchers in Nigeria, India and the US to prepare materials for publication. The publications will fill a gap in existing writings and analysis on deaths in custody – raising questions on the links between deaths in custody, the identities of those who are dying and equality and discrimination issues, including discrimination in law enforcement. The research so far confirms the need to develop an analytical framework of discrimination and equality to assist law and policy makers, practitioners and campaigners in more effective prevention of deaths in custody. The research has revealed widespread patterns of human rights violations in several countries, including Nigeria and the USA, in which victims' vulnerability is a combination of race, socio-economic status, nationality and mental health status.

### **Stateless Persons in Detention**

This project started in May 2008 with the aim of strengthening the protection of stateless persons who are in any kind of detention or imprisonment due at least in part to their

being stateless, and to ensure they can exercise their right to be free from arbitrary detention without discrimination. UNHCR and others have expressed the view that stateless persons should not be detained only because they are stateless. If detention has no alternative, its maximum length should be specified, based on strict and narrowly defined criteria. However, this principle has not been translated into international or national legal standards or into practice. Progress is hampered by a lack of information on cases of detention, including prolonged and indefinite detention, of stateless persons. The project therefore pursues two interrelated objectives: (i) to document the detention, or other forms of physical restriction of stateless persons (*de jure* and *de facto*) around the world; (ii) to use this information to develop detailed legal analysis as a basis for international and national advocacy against the arbitrary detention of stateless people.

In July 2010, ERT published a comprehensive 260-page report entitled *Unravelling Anomaly: Detention, Discrimination and the Protection Needs of Stateless Persons*, which has provided a solid basis of its advocacy. Below is a summary of ERT's activities in this project since the publication of ERR Volume 5 (August 2010):

In late September 2010, ERT co-hosted a side event on "Protecting the Human Rights of Stateless Persons" during the 15th Session of the UN Human Rights Council in Geneva. Volker Türk, Director of International Protection at UNHCR and Tamás Molnár, Senior Legal Advisor at the Ministry of Interior of

Hungary were amongst the speakers at the event. In Geneva, ERT also had many meetings on the issue of statelessness with key human rights bodies including the UNHCR, the Office of the High Commissioner for Human Rights, the Committee Against Torture and the Committee on the Elimination of Racial Discrimination.

ERT has begun work in the USA in partnership with the Law Clinic of the American University of Washington School of Law. The Law Clinic with ERT's support will focus on engaging relevant US civil society organisations to prioritise statelessness in their work, providing training on statelessness and conducting advocacy to promote the O'Leahy draft Refugee Protection Bill which has a section on the identification and protection of stateless persons in the USA.

ERT's advocacy work in the UK is also ongoing. As a member of the Detention Forum, ERT was one of the co-signatories of a letter to Minister of Immigration Damien Green, calling for a review of the immigration detention system in the UK. In November 2010, ERT participated in the first Detention Forum Parliamentary Meeting at the House of Commons. This meeting was the first such organised by the Detention Forum to engage parliamentarians on the issue of immigration detention.

Project coordinator Amal de Chickera also spoke on the topic of "Statelessness and Immigration Detention" at the launch of the London Detainee Support Group report titled No Return, No Release, No Reason, in London. During this period, ERT has also had meetings with Asylum Aid and UNHCR UK, who are conducting a joint mapping project on statelessness in the UK, to discuss joint advocacy strategies.

In December 2010, Stefanie Grant represented ERT at the second UNHCR expert meeting on statelessness in Geneva. This meeting focussed on statelessness determination procedures and statelessness status.

### **Promoting Better Implementation of Equality and Non-discrimination Law in India**

This project started in May 2009 with support from the UK Foreign and Commonwealth Office and in partnership with the Delhi-based Human Rights Law Network (HRLN). Its purpose is to build the capacity of NGOs and



(from left) Lord Lester of Herne Hill QC (UK), Justice Kate O'Regan (South Africa) and Justice Altamis Kabir (India) at the Judicial Colloquium in Delhi, 30 January 2011.



Participants at the Judicial Colloquium in Delhi, 30 January 2011

Photo credits: Ajanta Kaza and The Bar Human Rights Committee

lawyers to implement equality and non-discrimination law and policy in India through the promotion of national, regional and international standards and best practice. ERT and HRLN have continued to work on a comprehensive handbook for paralegals and human rights lawyers on equality and non-discrimination law in India, presented from an international and comparative perspective, which will be published and distributed widely to lawyers, activists and members of the judiciary.

On 29-30 January 2011, ERT and HRLN hosted a Judicial Colloquium on Equality and Non-Discrimination Law at the Nehru Memorial Library and Museum in Delhi. The colloquium was attended by 35 Supreme Court and High Court judges from India, including the forthcoming Chief Justice of the Supreme Court A. Kabir J. The following international participants also attended: Joshua Castellino, Richard Hermer QC, Lord Lester of Herne Hill QC, Sapna Malik, Colm O’Cinneide, Kate O’Regan, Elizabeth Palm, and Lord Walker of Gestingthorpe. The colloquium covered a broad range of topics including (1) recent equality and non-discrimination decisions from the Indian High Courts; (2) the Equality

Act 2010 and recent jurisprudence from the UK courts; (3) discrimination on the grounds of gender and sexual orientation in South Africa; and (4) race discrimination in Europe. The participants agreed that the colloquium provided an invaluable opportunity to share ideas and experiences relating to the development of equality and non-discrimination law and judicial practice.

### **Empowering Disadvantaged Groups in Kenya through Combating Discrimination and Promoting Equality**

This project started in July 2009 with the aim of enabling Kenyan civil society organisations (CSOs) to be key players in building a national anti-discrimination regime. ERT is working with two Kenyan partner organisations, the Federation of Women Lawyers (FIDA-Kenya) and the Kenya Human Rights Commission, on a range of activities with the view to promoting the adoption of comprehensive anti-discrimination legislation, including the development of draft comprehensive anti-discrimination law and adoption of a joint civil society strategy for promoting equality.

Over the course of the summer 2010, ERT and its partner organisations developed a detailed “Legislative Map”, providing the basis for a draft Anti-discrimination Bill. In October 2010, a simplified “Statement of Principles for Equality Law” was produced, to be used as the basis for securing support from a broad range of civil society actors for the introduction of a new equality law. In the period 18-28 October, ERT’s expert consultant Barbara Cohen, together with a Kenyan consultant, Dr Sarah Kinyanjui, delivered three one-day workshops for community-based organisations (CBOs) in three regional hubs: Mombasa, Nakuru and Kisumu. Combining

Photo credit: Ajanta Kaza and The Bar Human Rights Committee



Participants at the Judicial Colloquium in Delhi, 30 January 2011

training with awareness-raising, the workshops successfully secured CBO support for the Statement of Principles and their agreement to participate in awareness-raising activities.

Since October, ERT and its partner organisations have been engaged in sustained advocacy to build support for the adoption of a new Anti-discrimination Bill. Efforts have centred on the opportunity provided by the passage of the new Constitution, which requires the government to introduce legislation to establish a new Kenya National Human Rights and Equality Commission. ERT and its partners have taken the approach of arguing that this legislation must contain the substantive provisions for equality law included in the Legislative Map, if the Commission's mandate in respect of equality is to be effective. To this end, the project partners have met with the Kenya Law Reform Commission and participated in a roundtable convened by the current Kenya National Commission on Human Rights (KNCHR), where the proposals were well received. Following this, a statement containing a detailed response to proposals put forward by KNCHR was prepared, and advocacy aimed at securing the support of key stakeholders for the adoption of the partners' approach and the inclusion of the Legislative Map provisions in the new legislation has continued.

The project's penultimate workshop was delivered in Nairobi in February 2011, and targeted practising lawyers. The workshop combined technical training with awareness-raising about the importance of comprehensive anti-discrimination law among practising lawyers. The workshop was delivered alongside a public debate on the need for legal reform in the field of equality, and engaged political stakeholders and media. Plans

are currently being developed for a project visibility event to be held in London in March 2010, which will promote the project's approach and achievements, and seek to build support among equality lawyers for further work on anti-discrimination law as a means to alleviate poverty in developing countries.

### **The Unified Perspective on Equality and LGBT Rights**

This project started in October 2009. Benefitting from the conceptual framework of the Declaration of Principles on Equality, the purpose of the project is to study the different existing and possible advocacy approaches to advancing LGBTI rights. As a part of this project, ERT is currently preparing a paper on LGBT rights and Islam and on advancing LGBT rights in countries with Islam, on the basis of the integrated framework on equality. In parallel, ERT is working on a paper looking at the role of equality and discrimination law in advancing LGBT rights in the countries of the Commonwealth.

### **Malaysia: Empowering Civil Society to Combat Discrimination through Collective Advocacy and Litigation**

This project started in March 2010 with support from the European Commission and other funders, in partnership with the Kuala Lumpur-based NGO Tenaganita. Its purpose is to strengthen the role of Malaysian civil society in implementing equality and anti-discrimination provisions enshrined in the Federal Constitution, in line with international law. The project has two specific strategic objectives. They are: (i) to increase the capacity of civil society organisations and other professionals to improve the implementation of the right to equality and non-discrimination under the Federal Constitution and build a



Photo credit: Tenganita

Dimitrina Petrova, Andrew Khoo and Prof. Shad Faruqi at the Equality Forum, Kuala Lumpur.

national anti-discrimination regime through litigation and public advocacy work; (ii) to create an institutional framework for civil society dialogue and strategic interventions on equality and discrimination issues through establishing an Equality Forum.

The project has established an Equality Forum with the aim of providing CSOs with a platform for discussing equality and engaging in dialogue a variety of stakeholders. As of January 2011, three meetings of the Equality Forum have taken place with over 30 civil society organisations represented at each meeting. The third meeting took place on

29th January 2011, and Dimitrina Petrova, ERT Executive Director, gave a lecture entitled “Principles on Equality and European Approaches to Racial Equality”. Race discrimination is a key issue in Malaysia, where the Malay segment of the population enjoys a number of constitutionally guaranteed controversial privileges in key areas of life.

A baseline study which has been completed under this project provides an overview of civil society capacity and training needs. On the basis of this study, ERT and Tenganita are currently working towards a training workshop on equality and non-discrimination

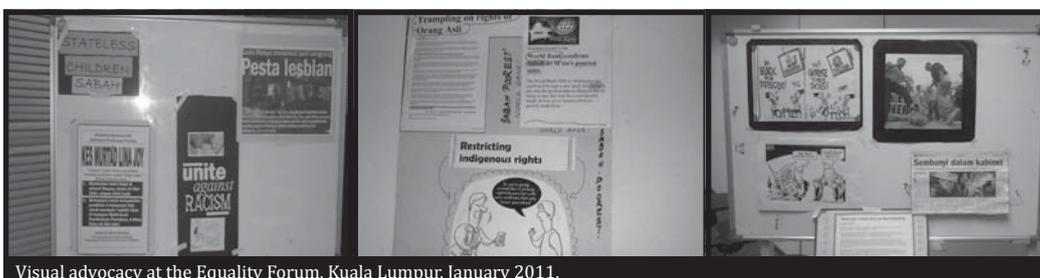


Photo credit: Tenganita

Visual advocacy at the Equality Forum, Kuala Lumpur, January 2011.



Photo credits: Tenaganita

Dimitrina Petrova, Executive Director of ERT



Irene Fernandez, Executive Director of Tenaganita

law which will take place in Kuala Lumpur in June 2011. Research is also underway with a view to publishing a report on equality and non-discrimination jurisprudence in Malaysia. The partners have also started to identify potential opportunities for intervention in strategic litigation cases involving the right to equality and non-discrimination in Malaysia.

### **Strengthening Legal Protection from and Raising Awareness of Discriminatory Ill-Treatment in the Republic of Moldova, including Transnistria**

This project started in March 2010 with support from the European Commission and other donors, in partnership with the Moldovan organisation Promo-LEX. The purpose of this 18-month project is to contribute to strengthening the legal protection from discriminatory ill-treatment and raising awareness of stakeholders on discriminatory ill-treatment. The project has nine specific objectives:

1. To develop key litigation partnerships with other national NGOs specialised in promoting respect for the rights of vulnerable groups;
2. To improve the application of the international human rights principles of prohibition of ill-treatment and non-discrimination in domestic litigation;
3. To provide legal representation to victims of discriminatory ill-treatment before domestic and international courts;
4. To provide assistance in litigation to local partners;
5. To undertake legal capacity building efforts to develop knowledge and understanding of the civil society actors of the nature and extent of the discriminatory ill-treatment;
6. To engage in dialogues with partners and key state institutions;
7. To contribute to The Equal Rights Review;
8. To produce and disseminate a report on discriminatory ill-treatment in the Republic of Moldova, including Transnistria.

The project aims to achieve these objectives through the following activities; (i) identifying and developing strategic litigation cases; (ii) publishing a report on discriminatory ill-treatment in the Republic of Moldova, including Transnistria; (iii) translating and disseminating *The Equal Rights Review* to Moldovan stakeholders; and (iv) undertaking advocacy action through intervening with letters of concern before law enforcement bodies and local authorities to support individuals requesting investigation of the alleged discriminatory ill-treatment.

In August 2010, ERT delivered training to approximately 30 human rights monitors and other human rights defenders in Chişinău, Moldova. The focus of the training was the intersection of discrimination and ill-treatment, covering the relevant law, jurisprudence and special issues, as well as conducting monitoring on discriminatory ill-treatment. In September 2010, ERT sent letters to Mr Valeriu Zubco (Prosecutor General), Ms Valentina Buliga (Minister of Labour, Social Protection and Family) and Mr Victor Catana (Minister of Interior) in relation to the domestic violence cases of three female clients of Promo-LEX. The letters requested full implementation of the recent legislative amendments concerning the prevention and combat of family violence so as to protect these victims of domestic violence from the harm they continue to suffer at the hands of the perpetrators.

In November 2010, project coordinator Libby Clarke represented ERT at the Launch Event of *The Equal Rights Review* in Romanian. The event took place in Chişinău and was well-attended by approximately 30 young lawyers and judges. Libby Clarke gave an introduction to *The Equal Rights Review*, explaining the philosophy behind the journal and its

key role within ERT's strategy. She then introduced *The Equal Rights Review* Volume Four, the first volume to be translated into Romanian, focusing on the importance of



(from left) Olga Manole (Promo-Lex), Libby Clarke (ERT) and Doina Straisteanu (Promo-Lex) at a public event in Chişinău, November 2010.

Photo credit: Promo-Lex

the unified perspective on equality for those promoting LGBT rights. Doina Ioana Straisteanu, the lawyer with responsibility for this project at Promo-LEX, then gave a lecture on domestic violence against women in Moldova, focusing particularly on the weak enforcement of the domestic legal provisions which should serve to prevent such discriminatory ill-treatment.



Dr Krassimir Kanev conducting interviewing skills training at ERT seminar, Chişinău, 3 August 2010.

Photo credit: Promo-Lex

As part of this project, ERT and Promo-LEX will produce a *Report on Discriminatory Ill-Treatment in Moldova*. The work on the substantive chapters for the report has been carried out by a team of monitors who have been appointed by Promo-LEX. A further aspect of this project involves ERT and Promo-LEX working together in support of selected strategic litigation cases. The Promo-LEX team has identified some potential cases which are currently being dealt with in the domestic courts, including (i) a domestic violence case involving a 71-year old woman; (ii) a trafficking case involving sexual violence against three minor females from Transnistria; (iii) a case involving the suicide of a homosexual man after he received threats from a police officer; and (iv) the death of a disabled man in a medical institution.

#### **Discrimination and Torture in Nigeria**

In August 2010, ERT commenced this project with support from the United Nations Voluntary Fund for Victims of Torture (UNVFVT) in order to provide practical and legal assistance to 20 victims of torture arising from discrimination in Nigeria. ERT and its partners in Nigeria have developed case briefs outlining the assistance needed by 20 victims of torture, and have subsequently procured the assistance set out in the briefs, which included filing legal claims for compensation in all cases, and providing medical, psychological or social assistance in some of the cases, as required by the circumstances.

#### **Promoting LGBTI Rights in Kenya in a Unified Equality Framework**

This project started in October 2010 with support from the Arcus Foundation. The purpose of the project is, during one planning and pilot year, to establish a working partnership

between The Equal Rights Trust (ERT), the Gay and Lesbian Coalition of Kenya (GALCK) and the Kenyan Human Rights Commission (KHRC) to develop strategies for improving the legal protection of LGBTI people in Kenya and promoting equality inclusive of sexual orientation and gender identity. The project is based on the assumption that advocacy of LGBTI rights can benefit from employing the unified framework of equality advocated by ERT and enshrined in the 2008 *Declaration of Principles on Equality*.

In late November and early December 2010, ERT Executive Director, Dimitrina Petrova, undertook a ten-day field mission in Kenya, visiting Nairobi, Mombasa and Turkana District. The mission provided the opportunity for ERT to collect testimony and undertake documentation of patterns of discrimination in Kenya, principally investigating discrimination against LGBTI persons as well as ethno-regional discrimination affecting those living in the remote and marginalised Turkana District in north-eastern Kenya. The field research will feed into the handbook on combating discrimination and the feasibility study which will be the outputs of the project.

#### **Embedding Equality under Kenya's New Constitution**

This project started in October 2010, in partnership with the Kenya Human Rights Commission. The project envisages the development of a detailed country report on discrimination in Kenya; delivery of training to judges, health and education professionals and certain categories of MPs; development of six strategic litigation cases on new elements of the law introduced by the new Constitution; and development and delivery of a public awareness "Your Rights" campaign

about the scope of the right to non-discrimination under the new Constitution.

In the period October – December 2010, substantial progress was made on the desk research and drafting phase of the country report on discrimination. In the project's next phase, an ERT consultant/staff member, together with a Kenyan consultant, will undertake a 10-day research visit to secure testimony to augment the report, in advance of its publication in the second quarter of 2011.

### **Empowering Civil Society in Sudan to Combat Discrimination**

This project started in October 2010 with support from the European Commission. It aims to develop civil society capacity to advocate for improved protection from discrimination through delivery of training, development of a country report on discrimination, and establishment of a civil society coalition to undertake advocacy. In so doing, the project aims to increase the space available for civil society advocacy on human rights issues, in a society where civil society freedoms have been severely restricted in recent years.

Given the difficult conditions in Sudan at the present time (including the referendum on independence for Southern Sudan which took place in January 2011), ERT and its partner organisation, the Sudanese Organisation for Research and Development (SORD), undertook a detailed planning and risk assessment exercise. The conclusions were that the project activities remained deliverable, but that specific advocacy priorities would need to be identified with great care in order to ensure their deliverability. The partners are currently carrying out a baseline study, which involves desk research on patterns of discrimination and inequality, a legal audit

and an assessment of the capacity and needs of civil society. The planning for three training workshops to be held in 2011 is also underway.

### **Guyana: Empowering Civil Society to Challenge Homophobic Laws and Discrimination against LGBTI Persons**

This project commenced in October 2010 with support from the European Commission. It focuses on building the capacity of civil society to challenge discrimination against LGBTI persons, by both increasing the technical skills and capacity of LGBTI organisations and by fostering improved cooperation between LGBTI organisations and other human rights NGOs. The project involves the delivery of training in human rights law and anti-discrimination law, the establishment of a civil society forum and the development of a country report.

ERT's project partners, the Society Against Sexual Orientation Discrimination (SASOD), spent the first six weeks of the project recruiting staff and hiring premises. In early December 2010, Jim Fitzgerald, ERT's project officer for this project, visited Georgetown, Guyana, for a three day planning visit. During the visit, the partners made plans for the completion of the Baseline study, discussed project implementation and agreed the format of the project training workshops and roundtable. In addition, Jim met with a wide range of civil society stakeholders and undertook research which will feed into the baseline study. Plans have been made for the delivery of workshops in April 2011 by Professor Michael O'Flaherty (University of Nottingham), a member of the UN Human Rights Committee, and Dimitrina Petrova, ERT Executive Director.

### **Indonesia: Empowering Civil Society to Use Non-discrimination Law to Combat Religious Discrimination and Promote Religious Freedom**

This project started in November 2010 with support from the European Commission. It focuses on building the capacity of civil society actors to tackle discrimination against religious minorities, and entails the development of a country report, establishment of a civil society forum and delivery of training. The project builds on the work of a number of civil society actors to challenge blasphemy laws which severely restrict the religious freedom of certain groups, by increasing their capacity to use anti-discrimination law in their advocacy and litigation.

In November, ERT undertook detailed planning discussions with the project partners, the Indonesian Legal Aid Institute (YLBHI) and the Institute for Policy Research and Advocacy (ELSAM). ERT produced guidelines for the completion of the project baseline study, which ELSAM is currently using as the basis for desk research on patterns of discrimination and inequality, while YLBHI is undertaking research on the capacity and needs of Indonesian civil society. In February 2011, ERT travelled to Indonesia for planning meetings with the partners and for meetings with other stakeholders, in preparation for seminars on equality and non-discrimination law in the coming months.

### **Developing Resources and Civil Society Capacities for Preventing Torture and Cruel, Inhuman and Degrading Treatment of Persons with Disabilities in India and Nigeria**

This project started in November 2010 with support from the European Commission and

the UN. It focuses on the widespread practice of torture and inhuman and degrading treatment of persons with disabilities in India and Nigeria. The project will run in parallel in both India, with Human Rights Law Network (HRLN) as partner, and Nigeria, with Legal Defence and Assistance Project (LEDAP). The project envisages the production of a Re-



ERT Legal Officer Libby Clarke (second from right) during a visit of partner NGO LEDAP, Lagos, 11 January 2011.

Photo credit: The Equal Rights Trust

source Pack on torture and inhuman and degrading treatment of persons with disabilities in each of India and Nigeria, two training workshops in each country, participation in litigation and an advocacy campaign focused on improving legislative protection for persons with disabilities against torture and inhuman and degrading treatment.

In January 2011, ERT Executive Director, Dimitrina Petrova, and project coordinator Libby Clarke visited Lagos, Nigeria, to hold planning meetings during which preparations for the first year were finalised. Libby Clarke held a similar meeting with HRLN in Delhi in late-January 2011. At present, baseline studies are being carried out in each country. The baseline studies will assess the current legal framework relating to the torture and inhuman and degrading treatment of persons with disabilities and civil society

capacity for identifying instances of such ill-treatment and for providing meaningful representation to the victims.

**Empowering Civil Society in Belarus to Combat Discrimination and Promote Equality**

This project started in December 2010 with support from the European Commission and other donors. A baseline study to underpin

work on this project is currently being produced. ERT Executive Director, Dimitrina Petrova travelled to Minsk in February 2011 to attend a planning meeting with ERT's informal partners, the Belarusian Helsinki Committee. The project envisages, inter alia, documentation of discrimination patterns, focusing on five vulnerable categories of persons: women, ethnic minorities, religious minorities, LGBT persons and persons with disability.

## ERT Work Itinerary: July – December 2010

**July 8-9, 2010:** Participated in expert workshop “Effective and Independent Structures for Promoting Equality”, organised by the Council of Europe Commissioner for Human Rights, in Strasbourg.

**July 13-14, 2010:** Hosted a two-day roundtable for Kenyan civil society, political and institutional stakeholders to discuss the development of a Legislative Map for a new comprehensive equality law, in Nairobi.

**July 19, 2010:** Published report entitled “Unravelling Anomaly: Detention, Discrimination and the Protection Needs of Stateless Persons”, 260 pp.

**August 2-5, 2010:** delivered training to approximately 30 human rights monitors and other human rights defenders in Moldova on the intersection of discrimination and ill-treatment, covering the relevant law, jurisprudence and special issues, in Chişinău.

**August 29-September 2:** held meetings with Fijian NGOs, academics, diplomats, political and religious leaders, and influential citizens to promote constitutional and legal reform and discuss action against discrimination, in Suva.

**September 1, 2010:** Delivered the Annual Public Lecture hosted by the Citizens’ Constitutional Forum and the University of the South Pacific, entitled “Recent Trends in the Development of Equality and Non-discrimination Law”, in Suva.

**September 15, 2010:** Hosted a meeting of legal NGOs to discuss legal approaches to development and tools for improving communication between legal NGOs and development organisations, in London.

**September 21, 2010:** Participated in Conference “Achieving Equality: Critical Reflections on the Role of Equality Bodies”, organised by the University of Leeds, and made a presentation on “Influencing Policy and Governmental Opinion: the Role of Equality Bodies”, in Leeds.

**September 27, 2010:** Spoke on the topic of “Statelessness and Immigration Detention” at launch of London Detainee Support Group report titled “No Return, No Release, No Reason”, in London.

**September 29, 2010:** Co-hosted a side event on statelessness at the 15<sup>th</sup> Session of the UN Human Rights Council, which featured an expert panel discussion on the human rights of stateless persons, informed by the findings of ERT’s report “Unravelling Anomaly”, in Geneva.

**October 4, 2010:** Hosted a meeting with the Sidreh Bedouin Women’s Organisation from Israel, and conducted interviews with Sidreh women, in London.

**October 6, 2010:** Presented a keynote address on “Intolerance against Migrants in the OSCE area” at the OSCE Review Conference, and submitted statements on “Tolerance and Non-discrimination” and “Problems Pertaining to Statelessness”, in Warsaw.

**October 12, 2010:** Met with the Chair of the Australian Human Rights Commission, to discuss issues related to equality legislation and statelessness, in London.

**October 13, 2010:** Gave interviews for a Canadian documentary on the situation of Roma in Europe and on contemporary forms of global racism, in London.

**October 18-28, 2010:** Delivered training on anti-discrimination law, advocacy and awareness-raising to staff from local community-based organisations (CBOs), in Mombasa, Nakuru and Kisumu, Kenya.

**November 2, 2010:** Participated in a public seminar attended by Moldovan lawyers and judges, which launched the Romanian translation of *The Equal Rights Review*, Volume 4, in Chişinău.

**November 2, 2010:** Provided input to the ECRI Draft Policy Recommendation No 13 on anti-Gypsyism and discrimination against Roma.

**November 8, 2010:** Participated in and supported the Detention Forum’s Parliamentary Meeting on Detention Reform, in London.

**November 19, 2010:** Participated as discussant and moderator in Workshop “Minority and Indigenous Rights”, organised by Institute of Commonwealth Studies and Brunel Law School, in London.

**November 27 – December 5, 2010:** Conducted field research in different places in Kenya on the human rights situation of LGBT persons, ethno-regional minorities and other groups vulnerable to discrimination, in the framework of a project “Strengthening LGBT rights through the unified framework on equality”, in Kenya.

**December 2, 2010:** Participated in Asylum Aid/UNHCR Expert Consultative Meeting on Mapping Statelessness in the UK, in London.

**December 6-7, 2010:** Participated in UNHCR Expert Meeting on Statelessness Determination Procedures and Statelessness Status, in Geneva.

**December 13-17, 2010:** Met with project partners and other civil society stakeholders to launch ERT’s new project “Empowering civil society in Guyana to challenge homophobic laws and discrimination against LGBTI persons”, in Georgetown.

**December 16-17, 2010:** Served as Expert in validation meeting of UN OHCHR “Technical Guidebook for the development of national action plans against racial discrimination”, in Geneva.

## Note to Contributors

The Equal Rights Trust invites original unpublished articles for the future issues of *The Equal Rights Review*. We welcome contributions on all aspects of equality law, policy or practice. We encourage articles that examine equality in respect to cross-cutting issues. We also encourage articles that examine equality law policy or practice from international, regional and national perspectives. Authors are particularly welcome to submit articles on the basis of their original current or past research in any discipline related to equality.

### Peer Review Process

Each article will be peer reviewed prior to being accepted for publication. We aim to carry out the peer review process and return comments to authors as quickly as possible.

### Further Information and Where to Submit

Articles must be submitted by email attachment in a Microsoft Word file to: [info@equalrightstrust.org](mailto:info@equalrightstrust.org)

For further information regarding submissions, please email: [nicola.simpson@equalrightstrust.org](mailto:nicola.simpson@equalrightstrust.org)

### Submission Guidelines

- Articles should be original, unpublished work.
- Articles must be written in United Kingdom English.
- Articles must contain footnote or endnote referencing.
- Articles should be between 5,000 and 10,000 words in length.
- Articles must adhere to the **ERT style guide, which is available at: <http://www.equalrightstrust.org/ertdocumentbank/ERR%20STYLE%20GUIDE.pdf>**





# The Equal Rights Trust

The Equal Rights Trust (ERT) is an independent international organisation whose purpose is to combat discrimination and promote equality as a fundamental human right and a basic principle of social justice.

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