

The Equal Rights Review

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

In this issue:

- Special: Equality of Persons with Disabilities
- Independent living vs institutionalisation
- Abortion in the Americas
- Testimony from a British man with cerebral palsy
- The anti-discrimination legal framework in Latvia
- Parental inequalities in the UK



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Equal Rights Irrespective of Disability

A few days ago, on a hot and humid late August morning, I was sitting in the breakfast hall of a cheap hotel in Sarajevo, sipping my third cup of instant coffee – the only type available in a place like this. I was trying to wake up for the challenging day ahead but my mind was still a cloud. The breakfast hall was empty, apart from the family at the table across from me – two boys of primary school age with their backs to me, and the parents facing in my direction. The excited voices of the boys mixed with the clutter of cutlery.

And something was wrong. Something had been wrong for some time, something that wouldn't come into focus. Then suddenly I saw it – the man's face, right in front of me, that I had been looking at for some time without seeing. The face was big, puffy, and dead. In the middle of all the noise and fuss at the table around him, the man sat perfectly still. There was no expression on his face. A child's body shifted in my line of vision to reveal part of the man's large body: one arm was missing below the elbow, with the elbow itself resting on the edge of the table. I leaned to the opposite side to check out the other hand but it wasn't there either. The second elbow, too, was resting on the edge of the table, forming the end of that limb. Then the woman put a huge piece of cake in the man's mouth and he chewed automatically. His vacant eyes, his motionless body gave the impression of an inanimate object, despite the moving jaws. He might as well be a piece of wood forgotten on the shelf of a carpen-

ter's shop one thousand years ago. Then the mother and the children went somewhere and he remained alone, waiting for them to come back, drowned in a deep stupor, either incapable of or unwilling to make the slightest movement on his own.

He looked around 40. Was he a war veteran? If that was the case, he had lived without hands for at least 17 years and fathered the children while handicapped, before he was overwhelmed by depression. Or had he lost his hands more recently, when the children were already born? And was this much worse, I wondered, recalling that Bosnian laws and policies officially privilege disabled persons who are war veterans over other disabled persons? But whatever had torn off his hands, what kind of support system had numbed him so cruelly, I wondered. What kind of health and social care arrangements had let him down so profoundly that he had become the very image of lifelessness?

Fully awake now, I thought about a different world that was lost to this Bosnian man. That other world was now preparing to celebrate the amazing abilities of the disabled, and with this – the spirit of dignity, independence and humanity in the Paralympic Games that would be opening in London in a couple of days. I thought about Theresia Degener, the fabulous member of the UN Committee on the Rights of Persons with Disabilities, a German professor without hands who has a full life and does every-

thing independently – eating, typing and carrying her luggage to a conference. Dear reader, if you do not know what I am talking about, please google her immediately and see one or two of these short videos, because few things can fill you with such immense joy and pride of being born human.

Disability is a natural part of the human experience, but two people having the same disability can live in different worlds. There is – there has always been – the dehumanising world of stigmatisation, care and dependency in which a person with a disability, even if surrounded by loved ones, is a lesser person. And there is – there should always be – the empowering world of independent living in which a disabled person is more accurately described as differently-abled, and participates equally in all areas of life, regardless of their disability. The UN Convention on the Rights of Persons with Disabilities represents the current global consensus that humanity must make a transition from the first world to the second. In this second world, persons with disabilities are equal in their dignity and their rights, and participate on an equal basis with others in all areas of economic, social, political, cultural and civil life.

This issue of *The Equal Rights Review* is focused on some of the key aspects of disability equality to which the UN Convention aspires. Three articles are devoted to the right to independent living, which is central to realising equality for disabled persons. Gerard Quinn and Suzanne Doyle analyse the obligations of the European Union in respect to disability rights at this critical stage, and state clearly what must be done to move from the medical model towards the much lauded “paradigm shift” on disability, particularly through the proper regulation of the EU’s structural funds. Camilla Parker

and Luke Clements argue that institutionalising persons with disabilities is a form of discrimination that deepens their disadvantage, and that there should be no excuse in allowing European Union funds or indeed any public funds to be used to perpetuate this form of discrimination. Georgette Mulhair brings in the research and experience of Lumos, the organisation she directs, and puts together the elements of an indictment of the whole practice of institutionalisation of children with disabilities. She shows how the linkages of disability, ethnicity and poverty have been weaving the patterns of disadvantage for children in Europe. The testimony provided by Joshua Hepple, a young British man living with cerebral palsy, provides a glimpse into the reality of growing up with disability in the UK, and the struggle for an independent life.

One of the most difficult outstanding issues in achieving equality for persons with disabilities is the issue of mental capacity. When it comes to autonomous decision-making and freedom to choose how to lead one’s life, the right to equality can easily be in ruins if the person has no legal capacity. Persons with mental health problems and intellectual disabilities are most at risk. Several pieces in this issue highlight the emerging trend from substituted legal capacity exercised through various forms of guardianship to supported legal capacity where the equality and autonomy of the person are the starting point. To be sure, this is not the realm of light choices. I personally am grateful not to be in the place of the judge in the recent UK case of E. summed up in the Special of this issue. This judge had to decide whether it would be legal to continue to force-feed E, a 32-year-old anorexic woman, overriding her stated will, on the basis that suffering from the mental illness of anorexia nervosa had deprived her of the ability to make decisions in her own best interest.

There are some excruciatingly difficult questions surrounding mental capacity. For example, is there a state of mind in which one can make a decision to die and which cannot be contested as being due to mental illness? The principles on which such issues should be approached are outlined in human rights law, but their operationalisation in national laws and policies is another matter.

In recognition that their mental capacity legislation is not yet in compliance with the requirements of the UN Convention on the Rights of Persons with Disabilities, and taking the challenge of introducing such legislation seriously, some states, including Finland, Ireland, the Netherlands and Norway, are yet to ratify the Convention. Many other states that have ratified the Convention, however, are far from meeting this challenge. Lawrence Mute analyses mental capacity law in Kenya and shows why it falls short of the standards enshrined in the Convention.

To build a world in which disabled persons would enjoy equal rights fully, technology

is an essential tool. The interview with Hiroshi Kawamura allows a quick look at cutting edge developments in this area, where companies such as the one of which he is CEO, are developing disability-friendly new information and communication technologies, as well as new instruments and tools to help overcome a disability. The Paralympic Games currently taking place are a triumph of technology as well as humanity. It is stunning to watch, for example, the athletes running on artificial legs. But as Kapka Panayotova of the Bulgarian Centre for Independent Living suggests, in the end culture is more important than technology. In order for the fascinating technologies that compete with science fiction to be an emancipating and empowering force, we need the attitudes that are inspired by certain humanistic values. Human rights are at the heart of such a culture of humanism. Without them, we would be helplessly looking at people who might as well be an embodiment of lifelessness, like pieces of wood forgotten on the shelves of the universe one thousand years ago.

Dimitrina Petrova

ARTICLES

"The issue of discrimination has not been very high on the agenda of policy makers in Latvia in recent years. Probably a more active stance of the EU institutions could help to activate debate at the domestic level - as it was the case in 2003-2004, before the EU accession of Latvia, when some progress in legislation and awareness was clearly observed."

Aleksejs Dimitrovs

Equality Law in Latvia: Current Trends and Challenges

Aleksejs Dimitrovs¹

This article covers recent developments in equality law and practice in Latvia. It comments on the latest trends and challenges in legislation, case law, administrative practice (in particular, the practice of the Ombudsman's Office) and public opinion, with the exception of those related to hate crimes. The time period covered is from 1 January 2010 till 1 July 2012 (unless indicated otherwise).

I. General Legal Framework

1) Constitution and Legislation

Article 91 of the Constitution of Latvia provides that all human beings in Latvia shall be equal before the law and the courts. Human rights shall be realised without discrimination of any kind.

The provision does not contain the list of grounds on which discrimination shall be prohibited. Nevertheless, as established in case-law and in the legal doctrine,² Article 91 covers at least the grounds mentioned in Article 21(1) of the Charter of Fundamental Rights of the European Union (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) alongside with other grounds initially suggested by the leg-

islator for the Constitution (membership of a political party, official capacity, other similar circumstances). For example, language is not explicitly mentioned as a prohibited ground for discrimination in the Constitution or law. Nevertheless, discrimination on the grounds of language is included in these "other circumstances" referred to in normative acts and the Constitutional Court has ruled that it is prohibited.³

According to case-law and the legal doctrine,⁴ the prohibition of discrimination in the Constitution may have a limited horizontal effect – in the absence of specific legal provisions in sectoral legislation. For example, in 2003 the court decreed that a particular black applicant should be compensated for an offence against his dignity, as a pre-election campaign advertisement incited negative attitudes towards all black people.⁵

The prohibition of discrimination in the Constitution is developed in other legislative acts. Under the Law on Free Development and Rights for Cultural Autonomy of National and Ethnic Groups, residents of the Republic of Latvia are guaranteed equal human rights according to international standards (section 1) regardless of their ethnic origin. Section 3 of the same law guarantees all permanent residents equal rights in the employment sphere.

Section 4(2) of the Law on Judicial Power states that a court shall adjudicate a trial irrespective of the origin, social and financial status, race or nationality, sex, education, language, attitude towards religion, type and nature of occupation, place of residence, or the political or other views of a person. Similar provisions are included in the Administrative Procedure Law (section 6) and the Criminal Procedure Law (section 8).

Section 7 of the Labour Law guarantees everyone equal rights to employment, to an equitable, safe work environment that is not harmful to health, and to fair payment for work; such rights are guaranteed without any direct or indirect discrimination in regard to race, skin colour, sex, age, disability, religious, political or other conviction, ethnic or social origin, material or family status, sexual orientation or other status. This principle also applies to the state civil service (section 2(4) of the State Civil Service Law).

Section 29 of the Labour Law prohibits direct and indirect discrimination (Paras 5 and 6) and also defines harassment as a form of discrimination (Para 7), and prohibits the instruction to discriminate (Para 4). If the discrimination ban is violated, the law guarantees financial compensation for pecuniary and moral damages, the sum of the compensation being defined by the court. Section 9 also prohibits victimisation – the creation of adverse consequences for someone as a reaction to his or her use of legal guarantees to obtain redress.

Section 3 of the Education Law stipulates that every resident shall be equally entitled to acquire education irrespective of their social or material status, race, ethnicity, sex, religious or political conviction, health, occupation or place of residence. A ban on discrimination is

also included in section 3(2) of the Children's Rights Protection Law.

The Law on Social Security (section 2(1)) prohibits direct or indirect discrimination in regard to race, ethnic origin, skin colour, sex, age, disability, health, religious, political or other conviction, national or social origin, or material, family or other status. It also prohibits harassment and the instruction to discriminate. Similar bans are mentioned in the Law on the Rights of Patients (section 3).

The Advertising Law prohibits advertising which expresses discrimination against a person on the grounds of race, skin colour, sex, age, religious, political or other convictions, national or social origin, material status or other circumstances (section 4, Para 2(1)).

The Consumers' Rights Protection Law (section 3(1)) prohibits direct or indirect discrimination on the grounds of sex, racial or ethnic origin. It also prohibits harassment and the instruction to discriminate. If the discrimination ban is violated, the law guarantees financial compensation for pecuniary and moral damages (the sum of the compensation is set by the court). The Law also prohibits victimisation – the creation of adverse consequences for a consumer due to the use of legal guarantees. Similar bans exist in the Law on the Prohibition of Discrimination Concerning Natural Persons Who Are Engaged in Business Activities and in the Support for Unemployed Persons and Persons Seeking Employment Law. Section 5(1) of the Law On Insurance Companies and Supervision Thereof prohibits discrimination on grounds of sex.

The legislation aimed at fighting against discrimination has been amended in recent

years due to the transposition of several EU Directives.⁶ But Latvia adopted only the minimum standards and rejected the idea of a more integrated approach, in particular the adoption of a framework law on discrimination⁷ which would also take into consideration the conventions of the Council of Europe and the UN.

2) Sanctions, Proof and Institutions

Apart from pecuniary sanctions, section 204(17) of the Administrative Violations Code stipulates a fine of between LVL 100 (EUR 143) and LVL 500 (EUR 715) for violating the discrimination law. The Criminal Law (section 149(1)) envisages fines for repeated (within one year) discrimination on the basis of racial or ethnic origin or other discrimination prohibited by law, but for the same deeds under aggravating circumstances (i.e. if it caused substantial damage, or is connected with violence, deception or threat, or is perpetrated by a group of persons or by civil servants, etc.) more serious punishment is envisaged – up to two years' imprisonment.

According to section 29(3) of the Labour Law, an employer shall bear the main burden of proof if there is alleged discrimination. The same principle can be found in the Consumer's Rights Protection Law and the Law on the Prohibition of Discrimination Concerning Natural Persons Who Are Engaged in Business Activities. The burden of proof in other civil cases rests with the plaintiff (section 93 of the Civil Procedure Law). The Administrative Procedure Law insists on impartial investigation (section 103); therefore the burden of proof does not lie with the applicant: the court decides which side has to prove certain facts and the court is itself entitled to search for evidence.

In accordance with section 11(2) of the Ombudsman Law, the Ombudsman's Office is responsible for fighting against discrimination. The Ombudsman has the right to file a civil lawsuit or administrative application to a court to protect the interests of an individual who has suffered from discrimination (section 13, Paras 9-10). In 2010 the Ombudsman's Office received 63 written complaints about discrimination,⁸ in 2011 – 72 such complaints.⁹

II. Sex

In the field of gender equality several problems have been mentioned in recent years in media, surveys and publications by official bodies. One group concerns direct discrimination – such as references to a particular gender in job postings¹⁰ or different night club entry fees. The former is prohibited by section 32(1) of the Labour Law; the latter – by section 3(1) of the Consumers' Rights Protection Law. The prohibition to enter a shop with a pram or a pushchair is mentioned by the Ombudsman as a case of indirect discrimination against women (as in Latvia they are more often on parental leave, compared with the men).¹¹

In Latvia members of decision-making bodies of enterprises are not normally covered by legal guarantees of the Labour Law, unless they have a valid labour contract. In turn, the Commercial Law does not contain a discrimination ban. In 2010 the European Court of Justice (ECJ) decided that EU law precludes Latvian legislation, which permits a member of a capital company's Board of Directors to be removed from that post without restriction, where the person concerned is a "pregnant worker" and the decision to remove her was taken essentially on account of her pregnancy. Even if the Board

Member concerned is not a “pregnant worker”, the fact remains that the removal, on account of pregnancy or essentially on account of pregnancy, of a member of a Board of Directors can affect only women and therefore constitutes direct discrimination on grounds of sex.¹² The Senate of the Supreme Court found, however, that the removal in the case was not essentially on account of pregnancy.¹³ Nevertheless, it might be feasible to amend laws which are considered to be *lex specialis* in relation to the Labour Law (such as the Commercial Law and the Law on Religious Organisations) in order to include an explicit discrimination ban.

In 2010 the Senate of the Supreme Court found that the provision of the Law on Unemployment Insurance contains indirect discrimination against women, since the Law did not take properly into account the situation of persons on maternity leave. As a result, the unemployed persons who had previously been on maternity leave received a lower unemployment benefit.¹⁴ The Law has since been amended.

Following the recent verdict of ECJ concerning the use of sex as a determining factor in the assessment of risk in the calculation of premiums and benefits for the purposes of insurance and related financial services,¹⁵ it is also necessary to amend the Law On Insurance Companies and Supervision Thereof before 21 December 2012. The government has already sent a corresponding draft law to the Parliament.¹⁶

III. Nationality

As of 1 January 2012, the population of Latvia was estimated to be 2,217,053, of whom 1,844,741 (83.2%) were Latvian citizens, 312,189 (14.1%) were “non-citizens” (now stateless former citizens of the USSR and

their descendants who already resided in Latvia in 1992), 173 were stateless persons, and the rest were foreign citizens.¹⁷

On 15 October 1991 the Latvian Parliament passed the Decision “On the Renewal of the Rights of the Citizens of the Republic of Latvia and on the Fundamental Principles of Naturalisation”, which was based on the concept of the pre-war citizenship continuity: only those persons who had been citizens of independent Latvia in 1940, and their descendants, had their citizenship restored. The legal status of people who were not recognised as citizens remained unclear until 1995, when the Law on the Status of Former USSR Citizens Who Do Not Have the Citizenship of Latvia or of Any Other State was adopted. The Law introduced a special legal status of “non-citizens”. It defined the status of those people who had registered domicile in Latvia on 1 July 1992 and who did not have citizenship of Latvia or any other country. The Constitutional Court declared that non-citizens are not Latvian nationals and are not considered stateless according to international law; it also mentioned that the Republic of Latvia recognises a certain legal link with “non-citizens”, thus this status cannot be revoked due to permanent residence abroad (unless a non-citizen receives a foreign nationality).¹⁸

“Non-citizens” have rights akin to citizens, for example, the right to reside in Latvia without visas or residence permits. However, in accordance with some legislative acts, some rights and opportunities are reserved only for citizens. This includes political rights (the right to participate in elections, or establish political parties) and social and economic rights (land property rights in some territories, public and private sector careers in some professions, or pension for work periods accrued during the Soviet period outside Latvia). Some of these rights

are also guaranteed to EU citizens if they reside in Latvia, but they are not granted to “non-citizens”. As of October 2011, there were 80 differences in rights between citizens and “non-citizens”, mainly relating to careers in the public sector.¹⁹

In September 2008 the Ombudsman completed an investigation into the differences in rights between citizens and “non-citizens”.²⁰ The Ombudsman found that some restrictions on “non-citizens” are not proportional, such as the ban for “non-citizens” to work as advocates or patent attorneys, to receive the first category licence for security work, or be head or member of the board in detective agencies. He also found disproportional restrictions on obtaining land property in the cities by “non-citizens”. The Ombudsman recommended verifying whether restrictions concerning those rights guaranteed for EU citizens but denied to “non-citizens” are justified. Nevertheless, the new Ombudsman who was elected in March 2012 declared that the principle of equality requires a differential treatment towards persons in legally different situations, and that therefore the difference in rights between citizens and “non-citizens” is not of a discriminatory nature, since the legal status of “non-citizens” is not comparable with that of citizens.²¹

The most widely discussed difference in rights between citizens and “non-citizens” concerns the calculation of pension for work periods accrued during the Soviet period outside Latvia – in other parts of the former USSR. For citizens such periods are to be taken into account, whereas for non-citizens they are not (with minor exceptions). In 2009 the European Court of Human Rights (ECtHR) declared that such difference of treatment based exclusively on the ground of nationality is not compatible with the requirements of Article 14 of the Conven-

tion for the Protection of Human Rights and Fundamental Freedoms taken in conjunction with Article 1 of Protocol No. 1.²² However, the Law on State Pensions has not been amended since. The Constitutional Court, when deciding on a subsequent similar complaint by several individuals, found that the position of ECtHR should be read only in the context of a particular case (where the applicant was in fact working on the territory of Latvia for an employer based outside Latvia),²³ thus suggesting a very narrow interpretation of the ECtHR judgment.²⁴ The applicants in the subsequent case decided by the Constitutional Court have submitted an application to ECtHR.²⁵

Following the recent verdicts of ECJ concerning the nationality of notaries²⁶ it might appear necessary to amend the Notary Law – according to section 9(1) currently in force, only Latvian nationals are entitled to work as notaries. Most probably the amendment, if adopted, will cover other EU nationals, but not non-citizens.

IV. Racial or Ethnic Origin

As of 1 January 2012, the population of Latvia was estimated to be 2,217,053, of whom 1,319,552 (59.5%) were ethnic Latvians, 603,125 (27.2%) Russians, 77,423 (3.5%) Belarusians, 54,041 (2.4%) Ukrainians, 50,498 (2.3%) Poles, 28,946 (1.3%) Lithuanians, 9,418 (0.4%) Jews, and 8,482 (0.4%) Roma. In some regions of the country, ethnic Latvians were a minority: in Riga, the capital, ethnic Latvians were estimated at 42.4%, while Russians made up 40.3% of the city’s population. In the second largest city in Latvia, Daugavpils, 17.8% of the population were Latvians and 51.7% were Russians.²⁷

Latvia’s Population Register contains information on the ethnic origin of each person

(Population Register Law, section 10, Para 1(9)). The registration is obligatory even for new-borns: their ethnicity is recorded as being the same as that of their parents. If the parents are of different ethnicity, they can choose one of the two for their baby. The Personal Data Protection Law, however, qualifies information about one's ethnicity as sensitive data (section 2(8)) and imposes certain restrictions on access to such information.

The Law on the Free Development and Rights to Cultural Autonomy for National and Ethnic Groups guarantees any Latvian citizen or a permanent resident (if he or she does not have citizenship of any other country) the right to declare their ethnic origin in compliance with their self-consciousness (section 2). Nevertheless, the Law on the Change of a Given Name, Surname and Ethnicity Record establishes the blood principle of ethnic determination, whereby ethnicity is traced back to an individual's predecessors. Individuals seeking to change their official ethnicity record (allowed once in a lifetime) are required to provide evidence that an ancestor was of the desired ethnicity (with the exception of the Livs, a small autochthonous minority – section 6, Para 2(1)). When changing to Latvian ethnicity, the applicant must also prove his/her command of the state (official) language (section 6, Para 2(5)). This approach is apparently motivated by certain privileges enjoyed by Latvians and Livs in accordance with the Citizenship Law and the Repatriation Law.

Since it has been mandatory to specify ethnicity in the Population Register in accordance with the blood principle, information on the ethnic self-identification of Latvians **in compliance with their choice** is not easily available. According to the 2011 Population Census, the number of people identifying as ethnic

Latvians was slightly higher than in the Population Register – 62.1%, while the number of people belonging to minorities was lower (Russians – 26.9%, Belarusians – 3.3%).²⁸

The Population Census in 2011 once again revealed a discrepancy between the official data on ethnicity and self-identification. Such approach might create problems both from the point of view of non-discrimination law and minority rights (for example, Article 3(1) of the Framework Convention for the Protection of National Minorities stipulates that every person belonging to a national minority shall have the right to freely choose to be treated or not to be treated as such and no disadvantage shall result from this choice or from the exercise of the rights which are connected to that choice).

In 2011 the Ombudsman dealt with several complaints related to a higher entry fee for foreigners in some night clubs. The Ombudsman's Office classified such cases as a direct discrimination on grounds of racial or ethnic origin.²⁹

The problem of discrimination against Roma (often unreported) remains the subject of concern. An opinion poll held in Riga in 2010 suggests that only 19% of respondents were ready to communicate with Roma as with close relatives or friends. For the majority of respondents there was a long social distance with Roma – 17% even said that Roma should not enter Latvia at all.³⁰

V. Language

1) General Situation

As a result of the Soviet language policy in Latvia, most non-Russian minorities in Latvia accepted Latvian or Russian as their main language and were thus assimilated

into the corresponding linguistic communities. According to the 2011 census, 56.3% of the respondents named Latvian as their first family language, 33.8% said their first family language was Russian, while 9.3% did not mention their first language.³¹ Latvian was the native language for 95.6% of Latvians. Russian was the native language not only of ethnic Russians but also of most ethnic Jews (79.1%), Belarusians (72.8%), Ukrainians (67.8%) and Poles (57.7%).³²

Since October 1998, Article 4 of the Constitution has been supplemented with a provision stipulating that Latvian is the state language. The current State Language Law came into force in 1999. It stipulates that all other languages, except the Latvian language, are defined as foreign languages with no exceptions for minority languages (section 5). The Liv language is defined as an autochthonous language enjoying some official support (section 4).

Under section 1(4) of the State Language Law, minorities have the right to choose any language in the private domain. However, the Law permits proportional interference in the private sphere if legitimate public interests, such as health, security or public order, are at stake (section 2(2)). At the same time, the private use of languages in unofficial communication between individuals, internal communication inside ethnic and national groups, as well as in religious activities, cannot be regulated by the Law (section 2(3)).

Given the strong correlation between native language and ethnic origin, it is almost inevitable that in some cases the lack of differential treatment of persons who have the official and non-official languages as their mother tongue is analysed from the viewpoint of indirect discrimination. The Con-

stitutional Court confirmed that the failure to differentiate in such situations may be qualified as discrimination, taking into account that the persons belonging to ethnic minorities are not in the same situation as those belonging to the majority, and this difference is characterised by ethnic origin and language.³³

2) Professional Language Requirements

Section 6 of the State Language Law states that employees of state and municipal institutions and enterprises must know and use the state language to the extent necessary for the performance of their professional duties. Employees of private institutions, organisations and enterprises (companies) must use the state language if their activities affect the legitimate interests of the community or if they perform specific public functions. For such occupations the Cabinet of Ministers defines the required language proficiency,³⁴ for example, the highest levels are compulsory for advocates and their assistants, lawyers, psychologists, doctors, pilots, heads of companies, and members of boards and councils of enterprises, if the employee communicates with consumers or provides information. As regards the rest of the private sector, employers and self-employed persons set their own requirements as to the state language proficiency of their employees within three months after starting business. The legislation does not make exceptions, not even for the territories where minorities account for the majority of the population. The only exception refers to foreign specialists and foreign business persons – they have to either obtain the proficiency certificate or ensure interpretation into Latvian.

There is some controversy concerning the status of members of the local councils and

parliament – whether the elected representatives are to be considered “employees” for the purposes of the professional language requirements. Currently C2 level (highest) is required for members of parliament, and C1 (second highest) was required for members of local councils until January 2012. Several members of the local councils tried to contest the fines imposed for poor use of Latvian, stating that the delegation to establish the level of proficiency covers only employees of municipal institutions, but members are elected officials, not employees, therefore the government has extended the limits of delegation. The Administrative Regional Court rejected this argument referring to section 2(1) of the State Language Law, which stipulates that the state language shall be used and protected in the state and municipal institutions. In the court’s view, the notion “municipal employees” covers also elected municipal officials, otherwise the legislator would provide for an exemption.³⁵ Moreover, according to amendments to the Law on the Status of a Member of the Republican City Council and Regional Council, after the local elections in 2013 a regional court will be entitled to annul mandates of elected members of local councils on account of lack of state language proficiency, if after the municipality-paid courses and within six months after the first check this member cannot pass the exam (section 4).

Interestingly, in June 2012, parliament approved amendments to the Labour Law, which stipulate that the employer is not entitled to demand foreign language proficiency (i.e., any language except for Latvian and Liv according to section 5 of the State Language Law) in a job posting, if the use of this language is not foreseen in the obligations of the employee. The reason for such amendment was alleged discrimination against Latvian-

speakers, as in practice employers often require the knowledge of Russian.

3) Spelling of Personal Names

Section 19 of the State Language Law stipulates that personal names shall be reproduced in accordance with the Latvian language traditions and shall be transliterated according to the accepted norms of the literary language. In a person’s passport or birth certificate, the person’s name and surname reproduced in accordance with Latvian language norms may be supplemented by the historical form of the person’s surname or the original form of the person’s name in another language transliterated in the Latin alphabet if the person or the parents of a minor so desire and can provide verifying documents.

The Cabinet of Ministers has issued detailed Regulations on Spelling and Identification of First Names and Family Names.³⁶ These Regulations establish the rules for spelling first names and family names and how they should be used in Latvian and spelled and identified in official documents. They make no exceptions for the names of the people belonging to minorities. Foreign names and family names have to be spelled in the Latvian language (expressed with Latvian language sounds and letters) as close as possible to their pronunciation in the original language. Besides, every name and family name has to have an ending corresponding to the Latvian language grammatical system (masculine or feminine endings according to the person’s gender). So, for instance, Ricardo Daniel Baranov Cardoso is changed to Rikardu Daniels Baranovs-Kardožu.

In 2010 the UN Human Rights Committee found a violation of the right to privacy (Article 17 of the International Covenant

on Civil and Political Rights) with respect to the unilateral change of the author's name by Latvia.³⁷ The Committee decided not to address the issue of possible violation of other provisions of the Covenant (the prohibition of discrimination and the rights of persons belonging to minorities). Still, the law has not been amended. The author has applied for a revision of his case *de novo* to the Senate of the Supreme Court. The Senate declared that, in principle, the Views of the Committee can be considered as an adjudication of the European Court of Human Rights or other international or supranational court for the purposes of revision on grounds of newly-discovered facts.³⁸ However, it decided to dismiss the author's application stating that the case can first be revised by competent administrative authorities (in particular, the State Language Centre).³⁹

In the meantime, in a similar case the Senate of the Supreme Court applied to the Constitutional Court for a preliminary ruling asking to declare that the legislation in force is not compatible with the Constitution, interpreted in light of the Views.⁴⁰ The Constitutional Court has declined this request and stated that it is not necessary to reevaluate such compatibility, as the evaluation had been made by the Constitutional Court in its previous case law. Nevertheless, the Constitutional Court has indicated that the Senate of the Supreme Court is entitled to review the proportionality of interference with the right to privacy in a particular case.⁴¹ The Senate has not found any weighty reasons to depart from legislation in force and rejected the application.⁴²

Apart from this, there is also another subject of debate: whether the legislation currently in force is compatible with Article 11(1) of the Framework Convention for the Protec-

tion of National Minorities. The latter stipulates that the Parties undertake to recognise that every person belonging to a national minority has the right to use his or her surname (patronym) and first names in the minority language and the right to official recognition of them, according to modalities provided for in their legal system.

VI. Religion

Historically, the largest religious groups in Latvia are Lutheran, Roman Catholic and Orthodox. As of 2012, the Register of Enterprises registered 1206 congregations. These included Lutheran congregations (306), Roman Catholic (254), Orthodox Christian (130), Baptist (108), Old Believers (75). Also, there were 14 Jewish and 23 Muslim registered congregations.⁴³

Article 99 of the Constitution and the Law on Religious Organisations provide for the separation of church and state, as well as for freedom of religion and the right to establish religious organisations. No religion has the status of official religion in Latvia. In practice "traditional" religions have more opportunities than "new" ones. In particular, only clerics of the following religions have the right to register marriages: Lutherans, Catholics, Orthodox Christians, Old Believers, Baptists, Methodists, Adventists and Jewish rabbis (section 53 of the Civil Law).

In accordance with section 1 of the Law on Holidays, Commemoration Days and Celebratory Days, the non-working days are Christmas (December 24-26) and Easter. Though the law does not mention the religious character of these holidays, the dates used are those celebrated by Catholics and Protestants but not Orthodox Christians (who use the Julian calendar). The Law provides that Orthodox, Old Believers and be-

lievers of other confessions celebrate Christmas and Easter on the days set by their confessions. However, if an employee wants to take a day off on one of these days, his or her employer is not obliged to pay him as if they were holidays. Thus, Orthodox, Old Believers and members of non-Christian communities are in a position of inequality.

VII. Disability

In 2010 Latvia ratified the Convention on the Rights of Persons with Disabilities and its Optional Protocol and adopted a new Disability Law. Article 7(3) of the Labour Law provides for the employer's obligation of reasonable accommodation.

Still, the issue of reasonable accommodation both within employment and outside represents a significant challenge. In 2010 it was discovered by the Ombudsman that only 26% of municipal services are fully available to disabled persons.⁴⁴ Also the lack of access to other services (such as night clubs) is reported.⁴⁵

The government's regulations on the standards applicable to public buildings prescribe the need to guarantee access for disabled persons.⁴⁶ But the standards are applicable only to new and reconstructed public buildings; the old ones frequently remain without access. Nevertheless, the public services are to be guaranteed also without such access. The Senate of the Supreme Court decided that the failure to provide such guarantees can be contested in court as the failure to act.⁴⁷

VIII. Age

In the field of age several problems have been mentioned in recent years in media, surveys and publications by official bodies. The most widely cited is references to a particular age

in job postings,⁴⁸ prohibited explicitly by section 32(2) of the Labour Law.

The Ombudsman also examined a complaint concerning the possible extension of age limitation for the presence in casinos and other places where gambling is taking place – from 18 to 21 years old. The Ombudsman found the new limitation proportional.⁴⁹

IX. Sexual Orientation

The issue of discrimination on grounds of sexual orientation is a “hot potato” issue for Latvian society given a high level of intolerance towards sexual minorities. In particular, in a recent survey 23.2% answered that both homosexual persons and homosexual relations are to be condemned, 27.6% declared that they tolerate homosexual persons, but not the relations, 30% answered that neither homosexual persons nor homosexual relations are to be condemned, 18.9% could not answer.⁵⁰

In 2011 the LGBT NGO “Mozaika” recommended the adoption of the Registered Partnership Law which would allow regulating personal and property relations of homosexual couples. Nevertheless, the draft has not been examined. Even the Ombudsman has not provided support to the new legal regulation – with a reference to a public opinion which does not welcome homosexual relations. The Ombudsman suggested instead amending sectoral laws – such as the Law on the Rights of Patients, anti-corruption laws, procedural laws, the laws on social benefits – in order to recognise the rights of unregistered partners in both homosexual and heterosexual relations.⁵¹

X. Conclusion

Despite a low number of reported and examined cases, discrimination remains a matter

of concern for Latvia. At the level of legislation it is necessary to establish a comprehensive legal framework covering all grounds and all fields – preferably via the adoption of a framework law on discrimination. At the level of practice it is important that all public institutions (in particular, the Ombudsman’s Office) take a proactive position in fighting against discrimination – both through awareness raising and legal sanctions.

Structural problems are to be addressed more effectively – for example, reasonable accommodation is required in order to prevent discrimination against disabled persons. Especially strong action is

needed in the fields where discrimination is based on prejudices and stereotypes of the society (for example, against Roma and sexual minorities). Also the issue of linguistic rights of minorities should be analysed from the viewpoint of potential indirect discrimination.

The issue of discrimination has not been very high on the agenda of policy makers in recent years. Probably a more active stance of the EU institutions could help to activate debate at the domestic level – as it was the case in 2003-2004, before the EU accession of Latvia, when some progress in legislation and awareness was clearly observed.

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2 Levits, E., “91.pants”, in *Latvijas Republikas Satversmes komentāri. VIII nodaļa. Cilvēka pamattiesības*, ed. Balodis, R., Riga: Latvijas Vēstnesis, 2011, pp. 98-104.

3 Judgment of the Constitutional Court, 14 September 2005, case no. 2005-02-0106.

4 See above, note 2, pp. 92-94.

5 Judgment of the Riga Latgale District Court, 8 September 2003, case no. C29240503.

6 Council Directive 2000/43/EC of 29 June 2000 implementing the principle of equal treatment between persons irrespective of racial or ethnic origin; Council Directive 2000/78/EC of 27 November 2000 establishing a general framework for equal treatment in employment and occupation; Council Directive 2004/113/EC of 13 December 2004 implementing the principle of equal treatment between men and women in the access to and supply of goods and services; Directive 2006/54/EC of the European Parliament and of the Council of 5 July 2006 on the implementation of the principle of equal opportunities and equal treatment of men and women in matters of employment and occupation (recast); Directive 2010/41/EU of the European Parliament and of the Council of 7 July 2010 on the application of the principle of equal treatment between men and women engaged in an activity in a self-employed capacity and repealing Council Directive 86/613/EEC.

7 Draft law “Diskriminācijas novēršanas likums” (reģ.nr. 741).

8 Latvijas Republikas tiesībsargs, *Gada ziņojums: 2010*, 2011, p. 142.

9 Latvijas Republikas tiesībsargs, *Gada ziņojums: 2011*, 2012, p. 149.

10 Ibid., p. 112.

11 Ibid., pp. 116-117.

12 Case C-232/09 *Danosa* [2010].

- 13 Judgment of the Supreme Court, 19 January 2011, case no. SKC-1/2011.
- 14 Judgment of the Supreme Court, 15 October 2010, case no. SKA-480/2010.
- 15 Case C-236/09 *Association Belge des Consommateurs Test-Achats and Others* [2011].
- 16 Draft law “Grozījumi Apdrošināšanas sabiedrību un to uzraudzības likumā” (TA-1305).
- 17 Data of the Population Register is available at: <http://www.pmlp.gov.lv/lv/statistika/iedzivotaju.html>.
- 18 Judgment of the Constitutional Court, 7 March 2005, case no. 2004-15-0106.
- 19 Latvian Human Rights Committee, *Citizens of a Non-Existent State*, 2011, pp. 29-33.
- 20 Atzinums pārbaudes lietā, available at: http://www.tiesibsargs.lv/files/downloads/Par_pilsonu_un_nepilsonu_atskiribam_Latvija.doc.
- 21 See above, note 9, p.122.
- 22 *Andrejeva v Latvia* [GC], Application no. 55707/00, ECHR 2009.
- 23 Judgment of the Constitutional Court, 17 February 2011, case no. 2010-20-0106.
- 24 European Commission against Racism and Intolerance, *Fourth Report on Latvia*, 2012, Para 130.
- 25 *Savickis and Others v Latvia*, Application no. 49270/11.
- 26 See, for example, Case C-47/08 *Commission/Belgium* [2011].
- 27 See above, note 17.
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- 29 See above, note 9, p. 116.
- 30 TNS Latvia, *Sabiedrības integrācija Rīgā*, 2010, available at: http://www.riga.lv/NR/rdonlyres/E27BFA8D-29AF-45AA-9D93-7F8D5A612DB4/30374/2473_RD_iedz_aptauja_2010_isais_var.pdf.
- 31 See above, note 28.
- 32 Valsts valodas politikas pamatnostādnes 2005.-2014. gadam, p. 8.
- 33 Judgment of the Constitutional Court, 13 May 2005, case no. 2004-18-0106.
- 34 07.07.2009. MK noteikumi Nr. 733 “Noteikumi par valsts valodas zināšanu apjomu un valsts valodas prasmes pārbaudes kārtību profesionālo un amata pienākumu veikšanai, pastāvīgās uzturēšanās atļaujas saņemšanai un Eiropas Kopienas pastāvīgā iedzīvotāja statusa iegūšanai un valsts nodevu par valsts valodas prasmes pārbaudi”.
- 35 Judgment of the Administrative Regional Court, 14 May 2012, case no. A420558710.
- 36 02.03.2004 MK noteikumi Nr.114 “Noteikumi par personvārdu rakstību un lietošanu latviešu valodā, kā arī to identifikāciju”.
- 37 Human Rights Committee, Views with regard to communication No.1621/2007 (*Raihan v Latvia*, adopted on 30 November 2010).
- 38 Decision of the Supreme Court, 12 May 2011, case no.SJA-8/2011.
- 39 Decision of the Supreme Court, 15 June 2011, case no.SJA-8/2011.
- 40 Decision of the Supreme Court, 27 April 2012, case no.SKA-184/2012.
- 41 Procedural decision of the Constitutional Court, 30 May 2012.
- 42 Judgment of the Supreme Court, 7 July 2012, case no.SKA-184/2012.
- 43 Data of the Register of Enterprises, available at: <http://www.ur.gov.lv/?a=1142>.
- 44 See above, note 8, pp. 74-75.
- 45 See above, note 9, p. 116.

- 46 21.07.2008. MK noteikumi Nr.567 "Noteikumi par Latvijas būvnormatīvu" LBN 208-08.
- 47 Decision of the Supreme Court, 8 July 2010, case no. SKA-635/2010.
- 48 See above, note 9, p. 112.
- 49 Tiesībsarga atzinums pārbaudes lietā Nr.2011-263-26C par likumprojektā "Azartspēļu un izložu likums" paredzēto aizliegumu azartspēļu organizēšanas vietās atrasties personām, kas nav sasniegušas 21 gada vec
- 50 Tirgus un sabiedriskās domas pētījumu centrs SKDS, Latvijas iedzīvotāju aptauja „Attieksme pret seksuālajām minoritātēm”, 2011, p. 22.
- 51 See above, note 9, pp. 120-121.

Abortion in the Americas: Non-discrimination and Equality as Tools for Advocacy and Litigation

Vickie Knox¹

Introduction

This article will explore to what extent International Human Rights Law (IHRL) can make a formal or substantive contribution to access to abortion, analyse aspects of discrimination caused by the criminalisation of abortion, and examine the benefits of using the rights to equality and non-discrimination in advocacy and litigation to secure access to safe abortion as a critical component of reproductive healthcare.²

Jurisdictions within the Americas provide varying levels of access to abortion, although laws are generally very restrictive in Latin America. Four jurisdictions currently criminalise abortion in all circumstances – even where its purpose is to save the life of a pregnant woman.³ Chile repealed its law permitting therapeutic abortion in 1989; El Salvador and Nicaragua introduced laws in 1998 and 2006, respectively, which removed previous exceptions for emergency and therapeutic abortion; the Constitution of the Dominican Republic of 2010 established the inviolable right to life from conception, creating a constitutional ban on abortion.⁴ However, in 2006, the Colombian Constitutional Court repealed such a no-exceptions ban on abortions, ruling that it conflicted with its obligations under the

Convention on the Elimination of Discrimination against Women (CEDAW) to deliver reproductive health services without discrimination.⁵ In the United States, abortion is permitted but, since 2010, a series of laws which restrict access in practice have been passed in several states.⁶ In contrast, legislative developments in Mexico City,⁷ and juridical decisions in Argentina⁸ and Brazil⁹ have recently extended the circumstances in which abortion is permitted.

This article will analyse whether a no-exception ban on abortion is legitimate under IHRL, and evaluate aspects of direct, indirect and multiple and systemic discrimination caused by such legislation. It will look at how IHRL supports therapeutic abortion in certain situations – through claims of rights to non-discrimination, health, reproductive autonomy and freedom from inhuman treatment – and explore how the principles of non-discrimination and equality can strengthen this argument, examining the interpretation and clarification of these rights by the treaty bodies which monitor them. It will then look at the lived experience of the no-exceptions abortions bans in Nicaragua and El Salvador, where abortion is criminalised under any circumstances. In doing so it will demon-

strate how such legislation violates the principle of non-discrimination in relation to the rights to health and equality before the law, and will examine the multiple discrimination which marginalised and vulnerable groups of women experience in relation to these laws. Finally, it will examine the use of the principles of equality and non-discrimination in litigation, including an analysis of the Colombian Supreme Court's decision in a constitutional challenge to a no-exceptions abortion ban. It will offer a comparison of subsequent claims for protection, contrasting these with the recent restrictive legislative moves in the United States. In doing so, it will evaluate the benefits of applying the principles of equality and non-discrimination within advocacy and litigation, and the impact of the mandatory and immediate obligations which are put upon the state as a result.

1. International Legal Framework

On one level, there appears to be a particular silence on abortion within human rights treaties. The sole exception where abortion is explicitly declared as a right in a legally binding international instrument is in the Protocol to the African Charter on Human and People's Rights on the Rights of Women in Africa.¹⁰ However, other international and regional IHRL instruments contain provisions which are applicable to abortion, including the rights to life, health, reproductive autonomy, freedom from cruel or inhuman treatment and the right to non-discrimination. Interpretations of these legal instruments by treaty bodies and courts have further clarified how the treaty provisions should be implemented in relation to abortion.

1.1 The Right to Life

The right to life is a fundamental provision within international and regional treaties:¹¹

it is a right from which there can be no derogation, even in times of emergency.¹² In the abortion debate, those against abortion have used IHRL to claim a foetal right to life¹³ whereas others have claimed that there is no legal basis for such a claim and that any absolute foetal right could violate the rights of the mother – and especially her own right to life.¹⁴ If there is a foetal right to life, the extent of the right's application must be established in order to analyse to what extent a pregnant woman's rights can be limited by the state's interest in protecting any foetal rights.

Legal Instruments

The terminology within the primary legal documents does not explicitly extend the right to life to the unborn, although neither does it preclude this. In the Universal Declaration on Human Rights (UDHR) and the European Convention for the Protection of Human Rights and Fundamental Freedoms (ECHR) the right to life belongs to "everyone" (Article 3 UDHR; Article 2(1) ECHR); in the International Covenant on Civil and Political Rights (ICCPR) it belongs to "every human being" (Article 6(1) ICCPR); in the United Nations Convention on the Rights of the Child (CRC) it belongs to "every child" (Article 6(1) CRC). The American Convention on Human Rights (ACHR) contains the most specific definition of the point at which the right to life could begin at Article 4(1): "Every person has the right to have his life respected. This right shall be protected by law, and, in general from the moment of conception." Much debate has been generated about the point at which the right to life begins and, although most treaties are silent on this matter, it is "generally recognised that international human rights conventions are not applicable before the birth of a human being".¹⁵ Indeed, the drafters of the ICCPR rejected, by majority vote,

the term “from the moment of conception” and analysis of the *travaux préparatoires*¹⁶ shows that the drafters of both the ICCPR and the CRC discussed this very matter, and purposefully chose language that would not extend the right to life to the unborn.¹⁷

International Judicial Decisions

In 1981 the Inter-American Commission on Human Rights (IACHR) confirmed in the “*Baby Boy*” Case that abortion was compatible with the ACHR and clarified the substantive meaning of the terminology.¹⁸ The judgment referred to the fact that the drafters had consciously changed the language of the treaty for the specific purpose of accommodating the domestic laws of those states which permitted therapeutic abortion, clarifying that the prenatal right to life is not absolute within the ACHR and that abortion is permitted under the treaty. The European Court of Human Rights (ECtHR)¹⁹ and the European Commission of Human Rights (ECommHR)²⁰ have allowed for a wide margin of appreciation where abortion is concerned, meaning that European states have a very broad range of abortion laws, ranging from Ireland’s restrictive laws to the UK’s extremely liberal laws. The ECtHR’s ruling in *A, B and C v Ireland* stressed that “[w]hile the State was entitled to a margin of appreciation to protect pre-natal life, it was not an absolute one”,²¹ and that:

“[The] prohibition of abortion to protect unborn life is not therefore automatically justified under the Convention on the basis of unqualified deference to the protection of pre-natal life or on the basis that the expectant mother’s right to respect for her private life is of a lesser stature.”²²

Therefore, whilst the ECtHR avoided ruling on whether there is a foetal right to life, it did state

that any prenatal right to life is not absolute and that European human rights law requires states to provide emergency abortion.²³ Thus, even if there is a foetal right to life under the ECHR, it appears to have a lesser status to that of the mother’s right to life: the state’s duty to protect the woman’s right to life has primacy over any foetal right to life. This reasoning has led to the general acceptance of emergency abortion as an essential medical procedure, which protects women’s fundamental human rights under IHRL.

Expansive Interpretation of the Right to Life

The inviolable duty to uphold women’s right to life requires the state to adopt both negative measures, such as the obligation not to kill, and positive measures, such as protection from unintentional death. Whilst this certainly supports emergency abortion to save a woman’s life from imminent risk, both the United Nations and Inter-American systems have stressed that the right to life must be interpreted in an expansive manner. The Human Rights Committee (HRC) in General Comment 6 stresses that:

“[T]he right to life has been too often narrowly interpreted. The expression ‘inherent right to life’ cannot properly be understood in a restrictive manner, and the protection of this right requires that States adopt positive measures.”²⁴

In the Americas, the Inter-American Court of Human Rights (IACtHR) has further aligned the right to life with the right to a dignified life (*vida digna*) free of inhuman treatment and supported by access to life’s essentials – food, water and healthcare,²⁵ reflecting the interrelatedness, interdependency and indivisibility of human rights. This expansive interpretation of the right to life suggests states should provide access to reproduc-

tive healthcare and therapeutic abortion in a broader range of circumstances. When applied together with the right to non-discrimination – which is compelling to all and of a non-derogable nature – this argument is significantly strengthened.

The Balancing of Rights

The concept of the balancing of rights is crucial to judicial decisions on both discrimination and abortion. Such decisions “seek to balance competing human rights so that they are not interpreted absolutely and undermine one another”²⁶ and are core to the concept of proportionality. This balancing of rights has also been used by the majority of constitutional tribunals which have been asked to examine laws governing abortion, and which have recognised the need to balance the life of the foetus with the various rights of the pregnant woman.

“Even though the various tribunals have differed on which of those interests must prevail in particular cases, they have shared common ground in affirming that a total prohibition on abortion is unconstitutional because under certain circumstances it imposes an intolerable burden on the pregnant woman which infringes upon her constitutional rights.”²⁷

When such judicial decisions are made with an expansive interpretation of the rights to life and with full consideration of women’s other rights and the right to non-discrimination, they can generate a powerful affirmation of women’s right to abortion in certain circumstances.

1.2 Women’s Rights to Health, Reproductive Autonomy and Non-Discrimination

In addition to the right to life, women hold several other rights which are relevant to

abortion, *inter alia*, the rights to health, reproductive autonomy and non-discrimination, as well as the rights to dignity, liberty of the person and respect for privacy and family life. Several commentators have comprehensively evaluated the meaning of these rights in relation to abortion,²⁸ and this article will now examine how the right to non-discrimination – specifically in relation to the rights to health, reproductive autonomy and freedom from inhuman treatment – relates to the debate on abortion. In doing so, it will draw on interpretations and rulings by treaty bodies, which have been particularly clear about access to abortion in the Concluding Observations issued to individual states.

The Right to Health without Discrimination

The Preamble to the Constitution of the World Health Organisation (WHO) defines health as “a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity” and 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.”²⁹

This right to health is granted in Article 12(1) of ICESCR, which must be implemented with the principle of non-discrimination accorded by Article 3, requiring:

“[A]t a minimum, the removal of legal and other obstacles that prevent men and women from accessing and benefiting from healthcare on a basis of equality. This includes, *inter alia*, (...) the removal of legal restrictions on reproductive health provisions.”³⁰

States can violate this right by “the denial of access to health facilities, goods and ser-

vices to particular individuals or groups as a result of *de jure* or *de facto* discrimination”,³¹ and, in order to respect this right, states must abstain “from imposing discriminatory practices relating to women’s health status and needs”.³²

The right to health – along with other economic, social and cultural rights – must be progressively realised according to available resources. By contrast, the right to non-discrimination is not subject to such progressive realisation but rather is of immediate effect and cannot be restricted.³³ States have:

“[V]arious obligations which are of immediate effect. States parties have immediate obligations in relation to the right to health, such as the guarantee that the right will be exercised without discrimination of any kind (art. 2.2).”³⁴

Ensuring “the right of access to health facilities, goods and services on a non-discriminatory basis, especially for vulnerable or marginalized groups”³⁵ is a non-derogable part of the core obligations under the treaty. States must not only grant these rights, but also the means to fulfil them: “[t]he right to health, like all human rights, imposes three types or levels of obligations on States parties: the obligations to *respect*, *protect* and *fulfil*”.³⁶ Furthermore, “guarantees of non-discrimination and equality in international human rights treaties mandate both *de facto* and *de jure* equality”.³⁷

Emergency and therapeutic abortions are medical services which are only required by women. When these are withheld to the point where they violate any right, *inter alia*, the rights to life and health, they must be read together with common Articles 2(2) and 3 of the ICESCR and ICCPR, which protect against discrimination.³⁸ In regard to ICESCR:

“By virtue of article 2.2 and article 3, the Covenant proscribes any discrimination in access to health care and underlying determinants of health (...) which has the intention or effect of nullifying or impairing the equal enjoyment or exercise of the right to health.”³⁹

The Committee on the Elimination of Discrimination against Women (CEDAW Committee) has further stated that “it is discriminatory for a State party to refuse to legally provide for the performance of certain reproductive health services for women”.⁴⁰ Thus, arbitrarily restricting access to emergency and therapeutic abortion at minimum – and possibly also to broader elective abortion – violates the principle of non-discrimination on the ground of sex.

The Guttmacher Institute⁴¹ and WHO report that criminalising abortion does not decrease the number of abortions performed in countries, but merely limits women’s abortion options to illegal and potentially unsafe options.⁴² Unsafe abortion is the single highest cause of maternal death in countries with total bans, such as Nicaragua, with up to 16% of maternal deaths linked to complications arising from illegal abortions.⁴³ The HRC has requested that “[w]hen reporting on the right to life protected by Article 6, States parties should (...) ensure that [women] do not have to undertake life-threatening clandestine abortions”.⁴⁴ The criminalisation of abortion therefore also discriminates against women by exposing them to unsafe procedures, jeopardising their right to life as well as their access to health – risks which are borne only by women and to which men are not exposed.

The criminalisation of abortion also causes a chilling effect on women who experience obstetric complications, miscarriage,

stillbirth or premature labour, who may be reluctant to seek medical help in case they are accused of procuring an abortion.⁴⁵ Furthermore, women face punitive criminal penalties for accessing healthcare which only they require, whereas men do not. In jurisdictions with no-exceptions abortion bans, these penalties can also extend to non-obstetric as well as obstetric healthcare, with medical professionals facing similar penalties for carrying out their professional duties. In such jurisdictions, the fear of criminal sanctions has a chilling effect on medical professionals' willingness to deliver specialised care to pregnant women or to attend to women who present in obstetric emergency or women who have undergone a clandestine abortion, causing further discrimination in the delivery of healthcare.⁴⁶

The Right to Reproductive Autonomy

The right to reproductive autonomy is granted in CEDAW Article 16(e), which states that women must be able "to decide freely and responsibly on the number and spacing of their children and to have access to the information, education and means to enable them to exercise these rights". The CEDAW Committee has specified that women should not be criminalised for seeking healthcare,⁴⁷ and that states must "remove punitive provisions imposed on women who undergo abortion" in order to comply with CEDAW.⁴⁸ A state's failure to uphold these rights places a disproportionate burden on women, violating the principles of non-discrimination and equality enshrined in CEDAW. The right to reproductive autonomy relates to abortion in a wider range of circumstances than the rights to health and life (unless an expansive reading of these is taken) creating a strong argument for elective as well as therapeutic abortion.

The Right to Freedom from Cruel and Inhuman Treatment

In the case of a pregnancy which results from rape or incest, the impact on the girl or woman of carrying a pregnancy to term must be considered. By its very nature, such a pregnancy would be forced, thus violating the right to reproductive autonomy of the girl or woman. The HRC has informed states that in order to assess their compliance with Article 7 of the ICCPR – the right to be free from cruel and inhuman treatment – it "needs to know whether the State party gives access to safe abortion to women who have become pregnant as a result of rape".⁴⁹ The HRC required this specifically for adherence with Articles 6 and 7 of the ICCPR: the right to life and the right to be free from torture and inhuman treatment, demonstrating that it considers the mental and physical suffering caused by a forced pregnancy to contravene Article 7. Further to this, the United Nations Committee Against Torture has expressed "deep concern" about absolute bans on abortion in its Concluding Observations on several countries.⁵⁰ The HRC was asked to consider the case⁵¹ of *K.N.L.H. v Peru*,⁵² which concerned a 17 year old pregnant girl who, after an ultrasound scan found that the foetus was anencephalic, was denied abortion, even though it was allowed under Peruvian law.⁵³ The 2006 HRC ruling evaluated the girl's "serious mental suffering" and the fact that medical staff had foreseen this suffering, concluding that the continued pregnancy was cruel or inhuman treatment,⁵⁴ violating Article 7 of the ICCPR.

The Right to Equality before the Law

The criminalisation of health services which only women require is a direct violation of the rights to health and non-discrimination: "it is discriminatory for a State party to re-

fuse to legally provide for the performance of certain reproductive health services for women”.⁵⁵ This criminalisation further impacts on women’s rights to equality before the law and equal protection of the law,⁵⁶ liberty of the person and due process.

The criminalisation of abortion generally imposes an obligation on medical professionals to report abortions, as they have to report other crimes. The HRC requires states to provide information on any laws and practices that:

“[M]ay interfere with women’s right to enjoy privacy and other rights protected by article 17 on the basis of equality with men, [for example] where States impose a legal duty upon doctors and other health personnel to report cases of women who have undergone abortion”.⁵⁷

The Committee emphasised that this could also impact on the right to life and the right to be free from cruel or inhuman treatment, and that states should report on any laws or practices that interfere with the equal enjoyment of the right to privacy by women, and on the measures taken to eliminate such laws or practices.⁵⁸ The obligation on medical professionals to make reports to the police breaches patient confidentiality, and, dependent on the reporting procedure, can violate the rights to privacy, freedom from reputational attacks⁵⁹ and the presumption of innocence.⁶⁰ This also has a chilling effect on women, who may be reluctant to seek medical help during or after such an obstetric emergency or illicit abortion,⁶¹ resulting in poor health outcomes and increasing possibility of maternal mortality.

The criminalisation of women who are suspected of having undergone an abortion can also lead to the failure to uphold guar-

antees of judicial process or to violations of the rights to a fair trial and equal protection of the law.⁶² Article 8 of the ACHR prescribes the right to a hearing “by a competent, independent and impartial tribunal” and outlines the specific minimum judicial guarantees – *inter alia*, the right to a hearing, the inalienable right to counsel, prior notification of charges and time to prepare defence, the right to examine witnesses, the right not to be compelled to self-incriminate and the right to appeal to a higher court. The pre-trial detention, judicial process and trials for abortion-related crimes in some jurisdictions have been found to systematically fail to meet these standards.⁶³ For instance, women may be presumed guilty before evidence has been gathered, denied access to legal counsel before their trial, prevented from testifying in their defence and subjected to trials which are based on conjecture rather than proof. Beyond this, women of low socio-economic status, in particular, lack the financial recourse to access legal support or expert opinion resources and often also lack knowledge about their rights, which can further impair their enjoyment of these rights.

Violence against Women

Violence against women “is a form of discrimination that seriously inhibits women’s ability to enjoy rights and freedoms on a basis of equality with men”.⁶⁴ States have both negative and positive obligations in relation to violence against women, including “to ensure that women are not forced to seek unsafe medical procedures such as illegal abortion because of lack of appropriate services in regard to fertility control”,⁶⁵ and “to provide appropriate specialized services for women who have been subjected to violence”.⁶⁶ The Committee Against Torture has also condemned the criminalisation of abortion in all circumstances. It has stated that

the ban has a serious effect on the mental health of:

“[W]omen victims of violence [who] were subjected to continuing violations, placing them under serious traumatic stress with the risk of incurring long-term psychological problems.”⁶⁷

Women who are victims of rape and who are unable to access safe abortion experience compound discrimination on the grounds of sex with regard to their rights to life, health, reproductive autonomy and to freedom from cruel and inhuman treatment.

Furthermore, the Inter-American Convention on the Elimination of Violence Against Women (Convention of Belém do Pará) holds that a state commits an act of violence against women not only by failing to refrain from it, but also by perpetuating or condoning an act of violence.⁶⁸ Forcing the continuation of a pregnancy that has resulted from rape perpetuates the violence. Inasmuch, prohibiting access to abortion in cases of rape can, in itself, be interpreted as an act of violence against women.

Intersectional Discrimination

Some groups of women experience discrimination due to the intersection of two or more prohibited grounds in relation to abortion, and “such cumulative discrimination has a unique and specific impact on individuals and merits particular consideration and remedying.”⁶⁹ Typically, groups of women which are statistically more likely to require emergency or therapeutic abortion include: women who are less able to access contraception and healthcare information and services, groups who have poorer overall standards of health, groups where girls become sexually active at a young age and groups which are

disproportionately affected by gender-based violence and rape. These may include, for example, indigenous women, ethnic minorities and internally-displaced women.⁷⁰ Low income and rural women and adolescent girls are disproportionately affected by the abortion bans in Central America,⁷¹ experiencing multiple discrimination on the grounds of sex, social origin, age and economic or other status, prohibited under ICESCR Article 2(2).⁷² In addition, “economic status” is a protected ground in the Inter-American system⁷³ and the right to health obliges states to satisfy “the health needs of the highest risk groups and of those whose poverty makes them the most vulnerable.”⁷⁴

Adolescent pregnancies are 50% more likely than average to incur complications which require emergency intervention, such as therapeutic abortion,⁷⁵ and adolescent girls are disproportionately affected by maternal mortality.⁷⁶ In order to guarantee the right to health for adolescents, states must develop “youth-friendly health care, which respects confidentiality and privacy and includes appropriate sexual and reproductive health services.”⁷⁷ The Committee on the Rights of the Child has issued Concluding Observations on several countries, calling on them to ensure that adolescent girls have access to contraception and safe abortion.⁷⁸ Furthermore, adolescents in Central America are disproportionately affected by rape and incest and are, therefore, more likely to require specialist services, including termination of pregnancy.⁷⁹ This group is therefore disproportionately affected by the lack of access to safe abortion, suffering further indirect and multiple discrimination, on grounds of sex and age in enjoyment of the rights to life and health.

Typically rural women are poorer, have high levels of malnutrition and restricted

access to drinking water, become sexually active younger and have a higher number of pregnancies.⁸⁰ In general, they also have low levels of education, restricted access to health information and sex education, and limited access to high quality health services and reproductive healthcare, as well as low levels of power, autonomy and decision-making ability, due to cultural factors.⁸¹ These factors lead to higher risk of obstetric complications and maternal mortality, making rural women statistically more likely to require reproductive health-care services, such as emergency and therapeutic abortion.⁸²

Poor women do not have the economic resources to attend a private clinic where they may be able to receive discrete treatment, nor to travel to another jurisdiction to obtain an abortion. Their lack of economic resources means that if they do access clandestine abortion, they are exposed to the highest risk and lowest sanitary conditions, which represents discrimination and social injustice.⁸³ There also is evidence that they are disproportionately affected as a result of the healthcare they are able to access within the country, with only public hospitals reporting suspected abortions to the police. Further to this, where women face criminal penalties for abortion, poor women rarely have the resources to access legal assistance, constituting further discrimination on grounds of their economic status.

Consequential Impact on Equality

Lack of substantive access to reproductive healthcare, including safe and legal abortion can have a compound discriminatory effect on women's ability to participate in all areas of public life, and has a profound effect on women's "exercise and enjoyment of human

rights and fundamental freedoms on a basis of equality with men".⁸⁴ In addition to the significant financial and personal impact which bearing and raising a child has on a woman, lack of access to reproductive healthcare has a consequential impact on other rights, *inter alia* the rights to education and work, perpetuating socio-economic and educational disadvantage, as well as gender inequalities.⁸⁵ By contrast:

"[I]ncreasing access for all women to reproductive health care services enables women to seek educational and employment opportunities and contributes to the elimination of social and economic discrimination against women."⁸⁶

Restrictive access to reproductive health-care serves to perpetuate gender stereotypes, poverty and social iniquities. The criminalisation of abortion "directly contributes to the feminization of poverty in [El Salvador] and further exacerbates the inequality that women face",⁸⁷ thus perpetuating disadvantage and discrimination. Furthermore, the inability of women to make decisions regarding their reproductive capacities further accentuates this situation. By contrast:

"[E]mpowering women by allowing them meaningful involvement in decision-making processes that affect them has been found to be instrumental in ensuring the success of programmes aimed at reducing poverty and increasing equality between men and women."⁸⁸

Thus any prohibition on abortion can have an ongoing impact on the right to equality in the enjoyment of an expansive range of rights, impairing women's ability to participate on an equal basis with men in all areas of public life.

Systemic Discrimination

Systemic discrimination is “pervasive and persistent and deeply entrenched in social behaviour and organization, often involving unchallenged or indirect discrimination,” typified by “legal rules, policies, practices or predominant cultural attitudes in either the public or private sector which create relative disadvantages for some groups”.⁸⁹ Inasmuch, the impact on women outlined above represents systemic discrimination. Additionally, in Central America, for instance, there are high levels of violence against women, including the phenomenon of “femicide”,⁹⁰ which is an extremely grave and widespread pattern of discrimination against women. When the context of these broad and pervasive patterns of discrimination against women is taken into consideration, a no-exceptions ban on abortion represents one element of systemic discrimination against women.

2. Discrimination: the Lived Experience under No-Exceptions Bans on Abortion

In Latin America, there has been a noticeable trend towards no-exceptions bans on abortion. Nicaragua, El Salvador, Chile and the Dominican Republic have introduced laws which permit no recourse, even when the woman’s life is at immediate risk.⁹¹ Article 37 of the Dominican Republic’s new constitution grants the inviolable right to life from conception and outlaws abortion in all circumstances. Mia So has stated that “there is no reading of Article 37 that would make it compatible with the Dominican Republic’s current standards of international law and fundamental principles of human dignity”.⁹² Further to the prohibition of emergency abortion – a prohibition which violates fundamental human rights, such bans can have a discriminatory impact on all aspects of women’s lives. This article will now

analyse the substantive impact of such legislation from a perspective of non-discrimination and equality, highlighting aspects of discrimination in two case studies and demonstrating the systematic violation of fundamental human rights.

2.1 Nicaragua: Discrimination and the Right to Health

In 2006, Nicaragua repealed the law allowing therapeutic abortion in limited circumstances, removing the rights to seek an abortion to save the mother’s life or health, to terminate a pregnancy that resulted from rape or incest, or to abort a foetus with fatal defects. Nicaragua’s new Penal Code (Law 641) was introduced in 2008 and criminalised abortion in all circumstances, placing extremely harsh sanctions on medical personnel who perform an abortion or provide any after-care, and on any woman or girl who seeks or has an abortion. Furthermore, administering any medical treatment which results in the death of a foetus or spontaneous abortion – even unintentionally – is also criminalised.⁹³ This has led to the discriminatory denial of both obstetric and non-obstetric healthcare.

When the law allowing therapeutic abortion was repealed, Victor Abramovich, the IACHR’s Special Rapporteur on Women’s Rights, wrote to the Nicaraguan Foreign Minister stating that:

“Therapeutic abortion is recognised internationally as a specialised and necessary health service for women. The denial of this health service constitutes a violation of women’s life and physical and psychological integrity. Equally [the prohibition on therapeutic abortion] would be an obstacle to the work of health professionals, whose obligation is to protect life and deliver adequate treatment to their patients.”⁹⁴

There are many documented examples where medical professionals have denied essential obstetric care to pregnant women. For instance, women with obstetric emergencies such as an ectopic pregnancy – a non-viable pregnancy, which has lethal consequences for the woman if left untreated – have been denied treatment.⁹⁵

Furthermore, there are cases where women have been refused life-saving treatment for non-obstetric conditions such as breast cancer because medical staff were concerned that it may cause foetal damage and spontaneous abortion.⁹⁶ CESCR has stated that:

“[T]he realisation of women’s right to health requires the removal of all barriers interfering with access to health services, education and information, including in the area of sexual and reproductive health.”⁹⁷

Therefore, we can see that this absolute ban on abortion clearly violates a woman’s right to access to healthcare – not only by not removing barriers, but by actually creating them – and, therefore, also violates the principle of non-discrimination in the delivery of healthcare.⁹⁸

Healthcare staff face harsh criminal sanctions for performing emergency abortions or medical treatment that unintentionally results in spontaneous abortion, violating their rights to deliver care. The president of the IACtHR has stated that:

“In certain cases, such as when continuing the pregnancy would endanger the life of the woman, or when the pregnancy is as a result of rape, the criminalization of abortion would cause a violation of the obligation of the state to protect the life of the woman.”⁹⁹

In *de la Cruz-Flores v Peru*,¹⁰⁰ Judge Garcia Ramirez stated of medical professionals that if the state:

“[P]revented them from complying with their ethical and juridical duty, and even imposed penalties for such compliance (...) the State would be harming the right to life and health of the individual, both directly and by intimidation or restrictions imposed on those who, due to their profession, are regularly obliged to intervene in the protection of those rights.”¹⁰¹

Thus it can be seen that the criminalisation of abortion further violates the rights of women both by subjecting them to criminal sanctions for pursuing their right to healthcare and also by impeding the medical professionals responsible for the frontline delivery of those rights. It also violates the rights of medical professionals by attracting criminal sanctions for carrying out their professional duty. The HRC has specifically stated that:

“The State party should bring its legislation on abortion into line with the provisions of the Covenant (...) and avoid penalising medical professionals in the conduct of their professional duties.”¹⁰²

In February 2010, the IACHR granted Precautionary Measures for “Amalia”,¹⁰³ a Nicaraguan woman with cancer who was being denied treatment because she was pregnant, and the treatment could cause spontaneous abortion or stillbirth. The request for Precautionary Measures required that Nicaragua treat “Amalia” according to her wishes and medical needs, and that the State respond within five days. These Precautionary Measures set precedent in recognising the need to deliver indicated medical treatment in pregnancy, and for the termination of pregnancy to acknowledge non-obstetric as well

as obstetric threat to life during pregnancy. This demonstrates “that the Commission understands and condemns the effects that the abortion negation can have in the rights to life, health, and to the integrity of women in the region”.¹⁰⁴

In its General Comment 14, CESCR presumes that retrogressive measures in relation to the right to health are not permissible, and are in themselves a violation of the right to health:

“If any deliberately retrogressive measures are taken, the State party has the burden of proving that they have been introduced after the most careful consideration of all alternatives and that they are duly justified by reference to the totality of the rights provided for in the Covenant.”¹⁰⁵

Emergency and therapeutic abortions were available in Nicaragua for over a hundred years until this recent ban, and medical care was also available to pregnant women. In this respect, Nicaragua’s abortion ban violates the principle of non-retrogression. CESCR illustrates the impact that this has on the state’s duty to uphold women’s rights noting with concern:

“[T]he general ban on abortion, even in cases of rape, incest and, apparently, pregnancies threatening the life of the mother, (...) and various documented cases in which the death of a pregnant woman has been associated with a lack of timely medical intervention to save her life such as would have taken place under the legislation in force before the law was revised”.¹⁰⁶

2.2 El Salvador: Discrimination and the Right to Equal Protection of the Law

The law in El Salvador outlaws abortion in all circumstances, including abortion to

save the life of a woman. Previous access to therapeutic and emergency abortion was repealed in 1998, and Chapter II of the Penal Code now prohibits Crimes Against the Life of Human Beings in the First Stages of Development, with strict criminal penalties prescribed by Section 133 for anyone who procures an abortion or allows one to be procured. Medical professionals face even harsher penalties for any involvement, and are obliged to report a suspected abortion to the police.¹⁰⁷ Poor women suffer disproportionately from El Salvador’s absolute ban on abortion, as they do in other jurisdictions with such laws.¹⁰⁸

Healthcare professionals in El Salvador are obliged to maintain patient confidentiality, but also to report any crimes to the police, including that of abortion. A note from the Attorney General’s Office is displayed in the maternity department of public hospitals, reminding staff of this duty and putting them under pressure to make reports.¹⁰⁹ The manner and speed with which reports are made – prior to any investigation or gathering of evidence – violates the right to the presumption of innocence. Women of low socio-economic status who are suspected of having undergone an abortion are regularly reported to the police. Poor women are disproportionately more likely to suffer from obstetric complications, but they are frequently reported to the police following a miscarriage (spontaneous abortion), stillbirth or premature labour. Significantly, not one such report has been made to the police by a private clinic or hospital.¹¹⁰ In this manner, poor women are disproportionately affected by these violations of their right to presumption of innocence, privacy and patient confidentiality. Following a report to the police, they are often shackled to their hospital bed and then transported straight from the hospital to prison, often in a grave medical situation.

Article 133 of the Penal Code establishes that anyone who causes an abortion or knowingly allows an abortion to take place can be punished with two to eight years in prison. In addition to imposing criminal sanctions for accessing an essential component of reproductive healthcare, this has also led to the arbitrary imprisonment of women who have suffered a miscarriage or an obstetric complication.¹¹¹ Furthermore, if the foetus is deemed to have been viable, the Prosecutor habitually converts this into the crime of aggravated homicide, which is punishable by 30 to 50 years in prison.¹¹² As of June 2012, the *Agrupación Ciudadana por la Despenalización del Aborto Terapéutico, Ético y Eugenésico* (ACDATEE, Citizens for the Decriminalisation of Therapeutic, Ethical and Eugenic Abortion) has met 128 women who have been imprisoned for abortion, and 25 who have been prosecuted for aggravated homicide, after an abortion, miscarriage or stillbirth. The majority of the women who have been imprisoned share a similar profile, according to Morena Herrera, president of the ACDATEE:

“They are women who live in a situation of poverty, young women who have low levels of education, know little of the law, and have little help to prepare a defence for their case. Therefore the Attorney General (*Fiscalía General de la Republica*) easily obtains prosecutions and the women remain incarcerated.”¹¹³

Further, the ensuing trials¹¹⁴ fall short of the international standards for a fair trial and equal protection of the law.¹¹⁵ There are documented cases of women who have been charged with abortion-related crimes in El Salvador who have been unable to meet with legal counsel prior to their trial and have not been permitted to testify in their own defence.¹¹⁶ Expert evidence is provided by the

prosecution only and is often insufficient to support the charges and in particular the charge of aggravated homicide. For instance, the autopsy may list the gender and approximate gestational age of a foetus, but not the cause of death, nor whether it was a live birth. It is thus apparent that women’s right to equality before the law and judicial guarantees is disproportionately and unjustifiably affected by this process.

The case of Sonia Esther Tábora¹¹⁷ is emblematic of the lived experience of El Salvador’s abortion law. In 2005, Tábora was sentenced to 30 years in prison for aggravated homicide after she suffered a miscarriage. All aspects of her detention and trial reflect intersectional discrimination on grounds of sex and socio-economic status. Her patient confidentiality was violated, she was presumed guilty rather than innocent, and transferred from hospital to remand as though she were a dangerous criminal. Her trial did not meet the standards of a fair trial under international standards. No autopsy was carried out and no direct or scientific evidence was presented by the prosecution during the trial, which relied on the conjecture of the judge rather than proof. Tábora spent seven and a half years in prison before being released on 14 August 2012, following a review of her sentence. Although she was released, she was not exonerated of the crime for which she had been prosecuted.¹¹⁸

In previous similar cases, the result of judicial reviews has been for the sentence to be commuted or annulled on the basis that evidence was insufficient to support prosecution or that the sentence was excessively severe and disproportionate.¹¹⁹ However, women have generally served a substantial time in prison before such a review is granted, and are not exonerated of the crimes. The refusal to exonerate these women means that they

cannot receive reparations for the time they have spent in prison. Furthermore, it has an ongoing impact on all aspects of their lives, and in particular on their right to work: their papers still contain their “criminal record” and they are unable to secure work as a result, thus suffering further discrimination.¹²⁰

The situation in El Salvador demonstrates that a no-exceptions ban on abortion causes direct sex discrimination in relation to the rights to life and health, as well multiple discrimination, on grounds of sex, age and economic status, in relation to the rights to equality before the law, privacy and judicial guarantees. Poor, young, rural women are statistically more likely to require these services, and – because of the nature of health and legal services which they have the resources to access – they are also disproportionately more likely to have their rights violated by the state bodies involved. This illustrates that the violations of rights are disproportionately borne by this group of women, constituting intersectional and systemic discrimination, and perpetuating iniquities.

3. Litigation: Abortion, Equality and Non-Discrimination in Litigation and Advocacy

The discrimination caused by restrictive abortion laws demonstrated above can be addressed through strategic litigation and advocacy. By using an analysis based on equality and discrimination, an argument can be developed which is grounded in compelling obligations under IHRL, and which can result in the development of legislation which places immediate and mandatory obligations on the state to ensure substantive access to reproductive health services, including therapeutic abortion. This article will now examine how judicial bodies have interpreted the principles of equality and non-discrimination and how the principles can

be used in advocacy and litigation in order to ensure abortion laws which comply with obligations under IHRL. These decisions can serve as useful advocacy tools, both for ensuring substantive and non-discriminatory enjoyment in the specific countries concerned, and also to support broader national and international advocacy work to repeal restrictive and discriminatory abortion laws.

At the international level, there appears to have been a general reluctance to rule on discrimination in relation to abortion.¹²¹ Legal reasoning tends to have focussed on the rights to health or on civil and political rights, such as privacy, freedom of information, freedom from inhuman treatment, rather than examining any issues of equality or discrimination. However, strategic litigation at a national level has successfully used the principle of equality to overturn a no-exceptions ban on abortion. For example, the Colombian Constitutional Court made a landmark decision in 2006, which gave an expansive interpretation of equality and non-discrimination, and ruled that access to abortion was a key component of equality. The Court’s jurisprudence will be analysed, looking particularly at the expansiveness of legal protection which comes from the positive rights paradigm, in comparison to a negative rights approach.

3.1 Colombia: Equality and Non-Discrimination in Litigation

In 2006, the Colombian Constitutional Court overturned a no-exceptions ban on abortions in the case C-355-2006.¹²² The constitutional challenge was brought by Monica Roa, a Colombian attorney, on behalf of Women’s Link Worldwide as part of their strategic litigation programme. The Court relied on international human rights law and its interpretation by treaty bodies,

and in particular the International Bill of Rights, CEDAW, the Convention of Belém do Pará, and the Convention on the CRC.

The Court ruled that abortion must be allowed in three situations: when the pregnancy presents a serious threat to the life or health of the women, when the pregnancy is the result of rape, incest or other non-consensual fertilisation or when the foetus has malformations incompatible with life outside the womb. As such, abortion is recognised as a component of the right to reproductive autonomy, but only women whose circumstances fall within the three stated criteria have the right to freely decide on and access this option.

Discrimination and Equality

The decision specifically recognised the connection between equality and abortion. The Court interpreted the notions of equality and discrimination in an expansive manner, drawing on the state's obligations under regional and international human rights treaties.¹²³ Despite the restrictions in scope, the decision is firmly grounded in the rights to equality and non-discrimination, and offers a broad interpretation of discrimination with regard to lack of access to abortion. The Court's interpretation of the scope of discrimination analysed the range of rights which were restricted by the abortion ban, as well as the consequential impact on rights in the future. The Court ruled that sexual and reproductive rights:

“[E]merge from the recognition that equality in general, gender equality in particular, and the emancipation of women and girls are essential to society. Protecting sexual and reproductive rights is a direct path to promoting the dignity of all human beings and a step forward in humanity's advancement towards social justice.”¹²⁴

The Court further ruled that:

“[I]llegal abortion is a violation of the right to equal access to health, according to the equality test (...) and the denial of an abortion is a clear example of discrimination against women, violating their right to health and life.”¹²⁵

The Court reasoned that the ban had discriminated against women as a group, that men were not similarly treated in regard to required medical procedures, and that the justification of protecting foetal life at all costs was subjective and unreasonable. The Court also ruled that imposing gender roles based on stereotypes was an act of discrimination which violated the right to equality, and that the criminalisation of abortion embodied the stereotype of a woman as a reproductive machine, without taking into account that she may want to decide on other things for her life or that her life may be sacrificed for a life-plan imposed upon her.¹²⁶

The Court also analysed the intersectional and multidimensional nature of discrimination, highlighting groups who were especially vulnerable to be affected and evaluating the ongoing impact of the ban on equality. The Court reasoned that:

“[T]he criminalisation of a medical procedure that is only required by women violates the right to equality, and ignores the particular impact that an unwanted pregnancy has on the lives of young women, and women from low income and/or ethnic backgrounds.”¹²⁷

It also ruled that the criminalisation of abortion is:

“[A] violation of the equality of women with less power and resources (...)

and violates the right to freedom from discrimination in relation to economic and/or marital status when the only choice on abortion, compromises the ability of women to support their children.”¹²⁸

The state has obligations of an immediate nature regarding the right to non-discrimination, in that it cannot be subject to progressive realisation. Additionally, the state must take positive measures to ensure substantive enjoyment of rights and to overcome systemic discrimination. In this manner, the Court’s reasoning on intersectionality obliges the state to take positive measures to ensure that marginalised women from vulnerable groups or of limited financial means are able to access reproductive healthcare on an equal basis with others, and to remove all obstacles, in law or in practice, which prevent *de facto* access to reproductive health services.

Positive Rights Paradigm Versus a Negative Rights Approach in Litigation

Emilia Ordolis has assessed the immediate benefits of using a positive rights paradigm in this Constitutional challenge.¹²⁹ Specifically, she has compared the strength and meaning of the Court’s decision with decisions on abortion by the courts in the United States and Canada. Ordolis notes that:

“[W]hile the equality-based reasoning of the Colombian Constitutional Court led to positive rights remedies, the liberty, security of the person, and privacy-based approaches to abortion articulated by the North American courts have led to more negative rights remedies.”¹³⁰

Negative Rights Paradigm

Abortion legislation deriving from litigation or judicial review in the negative rights para-

digm created from a privacy or liberty of the person perspective (such as *Roe v Wade*), obliges the state to refrain from violating these rights by decriminalising abortion but does not oblige the state to guarantee access to it. Whilst this should guarantee a minimum standard of access, the state is obliged only to uphold a minimum formal standard, and not to take positive measures to guarantee substantive access to abortion or to eliminate systemic discrimination by addressing the specific needs of marginalised groups of women. Thus, states cannot create barriers to abortion in law, but they can create barriers in practice, for instance by creating legislation which makes it more difficult to access abortion services.

The negative rights approach is vulnerable to regressive laws and actions to restrict *de facto* access. Examples of this vulnerability can be seen in the recent adoption of legislation in several US states which restricts access in practice.¹³¹ Examples of laws and policies which restrict access to abortion in practice include: imposing restrictions on access to abortion drugs;¹³² creating targeted regulations of abortion clinics;¹³³ restricting state funding for abortions;¹³⁴ banning abortions after 20 weeks;¹³⁵ and imposing conditions on women seeking an abortion, such as requiring them to listen to a foetal heartbeat,¹³⁶ to undergo an ultrasound – which may need to be performed using a vaginal probe,¹³⁷ to listen to a detailed verbal description of the foetus,¹³⁸ or to wait a certain period of time before receiving the procedure.¹³⁹ The obligation to provide only formal access to abortion can create a two-fold barrier to substantive access: firstly it does not require the states to remove any obstacles; and secondly, it does not oblige the state to refrain from creating further obstacles. In this manner, legislation is vulnerable to regressive developments.

Neither does such an approach result in legislation which obliges the state to take positive measures to ensure substantive access nor to overcome systemic disadvantage. There is no obligation to remove barriers which “primarily affect marginalised women,” an omission which often results in the “failure of the state to become engaged in ensuring women’s access to abortion”.¹⁴⁰ In this manner, only formal rather than substantive access is ensured, and systemic discrimination and iniquities can persist.

Positive Rights Paradigm

This is in contrast to the positive rights paradigm created by the use of an approach based on equality and non-discrimination, which places an obligation on the state to remove any barriers to substantive access and to take positive measures to eliminate any systemic discrimination. In contrast, the positive rights paradigm seen in Colombia can allow for expansive and progressive developments. Although the original ruling of C-355-2006 was limited in scope in terms of the situation in which abortion is permissible, subsequent claims for *tutela* (judicial protection) have resulted in further clarification from the Colombian Constitutional Court. The Court’s judgments demonstrate a reinforcement, strengthening and expansion of rights and of obligations, as well as a clarification of processes and state obligations in order to achieve substantive access.

In subsequent cases, the Court has established that access to abortion in the situations defined in C-355-2006 is a critical component of reproductive healthcare and reproductive rights and is a matter of fundamental human rights and a component of *vida digna* (a dignified life) and of equality, which the state and all involved in the health and social services must take all necessary

steps to protect, respect and fulfil.¹⁴¹ The Court has further ordered that health professionals must respect patient confidentiality, that women must have adequate information to be able to exercise their sexual and reproductive rights freely and without discrimination, that abortion services must be available throughout the jurisdiction and offered without delay, and that sex education must include information about when abortion is legally permitted.¹⁴² The Court has expounded on the specifics of the state obligation to remove all obstacles and take positive measures to ensure substantive enjoyment and *de facto* access.¹⁴³ These include obliging local authorities to ensure that there is sufficient availability within the public health service, and prohibiting health professionals from diluting or disregarding any evaluation of a pregnancy’s risk, requesting a judicial authorisation for an abortion and refusing an abortion when a woman is in one of the permitted situations or to a minor under 14 years who is in a serious situation and whose parents or legal guardians do not give permission.¹⁴⁴ The Court has also clarified that conscientious objection cannot be collective or institutional, but is only valid in relation to an individual’s beliefs,¹⁴⁵ and has mandated that a request for abortion must be responded to within five days.¹⁴⁶ Importantly, the Court has also established that a risk to mental health is a sufficient reason to seek an abortion and that a mental health evaluation must be conducted on a woman seeking an abortion, thus expanding the provision and protecting the right to voluntarily terminate a pregnancy.¹⁴⁷

This demonstrates that the use of the rights to non-discrimination and equality can produce legislation which is less vulnerable to regressive actions and restriction, and where the State has clear and non-derogable obligations to protect, respect and fulfil. Further to

this, it can be progressively expanded in order to secure a broader access to abortion in line with the principle of equality. Although both the Guttmacher Institute and Women's Link Worldwide have reported that substantive access to abortion in Colombia has not yet met the standards required and that many women are still denied their right to a legal abortion,¹⁴⁸ it is clear that the legislative framework supports this right, that it cannot be restricted, and that claims of *tutela* have been instrumental in clarifying state responsibility and process in order to progress towards universal access. This framework enables advocates to work towards securing the substantial enjoyment of this right by the women of Colombia.

3.2 International Jurisprudence on Abortion, Discrimination and Equality

United Nations

In *K.H.L.M. v Peru*, the HRC declared complaints under Articles 3 (non-discrimination) and 26 (equality before the law) of the ICCPR to be inadmissible, stating that they had not been properly substantiated, because the petitioner had not provided any evidence relating to the events which demonstrated discrimination under the articles.¹⁴⁹ In *V.D.A. v Argentina*,¹⁵⁰ which concerned a young, mentally-impaired girl who had been raped and subsequently refused an abortion, the HRC ruled that there had been a violation of Article 3 in relation to Articles 7, 17 and 2(3) of the ICCPR, confirming that "the State's failure to exercise due diligence in safeguarding the legal right to a procedure required solely by women resulted in discriminatory treatment".¹⁵¹

The CEDAW Committee examined the case of *L.C. v Peru*,¹⁵² which concerned the case of a young rape victim who was denied a

therapeutic abortion and suffered a delay in non-obstetric medical treatment, which resulted in her suffering permanent disability. The Committee found that the petitioner had suffered multiple discrimination in accessing medical care and judicial protection, and held that the denial of access to therapeutic abortion and the delay in non-obstetric treatment was discrimination and gender stereotyping. Finding a violation of CEDAW Article 12, which obliges states to eliminate discrimination against women in access to healthcare, the Committee declared that:

"[O]wing to her condition as a pregnant woman, L. C. did not have access to an effective and accessible procedure allowing her to establish her entitlement to the medical services that her physical and mental condition required."¹⁵³

The Committee ruled that the denial of an abortion and the delay in medical treatment violated Article 5 of CEDAW, which obliges States to take measures *inter alia* to eliminate gender stereotypes, and were "influenced by the stereotype that protection of the foetus should prevail over the health of the mother".¹⁵⁴ The Committee also ruled that "the State party is obliged to take all appropriate measures, including legislation, to modify or abolish existing laws which constitute discrimination against women".¹⁵⁵

The case of *Alyne da Silva Pimentel v Brazil*,¹⁵⁶ also before the CEDAW Committee, did not involve abortion but was the first case regarding a maternal death to be decided by an international human rights body. The decision is significant as it established the obligation of states to guarantee that all women in their jurisdiction have substantive access to timely, non-discriminatory, and appropriate maternal health services, finding that the state "did not provide timely emergency

obstetric care, hence infringing the right to non-discrimination based on gender, race and socio economic background”¹⁵⁷ and that the treatment of the victim constituted multiple discrimination.¹⁵⁸

These cases show that the UN treaty bodies are concerned about the direct and multiple discrimination which women experience in accessing abortion and reproductive healthcare.

*Europe*¹⁵⁹

The ECtHR and ECommHR have avoided ruling specifically on the point at which the right to life begins, but have ruled on other aspects in relation to abortion, such as the right to privacy and to access and disseminate information.¹⁶⁰ Similarly, the ECtHR has found it “unnecessary” to rule on the right to non-discrimination (Article 14 ECHR) in relation to abortion in *A, B and C v Ireland* and in *Tysic v Poland*.¹⁶¹ This reflects a general reluctance of the Court both to rule on Article 14 and to address reproductive rights from the perspective of equality and discrimination. As outlined previously, the ECtHR allows states a wide margin of appreciation in the scope of their abortion laws. Were it to rule on discrimination and equality in relation to abortion and reproductive rights, the immediate nature of these rights could make this margin much narrower, and states may be obliged to take positive measures to ensure access and may be liable to have to restrictive laws challenged on these grounds.

The Inter-American American System

The IACHR¹⁶² has decided on some cases involving abortion, but these have not evaluated equality and discrimination, although a clear statement on this has been issued. In 2010, the IACHR issued Precautionary

Measures for “Amalia”, which asked Nicaragua to ensure that she could access essential non-obstetric health-care whilst pregnant.¹⁶³ In a friendly settlement issued in 2007, the IACHR held that Mexico had violated the rights of an adolescent rape victim, who was denied a legal abortion by means of coercion by medical professionals.¹⁶⁴ Mexico was ordered to pay reparations to the victim, an order which acknowledged the real costs of raising a child and also included psychological care, reflecting the mental health costs of being forced to continue with a pregnancy as a result of rape.

Following the hearing on the Reproductive Rights of Women at its 141st Regular Session, on 1 April 2011, the IACHR issued its boldest statement on abortion yet, requiring all member states to review all laws which could have a *de jure* or *de facto*:

“[D]iscriminatory impact on women in terms of their access to reproductive health services, and [...] to prevent any negative consequences that such measures could have on the exercise of women’s human rights in general”.¹⁶⁵

It went on:

“This implies the obligation to analyze in detail all laws, regulations, practices, and public policies that, in words or in practice, could have a discriminatory impact on women in terms of their access to reproductive health services, and the obligation to prevent any negative consequences that such measures could have on the exercise of women’s human rights in general. The States are likewise obligated to eliminate all barriers of fact or of law that keep women from obtaining access to maternal health services they need, including criminal sanctions for seeking such services.”¹⁶⁶

The statement requires that states remove all barriers – including criminal sanctions – that limit women’s access to maternal healthcare and:

“[R]eminds the States that therapeutic abortion is recognised internationally as a specialised, necessary health services for women intended to save the mother’s life when it is at risk due to pregnancy, and that denying this service constitutes an attack on the life and physical and psychological integrity of women”.¹⁶⁷

This recent development is extremely significant, as it firmly positions therapeutic abortion as an established medical-indicated procedure, which can be accessed through human rights. It also underpins the conclusion that an absolute ban on abortion does not comply with international human rights law and violates the fundamental principle of non-discrimination. Whilst the most recent statements from the IACHR align abortion and discrimination, these have yet to be integrated into a judicial decision.

In March 2012, a petition was submitted to the IACHR by the Center for Reproductive Rights and local Salvadoran organizations ACDATEE and the Colectiva de Mujeres para el Desarrollo Local (Women’s Collective for Local Development).¹⁶⁸ The case regards “Manuela”, a woman who was sentenced to 30 years in prison after suffering an obstetric emergency. Medical professionals believed she had attempted an abortion and informed the police, who accused her of murder and shackled her to the bed. Following this, she was sentenced to 30 years in prison. The trial did not meet international standards as “Manuela” was not able to meet with her legal counsel, speak in her own defence, nor was she presumed innocent until proven guilty. In prison, she was diagnosed with cancer but denied the medi-

cal treatment which could have saved her, and she died in prison in 2010.

This will be the first time an international judicial body will hear the case of a woman who has been imprisoned as a result of seeking emergency obstetric healthcare in a jurisdiction with a no-exceptions abortion ban. The petitioners argue that El Salvador’s no-exceptions ban on abortion violates the right to life, the right to personal integrity and liberty, the right to humane treatment, and the right to a fair trial and judicial protection, as well as the principles of equality and non-discrimination as cross-cutting themes which intersect all these rights.¹⁶⁹ This case is vitally important in order to obtain a judicial decision about abortion in the Americas – and specifically about no-exception bans.

If this case proceeds to the IACtHR, this will open the opportunity for a legally binding decision on access to abortion in the Americas. Furthermore, the IACtHR has been less reluctant than its European counterpart to apply the principles of equality and non-discrimination as cross-cutting rights in its judgments. Taking into account the IACHR’s statement on discriminatory abortions laws and the Colombian Constitutional Court’s interpretation of IHRL and the principles of equality and discrimination in relation to abortion, it is hard to imagine that the IACtHR would not adopt the same reasoning. In this respect, this case represents a critical stage in the development of jurisprudence on abortion and an opportunity for the links between abortion, equality and non-discrimination to be formally made by an international judicial body.

Conclusion

The principles of equality and non-discrimination have the potential to make a signifi-

cant contribution to formal and substantive access to abortion. It is clear that no-exceptions bans on abortion conflict with states' inviolable obligation under IHRL to uphold women's rights – and in particular their rights to life and non-discrimination. As the most recent opinions and jurisprudence of the UN and OAS bodies indicate, restricting therapeutic abortion is also in contravention of IHRL, violating *inter alia* a woman's rights to health, non-discrimination and freedom from inhuman treatment. The argument for therapeutic abortion as a human right is significantly strengthened when the rights to equality and non-discrimination are applied as cross-cutting themes, and when evidence of systemic direct and intersectional discrimination is used to support it. Arguments for equality and non-discrimination should continue to be used to advocate for *de facto* as well as *de jure* access to abortion – a critical element of reproductive healthcare – as

well as to seek remedy when these rights are not upheld.

Moreover, the rights to equality and discrimination are of a mandatory and immediate nature, requiring states to ensure substantive enjoyment of rights on an equal basis. Using these in litigation and advocacy against legislation, practices or policies that have the purpose or effect of discrimination and which create and perpetrate inequalities can create a foundation for the subsequent development of legislation which is expansive and less vulnerable to regressive action. The positive rights approach enables a multidimensional approach, which obliges the state to ensure substantive access and to address compound inequities, and which has the potential to identify and address the systemic and multiple discrimination faced by the most marginalised and vulnerable women.

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2 In this article, the term "emergency abortion" will be used to denote termination of pregnancy where the woman's life is at immediate risk; the term "therapeutic abortion" will be used to denote abortion where there is a risk to the woman's health or life, where the foetus has a terminal defect or where the pregnancy was a result of rape or incest; the term "elective abortion" will denote abortion available on demand; the term "spontaneous abortion" will denote miscarriage. A no-exceptions ban on abortion is a ban on all abortions, including emergency abortion.

3 In Europe, Malta and Vatican City also have no-exceptions bans on abortion.

4 Constitución de la República Dominicana, proclamada el 26 de enero. Publicada en la Gaceta Oficial No. 10561, del 26 de enero de 2010, Article 37, available at: http://www.suprema.gov.do/PDF_2/constitucion/Constitucion.pdf.

5 Sentencia C-355 de 2006 Corte Constitucional [C-355/2006], available at: <http://www.corteconstitucional.gov.co/relatoria/2006/c-355-06.htm>.

6 See Guttmacher Institute, “Legislation Enacted: Monthly State Update: Major Developments in 2012”, available at: <http://www.guttmacher.org/statecenter/updates/index.html#FOCA>.

7 Legislation allowing elective abortion in the first trimester was passed in April 2007. Despite a legal challenge to this law, in August 2008 Mexico’s Supreme Court upheld this decision.

8 The Argentine Supreme Court handed down a decision in March 2012 which clarified Section 2, Article 86 of the Argentine Penal Code, decriminalising abortion in all cases of rape, and ruling that women would not have to obtain judicial permission to access this, but could rely on a doctor’s *affidavit*.

9 In April 2012, the Supreme Court of Brazil expanded the circumstances under which abortion is not a criminal offence to include cases of anencephaly, a fatal foetal defect. The ruling, holding that criminalisation of abortion in such cases would violate a woman’s constitutional rights, concluded eight years of reason on this matter.

10 Protocol to the African Charter on Human and People’s Rights on the Rights of Women in Africa, Article 14(2) (c), reads: “State parties shall take all appropriate measures to (...) protect the reproductive rights of women by authorising medical abortion in cases of sexual assault, rape, incest, and where the continued pregnancy endangers the mental and physical health of the mother or the life of the mother or the foetus.”

11 Defined within the following instruments: Universal Declaration on Human Rights, International Covenant on Civil and Political Rights (ICCPR), United Nations Convention on the Rights of the Child, European Convention for the Protection of Human Rights and Fundamental Freedoms (ECHR), American Convention on Human Rights (ACHR).

12 No derogation from the right to life is stipulated in: Article 4(2) ICCPR, Article 15(2) ECHR, and Article 27(2) ACHR.

13 For this argument, see: Flood, P.J., “Does International Law Protect the Unborn Child?”, *The National Catholic Bioethics Quarterly*, 7(2), 2007, pp. 73-96; Freeman, K., “The Unborn Child And The European Convention On Human Rights: To Whom Does ‘Everyone’s Right To Life’ Belong?”, *Emory International Law Review*, 8, 1994, pp. 615-665; Joseph, R., *Human Rights and the Unborn Child*, Martinus Nijhoff Publishers/Brill Academic, 2009. Note that although Joseph’s work appears thorough, it lacks an accurate and analytic approach, bending IHRL to support her moral argument, rather than providing an objective and analytical approach to the provisions of the law, resulting in arguments which contain several inaccuracies, omissions and unsubstantiated claims.

14 See Michel, A.E., “Abortion and International Law: the Status and Possible Extension of Women’s Right to Privacy”, *Journal of Family Law*, 20(2), 1981, pp. 241-261; Zampas, C. and Gher, J.M., “Abortion as a Human Right – International and Regional Standards”, *Human Rights Law Review*, 8(2), 2008, pp. 249-294; Alston, P., “The Unborn Child and Abortion Under the Draft Convention on the Rights of the Child”, *Human Rights Quarterly*, 12(1), 1990, pp. 156-178.

15 Cook, R.J. and Dickens, B.M., “Human Rights Dynamics of Abortion Law Reform”, *Human Rights Quarterly*, 25(1), 2003, p. 24.

16 Article 32 of the Vienna Convention on the Law of Treaties stipulates that the *travaux préparatoires* provide one of a number of “supplementary means of interpretation” which can be used when the meaning of the treaty is ambiguous or obscure.

17 Cook and Dickens, above note 15; Zampas and Gher, above note 14.

18 “*Baby Boy*” Case (*White and Potter v USA*), IACtHR Resolution No. 23/81, Case 2141 (6 March 1981). In 1973 the US Supreme Court ruled in *Roe v Wade* (410 U.S. 113, 1973) that women had the constitutional right to terminate their pregnancy before the foetus was viable, thus legalising abortion in the USA. In the “*Baby Boy*” Case, the petitioners asked the Inter-American Commission on Human Rights (IACHR) to interpret the compatibility of the *Roe v Wade* decision, reading the American Declaration of the Rights and Duties of Man (ADRDM) with ACHR Art. 4(1). The IACHR’s interpretation of Art. 4(1) refers extensively to the *travaux préparatoires*, using them to guide the judicial decision.

19 The European Court of Human Rights (ECtHR) is established and mandated by Section II of the ECHR.

20 The European Commission on Human Rights assisted the ECtHR with admissibility of cases and examination of merits until it was abolished in 1998 by the 11th Protocol to the ECHR.

21 *A, B and C v Ireland*, 25579/05 [2010] ECHR 2032 (16 December 2010), Para 172.

22 *Ibid.*, Para 238.

23 In *A, B and C v Ireland* the Court ruled that this must be both *de jure* and *de facto* access to abortion. Whilst

emergency abortion is legal in Ireland, C was not able to access this due to *de facto* barriers, such as the lack of access to information. The court ordered that these barriers be removed.

24 Human Rights Committee, *General Comment 6: The Right to Life (Art. 6)*, U.N. Doc. HRI/GEN/1/Rev.7, 1982, Para 5.

25 *The "Street Children" Case (Villagrán-Morales et al v Guatemala)*, IACtHR Series C No. 63 (19 November 1999); *Yakye Axa Indigenous Community v Paraguay*, IACtHR Series C No. 142 (6 February 2006); *Sawhoyamaya Indigenous Community v Paraguay*, IACtHR Series C No. 146 (29 March 2006).

26 Goonesekere, S., "A Rights-Based Approach to Realizing Gender Equality", Para 61, available at: <http://www.un.org/womenwatch/daw/news/rights.htm>.

27 Women's Link Worldwide, "C-355/2006: Excerpts from the Constitutional Court's Ruling that Liberalized Abortion in Colombia", 2007, p. 48, available at: <http://www.womenslinkworldwide.org/wlw/bajarFS.php?tl=3&per=18>.

28 See, for example, Michel and Zampas & Gher, above note 14.

29 World Health Organisation Constitution, Preamble, Para 1.

30 Committee on Economic, Social and Cultural Rights, *General Comment 16, "The equal right of men and women to the enjoyment of all economic, social and cultural Rights" (Art. 3 of the Covenant)*, U.N. Doc. E/C.12/2005/4, 2005, para.29

31 *Ibid.*, Para 50.

32 Committee on Economic, Social and Cultural Rights, *General Comment 14, "The right to the highest attainable standard of health"*, U.N. Doc. E/C.12/2000/4, 2000, Para 34.

33 Committee on Economic, Social and Cultural Rights, *General Comment 3, "The nature of State Parties' obligations" (Art. 2, Para 1 of the Covenant)*, U.N. Doc. E/1991/23, 1990, Para 9.

34 See above, note 32, Para 30.

35 *Ibid.*, Para 43(a).

36 *Ibid.*, Para 33.

37 See above, note 30, Para 7.

38 Common Article 3 of the ICESR and ICCPR is not a stand-alone provision; it cannot be read on its own, but must be read in conjunction with another article.

39 See above, note 32, Para 18.

40 Committee on the Elimination of Discrimination against Women, *General Recommendation 24, "Women and Health"*, U.N. Doc. A/54/38/Rev.1, 1999, Para 11.

41 The Guttmacher Institute is a non-profit organisation based in the US, which aims to advance sexual and reproductive health worldwide.

42 Guttmacher Institute and the World Health Organisation, "Facts on Induced Abortion Worldwide," 2012, available at: http://www.guttmacher.org/pubs/fb_IAW.html.

43 Shaw, D., "Abortion and human rights," *Best Practice & Research Clinical Obstetrics and Gynaecology*, 24(5), 2010, pp. 633-646.

44 Human Rights Committee, *General Comment No. 28: Equality of rights between men and women (article 3)*, CCPR/C/21/Rev.1/Add.10, 2000, Para 10.

45 Amnesty International, *The Total Abortion Ban in Nicaragua: Women's Lives and Health Endangered, Medical Professionals Criminalised*, 2009, available at: <http://www.amnesty.org/en/library/asset/AMR43/001/2009/en/ea2f24b4-648c-4389-91e0-fc584839a527/amr430012009en.pdf>.

46 *Ibid.*

47 See above, note 40, Para 14.

48 *Ibid.* See also the *Concluding Observations of the Committee on the Elimination of Discrimination against Women: Colombia*, 02/05/1999, A/54/38. Commenting on Colombia's (now repealed) absolute ban on abortion, the CEDAW Committee stated: "the Committee believes that legal provisions on abortion constitute a violation of the

rights of women to health and life and of Article 12 of the Convention” (Para 393).

49 See above, note 44, Para 11.

50 Committee against Torture, *Concluding Observations on Nicaragua*, U.N.Doc. CAT/C/NIC/CO/1, 2009; see also *Concluding Observations on Chile, El Salvador and Nepal*.

51 The HRC can receive petitions about alleged rights violations from individuals in states who have adopted the (First) Optional Protocol to the ICCPR, recognising the Committee’s jurisdiction.

52 *K.N.L.H. v Peru*, HRC Communication No. 1153/2003 (14 August 2006).

53 Anencephaly is a fatal foetal defect, which always results in stillbirth or death within days of birth. Peru allows abortion *inter alia* when a foetus has a fatal defect.

54 See above, note 52.

55 See above, note 40, Para 11.

56 Article 26 ICCPR and Articles 8(2) and 24 ACHR.

57 See above, note 44, Para 20.

58 Ibid.

59 Article 17 ICCPR and Article 11 ACHR.

60 Article 14(2) ICCPR and Article 8(2) ACHR.

61 See above, note 32. Para 12(d) states that: “While lack of respect for the confidentiality of patients will affect both men and women, it may deter women from seeking advice and treatment and thereby adversely affect their health and well-being. Women will be less willing, for that reason, to seek medical care for diseases of the genital tract, for contraception or for incomplete abortion and in cases where they have suffered sexual or physical violence.”

62 The rights to a fair trial and the due process of law within the Organisation of American States (OAS) are prescribed in Articles 7, 8, 9 and 25 of the ACHR and in Articles XVIII and XXVI of the American Declaration on Human Rights. The ACHR further states the minimum guarantees required in providing these rights, thus outlining the accepted standards of a trial. These standards are reflected in other international documents, such as in Articles 9, 10, 14 and 15 of the ICCPR, and further detailed in the Human Rights Committee. (See Human Rights Committee, *General Comment No. 32 (Article 14: Right to equality before courts and tribunals and to a fair trial)*, CCPR/C/GC/32, 2007.

63 For example, in El Salvador; see case study at 2.2 below.

64 Committee on the Elimination of Discrimination against Women, *General Recommendation 19, “Violence against women”*, 1992, Para 1.

65 Ibid., Para 24(m).

66 Inter-American Convention on the Elimination of Violence against Women (Convention of Belém do Pará), Article 8(d).

67 See above, note 50.

68 See above, note 66, Articles 2(c) and 7.

69 Committee on Economic, Social and Cultural Rights, *General comment No. 20: Non-discrimination in economic, social and cultural rights (Article 2 Para 2, of the International Covenant on Economic, Social and Cultural Rights)*, E/C.12/GC/20, 2009, Paras 17 and 27.

70 IPAS, *La Muerte Materna en Nicaragua: La Vida de Cada Mujer Cuenta*, 2008, p.12, available at: <http://www.ipas.org/en/Resourses/Ipas%20Publications/La-muerte-materna-en-Nicaragua-La-vida-de-cada-mujer-cuenta.aspx>.

71 Ibid. and above note 45.

72 See above, note 69. See clarification of “other status” in part B.

73 Additional Protocol to the American Convention on Human Rights in the Area of Economic, Social and Cultural Rights (Protocol of San Salvador), Article 4.

74 Ibid., Article 10.

- 75 See above, notes 42 and 70.
- 76 Ibid.
- 77 See above, note 32, Para 23.
- 78 Committee on the Rights of the Child, *Concluding Observations on Nicaragua*, U.N. Doc. CRC/C/NIC/CO/4, 2010.
- 79 See above, note 70.
- 80 Ibid.
- 81 Ibid.
- 82 Ibid.
- 83 Inter-American Commission on Human Rights, "Audience Tématica Regional: Derechos Reproductivos de las Mujeres en América Latina y el Caribe", 2011.
- 84 Article 3 CEDAW.
- 85 See, for instance, Crane, B.B. and Hord Smith, C.E., "Access to Safe Abortion: An Essential Strategy for Achieving the Millennium Development Goals to Improve Maternal Health, Promote Gender Equality, and Reduce Poverty", 2006, available at: www.unmillenniumproject.org/documents/Crane_and_Hord-Smith-final.pdf.
- 86 Lamacková, A. and Zampas, C., Astra Network, "Sexual and Reproductive Rights and Gender Equality," 2007, p. 3, available at: http://www.astra.org.pl/pdf/publications/srhr_demography.pdf.
- 87 Centre for Reproductive Rights, "Persecuted: Political Process and Abortion Legislation in El Salvador: A Human Rights Analysis", 2001, available at: <http://reproductiverights.org/sites/crr.civicaactions.net/files/documents/persecuted1.pdf>.
- 88 See above, note 45, p. 20.
- 89 See above, note 69, Para 12.
- 90 See, for instance, Fregoso, R.L. and Bejarano, C.L., *Terrorizing Women: Femicide in the Americas*, Duke University Press, 2010.
- 91 See Zampas, C. and Gher, J.M., above note 14; and Human Rights Watch, *International Human Rights Law and Abortion in Latin America*, 2005.
- 92 So, M., "Resolving Conflicts of Constitution: Inside the Dominican Republic's Constitutional Ban on Abortion", *Indiana Law Journal*, Vol. 86, 2010, p. 723.
- 93 Penal Code of the Republic of Nicaragua (Law 641), Articles 143-149.
- 94 Letter dated 10 November 2006, from Victor Abramovich and Santiago A. Canton to Norman Calderas Cardinal, Nicaraguan Foreign Minister, cited in Amnesty International, above note 45, p. 32.
- 95 See above, note 45. See also Human Rights Watch, *Over Their Dead Bodies: Denial of Access to Emergency Obstetric Care and Therapeutic Abortion in Nicaragua*, 2007.
- 96 Amnesty International, "Nicaragua: 'Amalia' case 'a human rights scandal'", 2010.
- 97 See above, note 32, Para 21.
- 98 Article 12(1) CEDAW.
- 99 Medina Quiroga, C., President of the Inter-American Court of Human Rights, *La Convención Americana: Teoría y Jurisprudencia*, Centro de Derechos Humanos de la Facultad de Derecho de la Universidad de Chile, 2003, p. 78.
- 100 *De la Cruz-Flores v Peru*, IACtHR Series C No. 115 (18 November 2004).
- 101 Ibid., the Separate Opinion of Judge Sergio Garcia Ramírez, Para 7.
- 102 Human Rights Committee, *Concluding Observations of Third Periodic Report on Nicaragua*, U.N. Doc. CCPR/C/NIC/CO/3, 2008, Para 13.
- 103 IACHR, PM 43-10 - "Amalia", Nicaragua, listed in "Precautionary Measures Granted by the Commission during 2010", available at: <http://www.cidh.org/medidas/2010.eng.htm>.

104 Women's Link Worldwide, "Historic legal precedent in Nicaragua: The Inter-American Commission on Human Rights demands that the State adopt urgent precautionary measures to save the life of Amalia", 2010, available at: www.womenslinkworldwide.org/pdf_press/press_release_20100301_en.pdf.

105 See above, note 32, Para 9.

106 Committee on Economic, Social and Cultural Rights, *Concluding Observations on Nicaragua*, U.N. Doc. E/C.12/NIC/CO/4, Para 13.

107 Código Penal de El Salvador, 1998.

108 Morena Herrera, quoted in "El aborto natural está penado con cárcel en 5 países. El caso de El Salvador", available at: <http://portaloaca.com/articulos/antipatriarcado/1576-el-aborto-natural-esta-penado-con-carcel-en-5-paises-el-caso-de-el-salvador.html>. (Translated by the author.)

109 Colectiva de Mujeres Feminista para el Desarrollo Local, *Informe El Salvador: Balance de cuatro experiencias mesoamericana en torno al aborto*, 2009, available at: http://www.colectivafeminista.com/vista_contenido.php?tipo=4&conten=5.

110 Ibid.

111 According to the Fundación Iberoamericana para el Desarrollo (Latin American Foundation for Development), around 6,000 women have been imprisoned in El Salvador, having attended hospital following either a spontaneous abortion (miscarriage) or a clandestine induced abortion. See "Especial IV: Encarceladas por abortar (El Salvador)", available at: <http://www.fundacionfide.org/comunicacion/noticias/archivo/81694.html>. Note that the Spanish term "abortar" can refer to both spontaneous abortion (miscarriage) and induced abortion.

112 See above, note 109.

113 See above, note 108.

114 See *inter alia* the cases of Sonia Esther Tábora Contreras, Isabel Cristina Quintanilla, María Edis Hernández Méndez de Castro, Karina del Carmen Herrera Climaco, available at: <http://www.jurisprudencia.gob.sv>.

115 See above, note 62.

116 See *inter alia* the case of Isabel Cristina Quintanilla, above note 114.

117 See above, note 114.

118 ACDATEE, "Nota de prensa, Tribunal de Sentencia Reconoce Error Judicial al Condenar a 30 Años a Sonia Tabora", 16 August 2012, available at: http://www.colectivafeminista.com/vista_contenido.php?tipo=208&conten=1.

119 See *inter alia* the cases of Isabel Cristina Quintanilla and Karina del Carmen Herrera Climaco, above note 114.

120 Author's interview with Isabel Cristina Quintanilla, 20 August 2012.

121 See section 3.2 below.

122 See above, notes 5 and 27.

123 See above, note 5.

124 See above, note 27, Para 32.

125 See above, note 5, at "Igualdad".

126 Ibid.

127 Ibid.

128 Ibid.

129 Ordolis, E., "Lessons from Colombia: Abortion, Equality and Constitutional Choices", *Canadian Journal of Women and Law*, Vol. 20, 2008, pp. 263-288.

130 Ibid., p. 280.

131 See above, note 6.

132 For instance, see Oklahoma's HB 1970 (Medical Abortion Law) and HB 2381, which require a doctor to be physically present when prescribing RU-486 to a patient.

133 For instance, Mississippi's HB 1390, which requires anyone performing abortions in a clinic to be certified in obstetrics and gynaecology and to obtain "official admitting privileges" at a local hospital. Alabama, Arizona, Indiana, Kansas, Missouri, Oklahoma, South Carolina and Utah also have laws which require doctors who perform abortions to have admitting privileges in local hospitals.

134 For instance, South Dakota only funds abortions to save the life of the woman, having removed the provision for cases of rape or incest in 2006. Several states introduced legislation restricting abortion funding in Health Plans during 2012. For more details, see <http://www.gutmacher.org/statecenter/updates/index.html#funding>.

135 For instance, Arizona's HB 2036, Ohio's SB 76, New Hampshire's HB 1660 and Alabama's HB 18, ban all abortions after 20 weeks except in absolute medical emergencies – i.e. to save the woman's life.

136 For instance, Virginia's HB462 of 2012 and Texas' HB15 of 2011 require the medical professional to make the heart auscultation, where present, audible to the woman and provide a simultaneous verbal description thereof.

137 For instance, Virginia's HB462 of 2012 and Texas' HB15 of 2011.

138 For instance, Texas' HB15 of 2011 requires the medical professional to provide "a simultaneous verbal explanation of the results of the live, real-time sonogram images".

139 For instance, South Dakota's HB1217 of 2011 requires a three-day wait for an abortion and North Carolina's "Women's Right to Know Act" HB 854 of 2011 and Texas' HB15 both require a 24-hour wait.

140 See above, note 129, p.281.

141 Colombian Constitutional Court, Sentencia T-585 de 2010, available at: <http://www.corteconstitucional.gov.co/relatoria/2010/t-585-10.htm>.

142 Colombian Constitutional Court Sentencia T-388 de 2009, available at: <http://www.corteconstitucional.gov.co/relatoria/2009/t-388-09.htm>.

143 Ibid.

144 Ibid.

145 Ibid.

146 See Colombian Constitutional Court, Sentencia T-841 de 2011, available at: <http://www.corteconstitucional.gov.co/relatoria/2011/t-841-11.htm>.

147 Ibid.

148 Womens Link Worldwide, "Progress and obstacles of implementing the C355/06 Decision", 2012, available at: http://www.womenslinkworldwide.org/wlw/new.php?modo=detalle_prensa&dc=356.

149 See above, note 52.

150 *V.D.A. v Argentina*, HRC Communication No. 1608/2007 (25 May 2007).

151 Ibid., Para 8.5.

152 *L.C. v Peru*, CEDAW/C/50/D/22/2009 (4 November 2011).

153 Ibid., Para 8.15.

154 Ibid.

155 Ibid., Para 8.16.

156 *Alyne da Silva Pimentel v Brazil* CEDAW/C/49/D/17/2008 (10 August 2011).

157 Ibid., Para 7.2.

158 Ibid., Para 7.7.

159 Whilst this article focuses on the Americas, jurisprudence from Europe is included, as the IACtHR has authority to interpret other treaties under Articles 29 and 64 of the ACHR. See "Other Treaties Subject to the Consultative Jurisdiction of the Court" (Art. 64 of the American Convention on Human Rights), Advisory Opinion OC-1/82, 24 September 1982, Inter-Am. Ct. H.R. (Ser. A) No. 1 (1982).

160 For example, *A, B and C v Ireland*, 25579/05 [2010] ECHR 2032 (16 December 2010); *Paton v United Kingdom*,

8416/79 [1980] 3 EHRR 408 EComHR (13 May 1980); and *Vo v France*, 53924/00 [2004] ECHR 326 (8 July 2004).

161 *Tysiāc v Poland*, 5410/03 [2007] (20 March 2007).

162 The IACHR is an advisory body, which – as well as receiving petitions and making referrals to the Court – acts in a similar way to treaty monitoring bodies, compiling thematic and country reports and issuing clarifications and comments on specific points of law and their substantive implementation.

163 See above, Section 2.1.

164 *Ramírez Jacinto v Mexico*, IACHR Report No. 21/07 Petition 161-02 (9 March 2007).

165 Inter-American Commission on Human Rights, “Situation on the Rights of Women”, Annex to Press Release 28/11 on the 141st Regular Session of the IACHR, 2011, available at: http://www.oas.org/en/iachr/media_center/PReleases/2011/028A.asp. See also Inter-American Commission on Human Rights, “Access To Maternal Health Services From a Human Rights Perspective”, OEA/Ser.L/V/II. Doc. 69, 2010, available at: <http://cidh.org/women/SaludMaterna10Eng/MaternalHealthTOCeng.htm>.

166 *Ibid.*

167 *Ibid.*

168 See Center for Reproductive Rights, “Center for Reproductive Rights Files Case Revealing the Horrifying Reality of El Salvador’s Ban on Abortion”, 21 March 2012, available at: <http://reproductiverights.org/en/press-room/center-for-reproductive-rights-files-case-revealing-the-horrifying-reality-of-el-salvador>.

169 *Ibid.*

Statutory Parental Leave and Pay in the UK: Stereotypes and Discrimination

Vanessa Long¹

I. Introduction

The gender pay gap in the UK is one of the highest in Europe. Women are consistently paid lower salaries than men and are less likely to be appointed to high level and high profile positions.² These statistics exist in contrast to the higher levels of enrolment by women than men in higher education.³ Therefore, at some stage between the completion of education and the height of women's careers, it appears that there is some form of systemic discrimination at play. At the same time, men are disproportionately over-represented in higher management positions and are less likely to be the primary carers of children.⁴ It is the thesis of this article that both men and women are subject to systemic discrimination in these regards and that this discrimination is exacerbated by the system of maternity and paternity benefits currently in operation.

In this article, I will first contextualise the issue by outlining the international and European standards in relation to parental rights in Part II. In Part III, I will then outline the current position in UK law, identifying the differences in the treatment of men and women with regard to parental leave and pay.⁵ In parts IV and V, by reference to the Declaration of Principles on Equality 2008 (Principles on Equality),⁶ I will argue that pa-

rental leave provisions in the UK constitute direct discrimination against both men and women, which is incompatible with international, European and domestic standards. Further, I will demonstrate how this has contributed to the perpetuation of gender stereotypes in the UK.

II. International and European Standards for Parental Leave

Maternity rights, and specifically the right to a period of leave from employment before and after childbirth, are mentioned in numerous international treaties. They were first mentioned in 1966 in Article 10(2) of the International Covenant on Economic, Social and Cultural Rights (ICESCR), which states that "special protection should be accorded to mothers (...) and working mothers should be accorded paid leave or leave with adequate social benefits".⁷ Subsequently, the Convention on the Elimination of all forms of Discrimination Against Women 1979 (CEDAW) in Article 11(2)(b) obliged states to introduce maternity leave, including the right to return to work "without loss of former employment, seniority or social allowances."⁸ Additionally, Article 3 of International Labour Organisation Convention No. 156, adopted in 1981, provides that:

“Member [States] shall make it an aim of national policy to enable persons with family responsibilities who are engaged (...) in employment to exercise their right to do so without being subject to discrimination.”⁹

Maternity rights relating to employment are also enshrined in a number of regional European texts. The original European Social Charter, adopted in 1991, provides in Article 8 that member states must:

“[F]rom public funds [provide] for women to take leave before and after childbirth up to a total of at least 12 weeks [and] to consider it as unlawful for an employer to give a women notice of dismissal during her absence on maternity leave”.¹⁰

Additionally, European Parliamentary Assembly Recommendation No. R (96) 5 on reconciling work and family life provides that:

“[W]omen should be entitled to legal protection in the event of pregnancy, and, in particular, an adequate period of maternity leave, adequate pay or allowance during this period and job protection.”¹¹

It is clear that there is a trend in both the international and European texts to include provisions encouraging states to implement laws to enable women to continue their employment following becoming mothers. The intention of these provisions has clearly been to ensure that women are not discriminated against due to their unique ability to bear children,¹² by creating obligations on states to take this fact into account in formulating social policies. However, by focussing solely on the role of women in relation to parenthood, men’s role in this sphere has been undermined and unaccounted for. Accordingly, whilst these instruments promote protec-

tion for mothers, equal protection for men as fathers is overlooked.

Earlier treaties made only passing reference to the equal sharing of parental roles. For example, the preamble of CEDAW states:

“Bearing in mind (...) the social significance of maternity and the role of both parents in the family and in the upbringing of children (...) the role of women in procreation should not be a basis for discrimination but that the upbringing of children requires a sharing of responsibility between men and women and society as a whole.”¹³

Despite recognising the necessity of shared responsibility, the Convention is dedicated to the rights of women and makes no provision for rights to paternity benefits. Furthermore, Article 4(1) of CEDAW specifically provides for “special measures aimed at accelerating de facto equality between men and women”, which will not be considered to be discriminatory.¹⁴ However, “special measures” is not defined within the text and accordingly, is left to be interpreted by national governments in the implementation of CEDAW as domestic policies. Due to the obvious impact of the physical act of childbirth on women it is clear that some “special measures” specifically for women are necessary to achieve equality, for example a short period of leave from employment to recover from the physical trauma of labour.

The UK’s provisions for women arguably go beyond what is required by way of “special measures” under Article 4(1) of CEDAW. The UK’s maternity provisions provide women with an extended period of leave which arguably goes far beyond what is required to recover from the physical effects of childbirth, and is intended also to enable her to care for the child in its early years. This

provision is based on an out-dated notion that the mother is the only parent properly able to fulfil the primary care role and has resulted in women being effectively forced into the primary care role, as only the mother, and not the father, of a child is entitled to take an extended period of leave.

However, the notion of shared parental rights has been increasingly recognised on the international scene. The Revised European Social Charter adopted in 1996 (not yet ratified by the UK) imposes a further obligation to provide for parental leave for either parent, although the terms are not as prescriptive as for maternity leave. States are obliged to:

“[P]rovide a possibility for either parent to obtain, during a period after maternity leave, parental leave to take care of a child, the duration and conditions of which should be determined by national legislation.”¹⁵

Additionally, in 2002, European Parliamentary Assembly Resolution 1274 stated that:

“Parental leave was first introduced in Europe (...) as a key element of social and employment policies for women in work (...) [it] has since been adapted to meet the needs not only of women but also of men who wish to balance work and family life (...) The issue of parental leave is closely linked to that of the role of men in family life, since it permits a genuine partnership in the sharing of responsibilities between women and men in both the private and public sphere.”¹⁶

Furthermore, in General Comment No. 20, adopted in 2009, the Committee on Economic, Social and Cultural Rights (CESCR) stated that:

“[D]ifferential treatment based on prohibited grounds will be viewed as discriminatory unless the justification for dif-

ferentiation is reasonable and objective (...) Refusal to grant paternity leave may also amount to discrimination against men.”¹⁷

Accordingly, it appears that a trend is emerging which more explicitly recognises the rights of men as fathers and promotes policies which genuinely encourage the sharing of parental responsibilities.

III. Parental Leave in the UK

Rights to parental leave in the UK are a relatively recent phenomenon. The notion of “maternity leave”, as it is currently understood, was not introduced until 1975¹⁸ and a very limited right for up to two weeks paternity leave has only been available since 2002,¹⁹ with some improvements implemented in 2010.²⁰ This changing landscape of parental rights arguably reflects the transformation of societal attitudes towards men and women’s roles, both at home and in the workplace, during this period. However, this article argues that the resulting framework of rights does not enable an equitable division of parental roles.

Maternity

Maternity rights were first introduced in the UK under the Social Security Act 1973. This Act provided for a “Maternity Allowance” to be paid at a statutory rate for an 18 week period commencing up to 11 weeks prior to the expected date of birth.²¹ This legislation did not confer any right of return to work following a period of absence to give birth and care for the child. The right to a period of absence from, and return to, work was not introduced until 1975 under the Employment Protection Act which provided for up to 29 weeks of leave for each pregnancy and the right to return to work with the original employer:

“[I]n the job in which she was employed under the original contract of employment and on terms and conditions not less favourable than those which would have been applicable to her if she had not been so absent”.²²

In essence, this provision attempts to ensure that, upon return to work, women are in the same position they would have been in had they not been absent. However, the extent to which this is possible in practice is questionable. Extended absences may lead to out-dated skills and mean that women lag behind their male peers in terms of years of experience.²³

These rights to maternity leave and allowances have been consistently improved upon since their inception to enable women to more effectively balance their role as a parent with their career. However, they appear to be premised on the expectation that women should be solely responsible for child care and have failed to challenge this underlying assumption.

At present all women are entitled to up to 52 weeks of leave for each pregnancy in addition to the subsequent right to return to work, as originally conferred in the Employment Protection Act 1975.²⁴ This right to maternity leave is available regardless of the length of time a woman has been employed by her present employer.²⁵ Women may also be entitled to statutory maternity pay (SMP), if they have been employed for at least 26 weeks by the end of the 15th week prior to the expected due date. Under SMP, the initial six weeks are paid at 90% of the individual’s average gross weekly earnings, the next 33 weeks are paid at the statutory rates of £135.45 (or 90% of the salary, whichever is lower), and the final 13 weeks are unpaid.²⁶

Paternity

Paternity leave and pay in the UK were not introduced until much later than the equivalent maternity provisions. In 2003 the Paternity and Adoption Leave Regulations 2002 and the Statutory Paternity Pay and Statutory Adoption Pay (General) Regulations 2002 came into force, conferring on fathers for the first time the right to take a limited period of leave from their employment specifically for the purpose of spending time with and caring for their child. Under these regulations, fathers are entitled to one or two consecutive weeks of paternity leave for each pregnancy.²⁷ In line with the maternity leave and pay provisions, the right to paternity pay was also available where the individual had been employed for at least 26 weeks by the end of the 15th week prior to the expected due date.²⁸

In 2010 the Additional Paternity Leave Regulations and Additional Statutory Paternity Pay (General) Regulations were passed, introducing more extensive rights for fathers to take leave and return to work following the birth of their child. These regulations entitle fathers of children born on or after 3 April 2011, the opportunity to take up to 26 weeks of paternity leave, in addition to the two weeks already provided, for each child.²⁹ Men are entitled to this Additional Paternity Leave (APL) if they have been employed for at least 26 weeks by the 15th week prior to the expected due date **and** the child’s mother was entitled to SMP or SML **and** the child’s mother has already returned to work.³⁰ During this time, men are entitled to Additional Paternity Pay (APP) which is payable at the same rate as SMP, but is only payable during the period that the mother would have been entitled to SMP, had she not returned to work.³¹

APL and APP provisions have vastly improved the situation for fathers wishing to

take time off to care for their children, providing them with a degree of job protection if they wish to take time off after the birth of a child and also providing limited financial support to enable them to do so.

Parental Leave

In addition to the maternity and paternity leave and pay available in the UK, there is also a period of 13 weeks unpaid parental leave that can be taken by each parent for each child.³² The leave can be taken at any point until the child is five years old and is not transferable between parents.³³ In order to be eligible the parent must have been employed for at least a year.³⁴

Differential Treatment

It is important to highlight both the overt differences in the current provisions for maternity and paternity leave, in addition to the less apparent practical implications of these policies. Whilst these provisions do allow for sharing of parental responsibilities on a much greater scale than was possible prior to the new regulations, they do not do so on an equal basis and therefore, arguably do not go far enough in challenging traditional gender stereotypes.

The first and most obvious differentiation of treatment between men and women under these provisions relates to the periods of leave entitlement. Mothers are entitled to up to 52 weeks of leave for each pregnancy, whereas fathers are only entitled to a maximum of 26 weeks leave. Secondly, for women the right to maternity leave becomes available solely upon the basis of becoming a mother. In contrast, men are only entitled to paternity leave once they have been employed by their current employer for a certain period of time, a restriction

which only applies for women in relation to SMP and not leave.

The final distinction is that a man's entitlement to APL and APP is tied to the rights of the woman and how she chooses to exercise them. In order for a man to be entitled to APL or APP, the mother of the relevant child must have been entitled to maternity leave or pay **and** she must have already returned to work. Accordingly, the APL and APP provisions essentially operate as an exchange system whereby the mother is entitled to leave and she may, if she so wishes, allow the child's father to take up to half of her leave and pay. In practice this results in the position that if the mother of the child is not employed or is employed but wants to take her full leave entitlement, then the father will have no right to take leave. On the contrary, a woman's entitlement to maternity leave and pay stands alone and exists regardless of the position of the father.

Accordingly, the law currently creates an ordered system of parental leave, which affords more generous parental rights to women than to men, implying a policy that recognises the role predominantly of mothers in childcare and only secondarily of fathers.

IV. Discrimination

As discussed above, the UK provisions for maternity and paternity benefits clearly constitute differential treatment. Not all differential treatment of men and women amounts to unlawful discrimination and the definition of unlawful discrimination varies both across international instruments and domestic laws. This article relies upon the Declaration of Principles on Equality to define discrimination and argues that the UK's statutory provisions amount to illegitimate discrimination on this basis.

The Declaration defines discrimination as including the following:

“Direct discrimination occurs when for a reason related to one or more prohibited grounds a person or group of persons is treated less favourably than another (...) in a comparable situation.

(...)

Indirect discrimination occurs when a provision, criterion or practice would put persons having a status or a characteristic associated with one or more prohibited grounds at a particular disadvantage compared with other persons, unless that provision, criterion or practice is objectively justified by a legitimate aim, and the means of achieving that aim are appropriate and necessary.”³⁵

Discrimination on the grounds of “sex” is one of the prohibited grounds under the Declaration of Principles on Equality.³⁶ Accordingly, the definition of discrimination has the effect that, if men and women are regarded as being in a “comparable situation” in relation to becoming parents, any differential treatment in relation to parental provisions is direct sex discrimination.

Historically, maternity leave provisions have not been considered to be directly discriminatory. Prior to maternity leave’s introduction there existed an expectation that women would leave their employment in order to give birth to and care for a child. Ceasing employment served the dual purpose of enabling the mother time to recover from the physical act of labour and of providing a full-time primary carer for the child during the early period of its life. Therefore, the introduction of maternity leave in 1975 had the positive impact of providing, for the first

time, the opportunity for women with children to continue in their careers.

Although it is obvious that this leave has always constituted a difference in treatment between men and women, in 1975 it was more likely to have been viewed by society as a justified difference in treatment or a form of necessary positive discrimination or affirmative action to correct for the disadvantage that women suffer in their careers as a result of being the physical bearers of children. Accordingly, as **only** women were considered capable of being primary carers in the early years of their child’s life, men and women would not have been regarded as in a “comparable situation” in relation to becoming parents.

Based on this view of parenting and the linking of leave to the physical act of child bearing, the provision of parental leave only for women could constitute a “practice [that] would put persons having a status or a characteristic associated with one or more prohibited grounds at a particular disadvantage compared with other persons” but that was nonetheless “objectively justified by a legitimate aim”.³⁷ That is, the leave put men in employment who had recently fathered a child at a disadvantage in comparison with women in employment who had just had a child as they were not entitled to the same period of leave. However, the argument would follow that this was objectively justified by the legitimate aim of allowing the only appropriate carer of the child time away from her job to care for the child without ending her career.

Traditional gender stereotypes promoting the perception that women are the most appropriate primary carers of children were extremely influential in British society in 1975 and remain so today. The current maternity

and paternity provisions, whilst constituting an improvement, continue to be based on this out-dated attitude to parental roles. A matter of particular concern is that the Equality Act 2010, the UK's primary piece of anti-discrimination legislation, specifically carves the maternity leave and pay provisions out of its provisions on discrimination, so the leave and pay provisions remain lawful under UK equality law.³⁸

It is submitted that this carve out by the Equality Act is incorrect, and is not in line with modern attitudes to parental roles. The definition in the Declaration of Principles on Equality constitutes the embodiment of what the law should be in this area and the absence of such a carve out in the Principles is in line with a change in social attitudes.

Over the last 40 years there has been a transformation of social attitudes across Europe to these types of gender stereotypes regarding raising children. This is not only evidenced by the provision of parental leave on an equal basis in a number of European countries, but also by judgments from both the European Court of Human Rights (ECtHR) and the Court of Justice of the European Union (CJEU), as discussed below.

Following this change in perception of the purpose of parental leave from being inherently linked to the physical act of child bearing, in which women are uniquely capable, to being more closely entwined with the role of caring for the child, in which both parents are equally capable and should be equally entitled, it is submitted that differences in the parental leave afforded to men and women can no longer be justified as necessary affirmative action for women. As men and women are in a "comparable situation" as regards becoming parents, any differences in

leave entitlement should be viewed as direct discrimination on the basis of gender.

Following this analysis, it becomes clear that the current provisions in the UK for maternity and paternity leave, as described above, directly discriminate against men in relation to their family life by denying them the opportunity to spend equal amounts of time as their partner with their children.

Unintended Consequences

As a result of this direct positive discrimination in favour of women regarding their role as a mother, they have also suffered a distinct disadvantage. As previously only women have been entitled to extended periods of parental leave, and are still entitled to a longer period of leave under less stringent criteria, they have effectively been forced to take up to a year away from employment for each pregnancy. Although women are not required to utilise the full year of their maternity leave allowance, until 2011 leave was not transferable and therefore if it was not used it would be forfeited. Therefore, as the majority of parents consider it beneficial for at least one parent to stay at home with the child, taking an extended period of leave from work has been the only practical option for many mothers.

Accordingly, women have been subject to a detriment in the progression of their careers. It is commonly recognised that taking a year, or several years depending on the number of children, away from employment will necessarily result in slower career progression and lower wages. This was explicitly acknowledged by the UK Commission for Employment and Skills in 2006 when it stated in a report that:

"It has long been known that taking time out of the labour market to have chil-

dren is one of the main reasons that women earn less than men. It reduces the years of work experience that a woman builds up, and therefore reduces one of the factors valued through pay by employers. After an extended period out of work women may face many barriers to returning, such as low confidence and outdated skills. Even after a relatively short period away from work it can be difficult for women to return to or find jobs that match their skills, particularly if they want to work more locally or part time.”³⁹

Accordingly, forcing women to be primary carers necessarily denies them the opportunity to achieve their career goals in the same way as is open to men, on the basis of outdated attitudes to parenting.

In 2007, the UK submitted a report to the Committee on the Elimination of Discrimination against Women. In its concluding observations the Committee stated:

“The Committee continues to be concerned (...) about the persistence of occupational segregation between women and men in the labour market and the continuing pay gap, one of the highest in Europe (...) The Committee also recommends that the State party continue its efforts to assist women and men to reconcile family and professional responsibilities and for its promotion of equal sharing of domestic and family tasks (...) The Committee further recommends that the State party encourage men to share responsibility for childcare, including through awareness-raising activities and by taking parental leave.”⁴⁰

Despite growing consensus amongst European states on shared parenting and the move away from traditional gender roles in this sphere, it is clear that the UK provisions continue to disadvantage mothers in their careers.

Whilst provisions governing parental leave in the UK have been consistently improved upon since their inception, it is submitted that these developments have focused too strongly on fixing immediate problems as opposed to creating an equitable distribution of parental benefits between men and women. The original provisions were introduced to correct the immediate ill of women being required to cease their employment upon becoming a mother, a laudable aim. However, the effects of this provision have in fact had pernicious consequences for both men and women. In such circumstances a unified approach to equality which devised policies on the basis of the equal treatment of mothers and fathers, as opposed to present societal attitudes, would have resulted in a fairer system of parental leave.

Even the recent review and consolidation of UK anti-discrimination laws into the Equality Act 2010 has not addressed this issue, but rather has explicitly excluded maternity provisions from the scope of the definition of discrimination. However, as discussed below, recent developments in European law may have significant consequences for the UK legislation in this sphere and raise questions as to its compatibility with European standards.

V. Challenging the Law

Whilst the Declaration of Principles on Equality is not currently enforceable before a court, there are a number of legal mechanisms by which the current UK parental leave provisions may be challenged. In recent years, various preferential provisions for female employees who are mothers have been challenged on the grounds of sex discrimination before regional courts in Europe.

In *Joseph Griesmar v Ministre de L'Economie des Finances et de l'Industrie, Ministre de la*

Fonction publique, de la Réforme de l'Etat et de la Démocratisation,⁴¹ the Court of Justice of the European Union (CJEU) addressed the issue of the differential allocation of service credits to male and female Civil Servants, which were allocated to female employees according to how many children they had and used in conjunction with the length of service to determine pension entitlements. The CJEU established that:

“[T]he national legislature used a single criterion for granting the credit (...) namely that relating to the bringing-up of the children and (...) it simply took it for granted that they were brought up at the home of their mother”.⁴²

It further found that:

“[T]he situations of a male civil servant and a female civil servant may be comparable as regard the bringing-up of children. In particular, the fact that female civil servants are more affected by the occupational disadvantages entailed in bringing up children, because this is a task generally carried out by women, does not prevent their situation from being comparable to that of a male civil servant who has assumed the task of bringing up his children and has thereby been exposed to the same career-related disadvantages.”⁴³

Accordingly, the provisions related to service credits were found to constitute “a difference in treatment on grounds of sex: in regard to male civil servants who have in fact assumed the task of bringing up their children”.⁴⁴

Then, in the 2010 preliminary ruling in *Roca Álvarez v Sesa Start España ETT*,⁴⁵ the CJEU ruled that the denial of “breast-feeding leave” – a 30 minute reduction in the working day available only to mothers for the purpose

of feeding their unweaned child – to male employees who had become fathers where the mother was not also an employee, was a breach of the European Equal Treatment Directive.⁴⁶ Article 2 of the Directive states that:

“1. For the purposes of the following provisions, the principle of equal treatment shall mean that there shall be no discrimination whatsoever on grounds of sex either directly or indirectly by reference in particular to marital or family status.

(...)

3. This Directive shall be without prejudice to provisions concerning the protection of women, particularly as regards pregnancy and maternity.”

The CJEU found that “the positions of a male and a female worker, father and mother of a young child, are comparable with regard to their possible need to reduce their daily working time in order to look after their child” and therefore “the measure (...) establishes a difference on grounds of sex, within the meaning of Article 2(1)”.⁴⁷

The CJEU was therefore required to determine whether the “breast-feeding leave” was a provision “concerning the protection of women, particularly as regards pregnancy and maternity” falling within Article 2(3). It was held that:

“The leave has been detached from the biological fact of breastfeeding, so that it can be considered as time purely devoted to the child and as a measure which reconciles family life and work following maternity leave.”⁴⁸

Accordingly, the leave did not fall within the meaning of Article 2(3) and was discriminatory.

Following these judgments, it appears that the current UK provisions are not compatible with the European Equal Treatment Directive. The UK system of maternity and paternity does not create a distinction between the period of leave for physical recovery of the mother and the time purely dedicated to caring for the child, nor does it provide for any period of the leave to be shared on an equitable basis.

Most recently, the European Court of Human Rights has considered differential treatment of male and female employees with regard to parental leave. Its judgment in *Konstantin Markin v Russia*⁴⁹ was handed down on 22 March 2012 and addressed the issue of whether parental leave provisions in the Russian Military constituted sex discrimination. Mr Markin, a divorced member of the Russian Military, brought a case against the Russian government for denying him the opportunity to take the three years parental leave to care for his children, an opportunity which was available to all female personnel. The Military Court dismissed Mr Markin's claim for parental leave as having "no basis in domestic law", and declared that under the existing rules he was entitled to either three months parental leave or early termination of his military contract. On appeal the decision was upheld and it was stated that "male military personnel were not in any circumstances entitled to parental leave" under domestic law.⁵⁰

On further appeal, the Russian Constitutional Court also dismissed the applicant's case. Referring to the "special legal status" of the military, the Court held that by voluntarily joining the military the applicant had accepted a limitation on his civil rights and freedoms and therefore denial of parental leave was not incompatible with the right to equality enshrined in the Russian Constitu-

tion.⁵¹ The Court accepted the Russian Government's argument that in granting parental leave only to women it had considered the "limited participation of women in military service" and "the special role of women associated with motherhood", and that if servicemen were entitled to parental leave this would "cause detriment to the public interests protected by law".⁵²

Mr Markin complained of this decision in the ECtHR alleging a breach of his Article 14 right not to be discriminated against in conjunction with his Article 8 right to respect for his private and family life. The first section of the ECtHR found in favour of Mr Markin, holding that there had been a difference of treatment because:

"[I]n contrast to maternity leave (...) which [is] primarily intended to enable the mother to recover from the fatigue of childbirth (...) parental leave and the parental leave allowances (...) are intended to enable the parent to stay at home to look after the infant."

Accordingly, they considered that both parents were "similarly placed" regarding caring for the child.⁵³ The Court subsequently dismissed the Russian government's arguments that the differential treatment was justified in order to protect the operational effectiveness of the armed forces. It found there was a "lack of concrete evidence to substantiate the alleged damage to national security" and further considered that the Russian Constitutional Court, in finding in favour of the government, had:

"[B]ased its decision on a pure assumption, without attempting to probe its validity by checking it against statistical data or by weighing the conflicting interests of maintaining the operational effectiveness of

the army, on the one hand, and of protecting servicemen against discrimination in the sphere of family life and promoting the best interests of their children, on the other”.⁵⁴

Therefore, the Court held that Mr Markin’s Article 14 rights had been breached. The government was then granted leave to appeal to the Grand Chamber.

The Grand Chamber of the ECtHR held that although Article 8 does not “impose any positive obligation on States to provide parental leave allowances”, as such allowances “necessarily affect the way in which [family life] is organised” they fell within the scope of Article 8 and thus “if a State does decide to create a parental leave scheme, it must do so in a manner which is compatible with Article 14”.⁵⁵

In giving its judgment, the Grand Chamber of the Court dealt with a number of arguments that had been put forward by the Russian Government when seeking to justify this differentiation of treatment between male and female military personnel, including the arguments that: the efficiency of the Russian army would be compromised if all personnel were entitled to three years parental leave regardless of gender; the differential treatment acknowledged the special role of women in relation to parenthood; and that military personnel should be considered to have voluntarily waived a number of civil rights by signing up for military service. In examining these arguments, the Grand Chamber reiterated that differential treatment will be considered discriminatory if there is no objective or reasonable justification; that is, no legitimate aim and no proportionality between the aim and the measures used.⁵⁶

As to the first of the government’s arguments, the Grand Chamber stated that measures must be found to constitute a “real threat” to

the operational effectiveness of the military for discriminatory treatment to satisfy the proportionality requirement. Due to the lack of empirical evidence produced by the Russian government it could not be established that allowing male personnel to take parental leave would have any significant impact on the efficiency of the military. Female personnel were entitled to three years regardless of the position, and as Mr Markin had proved, women in his particular position were entitled to the leave without any concern of an impact on operational effectiveness.⁵⁷

As to the government’s argument that women have a special role in relation to parenthood, the Court reiterated that “gender equality is today a major goal” of the Council of Europe and that “reference to traditions, general assumptions or prevailing social attitudes in a particular country are insufficient justification for a difference in treatment on grounds of sex.”⁵⁸ The Court noted the change in societal attitudes by pointing out that sufficient consensus amongst European states demonstrated a move away from the Court’s earlier judgment in *Petrovic v Austria*⁵⁹, in which maternity leave provisions were held not to discriminate against men. Emphasising this issue, the Court considered:

“[T]hat the Government’s reference to positive discrimination is misconceived. The different treatment of servicemen and servicewomen as regards entitlement to parental leave is clearly not intended to correct the disadvantaged position of women in society of ‘factual inequalities’ between men and women (...) The Court agrees with the applicant and the third party that such difference has the effect of perpetuating gender stereotypes and is disadvantageous both to women’s careers and to men’s family life.”⁶⁰

Finally, in relation to the government's argument that servicemen voluntarily waive their constitutional rights, the Court accepted that for the protection of "national security" certain restrictions regarding the entitlement to parental leave would be permissible in order to ensure the efficient running of the army. However, these limitations must not discriminate on the basis of gender. For example, it may be permissible to offer only two years parental leave to service men and women as opposed to the three years available to the civilian population, as although this may be considered discrimination on the basis of professional occupation, it is justifiable under Article 8(2) in the interests of national security. It stated that:

"[S]uch a general and automatic restriction applied to a group of people on the basis of their sex must be seen as falling outside any acceptable margin of appreciation, however wide (...) and as being incompatible with article 14."⁶¹

The implications of this judgment cannot be overstated. The judgment clearly emphasises the importance of the advancement of gender equality and recognises the societal move away from the gender stereotype of the woman as the primary carer towards a model of equal sharing. With these acknowledgements made, the Court has set a high threshold for governments to cross in order to be able to successfully justify differential parental leave provisions for men and women. In particular, the Court was clear that, even in the armed forces context (and its close association with national security), in the absence of expert evidence or statistical data to back up a claim on the impact of a requirement of equal treatment on operational effectiveness, no such justification would be accepted.

In light of this latest judgment, it is difficult to envisage an argument that could be made by the UK government to successfully justify the current differential treatment under UK law. It appears that the current UK provisions are not compatible with the ECHR as interpreted by the ECtHR in *Konstantin Markin v Russia*. Therefore, the current statutory schemes in the UK are ripe to be challenged before the courts – challenges which would appear to have a strong chance of success.

VI. Conclusion

Throughout this article I have explored both international and domestic standards of parental leave and the effects which these have had on men's and women's roles as parents and employees. It has been demonstrated that the current provisions governing entitlement to parental leave in the UK directly discriminate against men and have indirectly had a negative impact on women in the progression of their careers. Despite advancements in societal attitudes, the statutory scheme of maternity and paternity benefits in the UK continues to promote out-dated stereotypes and inhibit men and women from partaking in the work and home life on equal terms. Finally, I have highlighted the incompatibility of these provisions with the ethos of recent international texts and developments in European case law.

Although current standards do not effectively guarantee equality at home and in the work place, they have at each stage of development represented significant improvements and reflected the gradual evolution of societal attitudes towards shared parental responsibilities and away from traditional gender stereotypes. However, the lack of attention to the indirect consequences of these provisions has resulted in working men being effectively excluded from primary care roles and women

being effectively forced into them. Accordingly, at present further advancements are required to keep apace with current attitudes and domestically enforceable rights to non-discrimination in the workplace. Employment

benefits based on traditional stereotypes of both women's and men's roles in the home and workplace cannot be continued, and must be reassessed in light of new legislation and modern attitudes.

1 Vanessa Long is an expert in human rights, holding an LLM in International and Human Rights Law. She would like to acknowledge the assistance of Sarah Mitchell and Joanna Whiteman who provided detailed comments on a draft of this article.

2 As reported by the Fawcett Society, available at: <http://www.fawcettsociety.org.uk/index.asp?PageID=321>.

3 Vincent-Lancrin, S., "The Reversal of Gender Inequalities in Higher Education: An On-going Trend", in OECD, *Higher Education to 2030*, OECD Centre for Educational Research and Innovation, 2008, Chapter 10, available at: <http://www.oecd.org/edu/cei/41939699.pdf>.

4 European Commission, Employment, Social Affairs and Equal Opportunities, "Men and Gender Equality – tackling segregated family roles and social care jobs", 2012.

5 Due to length restrictions, this article does not address equality issues surrounding same sex couples' rights to parental leave and pay, nor does it discuss adoption, leave and pay provisions.

6 *Declaration of Principles on Equality*, The Equal Rights Trust, 2008.

7 International Covenant on Economic, Social and Cultural Rights, G.A. Res. 2200A (XXI)(1966).

8 Convention on the Elimination of All Forms of Discrimination against Women, G.A. Res. 34/180 (1979).

9 Workers with Family Responsibilities Convention, C156, 67th ILC session (23 June 1981).

10 Council of Europe, European Social Charter, 18 October 1961, ETS 35.

11 European Parliamentary Assembly Recommendation, No. R (96) 5.

12 This article acknowledges, but does not seek to address the fact that the status of pregnancy as being "unique" to women is no longer entirely accurate given the potential, in certain circumstances, for transgendered men who have kept their female reproductive organs, to give birth. See for example, the case of Thomas Beattie, as reported by the BBC at: <http://news.bbc.co.uk/1/hi/world/americas/7488894.stm>.

13 See above, note 8.

14 Ibid.

15 Council of Europe, European Social Charter (Revised), 3 May 1996, ETS 163.

16 European Parliamentary Assembly Resolution 1274, 26 March 2002.

17 Committee on Economic, Social and Cultural Rights, *General Comment No. 20*, E/C.12/GC/20, 2 July 2009.

18 Section 35, Employment Protection Act 1975, c. 71.

19 Regulation 4, The Paternity and Adoption Leave Regulations, 2002, No. 2788.

20 Additional Paternity Leave Regulations and Additional Statutory Paternity Pay (General) Regulations, 2010, No. 1056.

21 Social Security Act 1973, c. 38, section 16.

22 See above, note 18, section 48.

23 Department for Work and Pensions, "Maternity rights and mothers' employment decisions", Research Report No 496, 2008, p. 3, available at: <http://research.dwp.gov.uk/asd/asd5/rports2007-2008/rrep496.pdf>.

24 The Maternity and Parental Leave etc. Regulations, 1999, No. 3312, section 7.

- 25 Ibid., sections 4-5.
- 26 Statutory Maternity Pay (General) Regulations, 1986, No. 1960, regulations 2(5) and 22.
- 27 See above, note 19, regulation 5.
- 28 Social Security Contributions and Benefits Act 1992, sections 171ZA-171ZE of Part XIIIA.
- 29 See above, note 20, regulation 5(2).
- 30 Ibid., regulation 4(2).
- 31 See above, note 28, section 171ZEA(2).
- 32 See above, note 24, regulation 14.
- 33 Ibid., regulation 15.
- 34 Ibid., regulation 13.
- 35 See above, note 6, Principle 5.
- 36 Ibid.
- 37 See above, note 6, Principle 5.
- 38 See Equality Act 2010, Schedule 22, section 2(1)(a).
- 39 UK Commission for Employment and Skills, “Women and Work – Shaping a Fairer Future”, 2006, p. 29, available at: <http://www.ukces.org.uk/publications/women-and-work-fairer-future>.
- 40 Committee on the Elimination of Discrimination against Women, Forty-first session, 18 July 2008, Para 39.
- 41 *Joseph Griesmar v Ministre de L'Economie des Finances et de l'Industrie, Ministre de la Fonction publique, de la Réforme de l'Etat et de le Démocratisation*, Case C-366/99, 29 November 2001.
- 42 Ibid., Para 55.
- 43 Ibid., Paras 55-56.
- 44 Ibid., Para 58.
- 45 *Pedro Manuel Roca Álvarez v Sesa Start España ETT SA*, Case C-104/09, 30 September 2010.
- 46 Council Directive 76/207/EEC of 9 February 1976 on the implementation of the principle of equal treatment for men and women as regards access to employment, vocational training and promotion, and working conditions.
- 47 See above, note 45, Paras 24-25.
- 48 Ibid., Para 28.
- 49 *Konstantin Markin v Russia* (Application No. 30078/06) European Court of Human Rights, 22 March 2012.
- 50 Ibid., Para 145.
- 51 Ibid., Para 34.
- 52 Ibid.
- 53 Ibid., Para 48.
- 54 Ibid., Para 57.
- 55 Ibid., Para 130.
- 56 Ibid., Para 125.
- 57 Ibid., Para 149.
- 58 Ibid., Para 127.
- 59 *Petrovic v Austria* (156/1996/775/976) European Court of Human Rights, 27 March 1998.
- 60 See above, note 49, Para 141.
- 61 Ibid., Para 148.

SPECIAL

The background of the page features a light gray gradient. In the upper left, there are faint, semi-transparent silhouettes of three people. One person on the left is gesturing with their hand, another in the center has their arm raised, and a third on the right is looking towards the center. The overall aesthetic is clean and professional.

“What really distinguishes the EU is its mix of power and principles. The addition of principles is not meant to simply add a list of side-constraints that, after the fact, can be used to question power. These principles can only be made real if they inform the use of the power. At the end of the day it is not really disability alone that is at stake. It is the very possibility of a Union based on the rule of law, human rights and democracy that is at stake. For this reason it is hoped that the EU will not fail its first serious test under the Convention on the Rights of Persons with Disabilities and that ways will be found to restore the conditionalities (or their equivalent) proposed by the European Commission to the Structural Fund Regulations.”

*Gerard Quinn
and Suzanne Doyle*

Taking the UN Convention on the Rights of Persons with Disabilities Seriously:

The Past and Future of the EU Structural Funds as a Tool to Achieve Community Living

Gerard Quinn and Suzanne Doyle¹

The European Union (EU) is facing a major test of its sincerity and commitment to the UN Convention on the Rights of Persons with Disabilities (CRPD). Current and positive proposals from the European Commission designed to bring EU Structural Funds into alignment with the CRPD are under pressure from Council. Failure to take the CRPD seriously will needlessly expose the EU – and its member states – to international legal liability if the Funds are used to build new institutions. And such failure will amount to a wasted opportunity to harness the Funds to ease a major process of transition needed to embed the right to community living for all.

1. The European Union Acquires a Human Face: EU Ratification of the United Nations Convention on the Rights of Persons with Disabilities

The EU is a formidable engine for economic integration. But from the outset its economic mission has been tied to a larger social and political mission. Famously, the founders foresaw a “spill-over” effect from economic integration into the evolution of a deeper union – a union with a human face. To a certain extent, the steady accretion of legal competence in the field of human rights by the EU mirrors this ambition and carries it forward. By happenstance one of the early beneficiar-

ies of this evolution has been Europe’s estimated 80 million citizens with disabilities. It is the (potential) marriage of power with principle that, unlike the Council of Europe, marks the EU apart as a force for good as well as a voice for good.

Partly because of the inspiration of the Americans with Disabilities Act (1990) the EU had switched dramatically away from welfare to a human rights and equal opportunities perspective on disability from the mid-1990s. A qualitative leap forward took place in late 2010 when the EU ratified (technically “confirmed” – this paper uses the two terms interchangeably) the UN Convention on the Rights of Persons with Disabilities (CRPD). This was a landmark event generally for the EU since it is the first international human rights convention to which it is a Party. Due to its status as a legally binding treaty, confirmation of the Convention has the potential to drive the evolution of a much more focused and robust set of EU-level responses in the form of legislation and policy change on disability. More to the point, all relevant EU financial instruments will have to be calibrated to ensure that they do not lead to results which cannot be squared with Convention obligations and which should, instead, play a much more constructive role in achieving its objectives.

The Council Decision to confirm CRPD was made on 26 November 2009 (the Decision to Confirm).² The actual instrument of confirmation was deposited over a year later in December 2010 after the Council adopted a Code of Conduct on the modalities by which the EU and its member states would appear before the UN on the Convention.³

In practical terms confirmation of the Convention ought to mean that a thorough review of legislation, policies and funding instruments should take place on an on-going basis to ensure conformity. It ought to mean that legislation, etc., found to be incompatible should be repealed or amended. It ought to mean that poor political processes that brought about such laws in the first place (largely through the absence of the voice of persons with disabilities) will have to be expanded to ensure that active – and meaningful – consultation takes place.

This essay focuses on one of the most important financial instruments of the EU and its relationship to the CRPD – the Structural Funds. The current debate about the need to radically amend the Regulations governing the EU Structural Funds to ensure compliance with the CRPD is rightly seen as a major test of EU commitment to the Convention. Considerable disquiet has been expressed at the way the Funds have been used in the past to fund the creation of new residential institutions for persons with disabilities (especially those with intellectual disabilities) in several recipient countries. Those who advocate for a radical change from the past argue that, at a minimum, the Funds should no longer be used (as they once were) to build new institutions to warehouse people with disabilities and that new innovative ways of transitioning people to community living should be found using the Funds as a spur. It is hard to characterise the building of institu-

tions as a “misuse” of the Funds in the past since the underlying Regulations were in fact permissive toward this kind of use. So the focus of attention is to change the underlying Regulations to make it plain that EU monies cannot be spent to open new institutions and that they should, ideally, be spent to enable transitions to community living to occur.

Many fine-sounding policy instruments on disability had been adopted by the EU before. Relying on them one might have made a cogent moral argument in the past that such expenditures should desist. The difference now is that the CRPD is a legally binding international treaty. So the arguments for change in the underlying Regulations have a lot more traction.

EU law is to the effect that “[a]greements concluded by the Union are binding upon the institutions of the Union and on its Member States” (Article 216(2) of the Treaty on the Functioning of the European Union). It has been held by the Court of Justice of the EU (CJEU) that while international agreements concluded by the EU are inferior to the EU Treaties they nonetheless rank superior to secondary EU law (which includes Regulations and Directives).⁴ In practical terms this ought to mean that such agreements have some form of lexical priority – secondary law should be interpreted in such a way as would optimise the possibility of compliance. More to the point, fidelity to such agreements ought to be the controlling factor when it comes to amending secondary legislation. This is of particular relevance in the context of the EU Structural Funds which are governed by Regulations and which are periodically renewed every seven years. At a minimum such Regulations must be drafted and interpreted in a manner that is consistent with the EU’s obligations under the CRPD.⁵

Of course, the EU did not confirm the Convention in a vacuum. It did so alongside its member states, all of which have signed the CRPD and the majority of which have ratified it. Such agreements are generally known as “mixed agreements” in the sense that they engage the often overlapping legal competences of the Union and its member states.⁶ It has been commented that its confirmation by the EU confers on it a quasi-constitutional status since it hovers somewhere between EU treaty law and secondary legislation.⁷ Therefore, “post-confirmation” EU legislative proposals must be self-consciously crafted not only to fit with, but also help to advance, the goals of the CRPD.

It is accepted practice that in the case of such “mixed agreements” both the EU and its member states will step up cooperation in order to ensure coherence and thus avoid needless legal entanglement and embarrassment at the international level. This desideratum of coherence and cooperation is reflected in the preamble to the Decision to Confirm, which states that:

“Both the Community and its Member States have competence in the fields covered by the [CRPD]. The Community and the Member States should therefore become Contracting Parties to it, so that together they can fulfil the obligations laid down by the [CRPD] and exercise the rights invested in them, in situations of mixed competence in a coherent manner.”

Naturally, the EU as such is answerable to the relevant international monitoring mechanism for matters that lie within its sphere of competence. But interestingly its member states also have an EU law obligation to implement the treaty to the extent that its provisions are “within the scope of Community competence”.⁸ Therefore, member states

which do not comply with the relevant obligations arising from such mixed agreements may be held in violation both of the Convention and EU law as such.

The tangled skein of EU competence and member state competence has long vexed commentators and judges alike. One thing is clear. Based on the reasoning in the European Court of Justice’s decision in *Kadi*,⁹ the CRPD cannot create any new EU competence where one did not exist before – nor can it expand any existing competence. But of course it can and should animate how such competences are to be used – which is directly relevant to the re-drafting of the Structural Funds Regulations.

As the Decision to Confirm makes plain, two sets of EU competences were put forward to justify or provide a legal base for EU confirmation: the internal market and non-discrimination. EU competence in the area of non-discrimination has been re-emphasised by Article 10 of the TFEU which states that:

“In defining and implementing its policies and activities, the Union shall aim to combat discrimination based on sex, racial or ethnic origin, religion or belief, disability, age or sexual orientation.”

The first big test of EU ratification has to do with the reform of the Structural Funds which impacts very visibly and very directly on the right of Europeans to live independently and be included in the community. One might say that a special onus falls on the EU in the eyes of the world since it took such a prominent part in the drafting of the Convention.¹⁰ If it fails this first big test many fingers will point to the EU as a body that does not practice what it preaches, which of course undermines its credibility (especially as it criticises others) and invites cynicism

about its motives. What is this big test and how can the EU successfully navigate it?

2. Home Sweet Home: The Centrality of the Right to Live Independently and be Included in the Community

Why is the right to live independently and be included in the community so important? Why is this seen as the first big test of EU sincerity and commitment to the CRPD? This is a good question since there are many other pressing issues such as inhuman and degrading treatment as well as employment and inclusive education.

Part of the answer lies in the nature of the right itself. The right (contained in Article 19 CRPD) is seen as emblematic of the much-vaunted “paradigm shift” in the Convention.¹¹ This paradigm shift is away from treating people with disabilities as “objects” to be managed or pitied and towards treating them as “subjects” and rights holders capable of directing their own personal destinies. It gives “voice” to people and forces others to respect their will and preferences. The edifice of the Convention is built atop this logic. It gives “voice” to persons with disabilities to form their own preferences, to express them and to have their will and preferences respected by third parties. It gives “choice” to persons with disabilities especially in how to live their own lives and particularly with respect to decisions having to do with personal living arrangements. And it opens up life “chances” by removing barriers to inclusion which can be tangible as well as intangible. Furthermore, it re-images welfare supports to ensure that they do not entrap people and to ensure that inclusion and community engagement is accentuated. This latter emphasis is entirely in keeping with EU2020 strategy toward a “smart, sustainable and inclusive” economy¹² and society which calls for

innovation with respect to the future of our social model.

Article 19 of the CRPD is much celebrated since it is the one that delivers on “choice” where it matters most to people – where to live and with whom. It reads:

“States Parties to the present Convention recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community, including by ensuring that:

- a) Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement;
- b) Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community;
- c) Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.”

Where you live – and whom you live with – is about so much more than bricks and mortar. It is foundational to identity – to a viable sense of self. Human personhood is something to be shared – it is through that sharing that we see “ourselves”. And it is through the intimate social connectedness that this facilitates that we build bridges into the community. This is why having the right to choose where to live and with whom is so

central. In a way it is the key portal to living a fuller life.¹³

Ensuring that this choice exists requires the affirmation of a number of other rights contained within the CRPD, primarily Article 12 which places an obligation on states parties to ensure that the necessary supports are put in place to ensure that individuals can exercise their inherent legal capacity and make their own decisions, such as those regarding their residence. Article 9 on accessibility is also implicated since there is no point choosing where to live – which is a bridge into the lifeworld – if all aspects of the lifeworld are not open and accessible.

Article 19 requires putting in place a web of personalised supports to meet the personal circumstances of the person. This is not so much about needs and services – it is more about the silent revolution in traditional understandings of welfare which is to get away from gross proxies of need (with equally gross services) and to focus instead on the life plans and ambitions of the person. And Article 19 requires that community services be made fully inclusive of, and accessible to persons with disabilities. This requires a transition away from institutions (and locking away scarce public money in institutions) and unbundling resources to enable genuine community living to occur. In many poorer EU member states this is precisely the facilitating role one might expect of the Structural Funds. Institutionalisation affects all persons with disabilities. But it particularly affects persons with intellectual disabilities. There is a paradox here. As institutionalisation sets in people become progressively stripped of their capacities to engage in the community. A self-fulfilling cycle kicks in to rationalise their exclusion. That cycle needs to be broken. Lying behind Article 19 is a faith in the evolutive nature of human capacities – espe-

cially the capacity of even persons with profound intellectual disabilities – to respond to social stimuli and to live more fulfilling lives – lives they choose.

The very novelty of Article 19 has prompted many authoritative commentaries. Chief among them is an Issue Paper published in March 2012 by the former Council of Europe Commissioner for Human Rights, Thomas Hammarberg, entitled “The Right of People with Disabilities to Live Independently and Be Included in the Community”.¹⁴ This is of course not an official interpretation of the Convention and it could not, in any event, bind the European Union. But it is worth quoting for illustrative purposes. In it Commissioner Hammarberg summarises the core elements of the right as follows:

“Article 19 of the CRPD embodies a positive philosophy, which is about enabling people to live their lives to their fullest, within society. The core of the right, which is not covered by the sum of the other rights, is about neutralising the devastating isolation and loss of control over one’s life, wrought on people with disabilities because of their need for support against the background of an inaccessible society. ‘Neutralising’ is understood as both removing the barriers to community access in housing and other domains, and providing access to individualised disability-related supports on which enjoyment of this right depends for many individuals.”¹⁵

In his view, Article 19 requires states parties to the CRPD to not only cease placing persons with disabilities in an institutional environment but also to actively ensure the vindication of the rights of persons with disabilities to live independently and be included in the community. In particular, the Commissioner has warned of the

dangers of replacing one form of institution with another:

“An incorrect understanding of the right to live in the community risks replacing one type of exclusion with another. Though governments increasingly recognise the inevitability of deinstitutionalisation, there is less clarity with regard to the mechanisms that replace institutionalisation and what would constitute a human rights-based response.

This is not merely a theoretical concern. Countries which have already closed down large-scale institutions are showing worrying trends of grouping apartments into residential compounds, comprised of dozens of units targeted exclusively to people with disabilities. (...) Such a solution compromises the individual’s ability to choose or to interact with and be included in the community.”¹⁶

Other bodies closer to the European Union such as the European Union Agency for Fundamental Rights (FRA) have also made their views on Article 19 known. FRA published a report in June 2012 entitled: *Choice and Control: the Right to Independent Living*.¹⁷ The FRA report contained the findings of interview-based research carried out in nine EU member states with persons with mental health problems and persons with intellectual disabilities. The research examined how they experience the principles of autonomy, inclusion and participation in their day-to-day lives. The report also sought to provide some examples of promising practices regarding independent living. Crucially, the FRA noted that:

“While Article 19 codifies the right to independent living, to be made meaningful in its fullest sense it must be read in conjunction with a number the convention’s other

articles, because the concept of independent living brings together many aspects of an individual’s life, and thus requires the realisation of many other human rights.”¹⁸

The interaction of Article 19 with other provisions in the Convention gives rise to interesting conundrums. Does the exercise of the right depend on a prior finding that the person possesses sufficient legal capacity to “choose”? The formulation used in Article 19 does give rise to the impression that one has to first wait to be declared capable of choosing before exercising Article 19 rights. Article 12 itself moves traditional analysis of legal capacity away from deficits and focuses instead on decision-making supports. It is therefore possible to view community living as a support necessary to enable a person to exercise his/her legal capacity under Article 12.3. In other words, there is no need to wait for a formal declaration of competence. This, at any rate, is the view taken by Commissioner Hammerberg:

“Curtailing the overall ability of individuals to make choices or have them respected naturally compromises opportunities to make more specific choices about where to live and how one’s life will look in relation to the community. At the same time, exclusion from life within the community increases the risk of legal capacity being denied. Little opportunity exists in the strictly controlled lifestyle, and lack of choice, inherent to institutional life, for an individual to voice his or her will.”¹⁹

Another interesting conundrum arises again from the concept of the right to “choose” where to live and with whom. What if a person genuinely chooses to live in a large institution or even a smaller one that effectively precludes genuine community engagement and inclusion? At one

level there seems to be a contradiction between the right to live independently (and one might choose to live as a hermit on an island) and the right to be included in the community. Surely we must give pride of place to individual preferences? What of the argument that the only way to genuinely respect the right to choose (which may entail choosing to remain in an institution or to go into one) is to ensure the continued existence of such institutions and a reasonable spread of them throughout the jurisdiction? This might be another way of saying that institutions should continue to exist and have a role – only this time the role is directly (albeit notionally) referable back to the wishes and preferences of the individual.

This is important for it would appear to leave some space (and therefore some national discretion) for the preservation of institutionalisation. If that were so, it would be permissible for the Regulations of the EU Structural Funds to allow recipient states to use the Funds to open new institutions and refurbish old ones. However, there would appear to be at least three strong countervailing arguments.

The first is that the autonomy to choose should be set against the general context of a right to inclusion and community engagement. This is apparent on its face in the opening narrative of Article 19 and is immanent in the general logic of the Convention. The second is that Article 19 has to be viewed against Article 8 (awareness raising) and especially the obligations of states parties to “nurture receptiveness” to the rights of persons with disabilities. That is highly unlikely to happen if popular prejudice about disability is reinforced by the continued existence of institutions. In a sense, the short term preference of the individual has to be set against the long

term goal of reform which is to prise open the popular imagination to the capabilities of persons with disabilities. Again, this is highly unlikely to happen in congregated settings. The third argument is that if this opening were allowed for institutions to continue (not on the grounds of cost but more on the basis, ostensibly, to respect individual preferences) then this would undermine the very possibility of a transition taking place from institutional to more personalised arrangements. This is primarily the case since budgets that are tied up in institutions are unlikely to be moved sufficiently over a reasonable period of time to enable more personalised arrangements to happen. The exception (institutions) could and probably would swallow up the rule. No dynamic of reform, no matter how well intentioned, could then gain traction over time. It would be much preferable to set a goal of securing personalised living arrangements that allow for the optimum possibility of community inclusion and engagement. Exceptions should be avoided in order to preclude them swallowing the rule. This does not mean that everything has to happen at once – that’s why international law endorses the concept of “progressive achievement”. But it is to say that no “progressive achievement” can ever realistically happen if the new rule (independent living) is constantly dragged back by exceptions that will only perpetuate isolation.

Article 19(b) provides for the right of persons with disabilities to access a range of community-support services. The design and delivery of social services in the past left much to be desired throughout the world and particularly in developed countries that could afford an elaborate social security safety net. For one thing, they were largely crafted around proxies of “need” – ideal images or categories of need that paid scant regard to individual circumstances. The result

of these practices has been services that fail to address the myriad of extremely personal factors that can only be taken into account in more personalised services. The result has also been the provision of costly services that may not map onto actual need but which are held on to by individuals (and their families) out of fear of not having an assured level of access when the need actually arises. For another thing, the services – or their manner of delivery – may well have met need but tended to do so in a way that accentuated isolation and exclusion from the community.²⁰

So Article 19 is not just about a home of one's own – it is about the social services needed to enable individuals to imagine and lead the lives they want. And that increasingly calls for not just a new philosophy of services that is clearly animated in the CRPD but also a new kind of personal assistance – a transfer of emphasis onto a new kind of social support that takes the individuals' preferences seriously. Article 19(c) sets out the right of persons with disabilities to equal access to mainstream services that are tailored to the individual's requirements. This element not only requires that community services and facilities for the general public are available to persons with disabilities on an equal basis with others but are in addition responsive to their needs. In countries that have expended a large percentage of their resources on institutions, this will be particularly hard to achieve. To make it happen will require forethought, deliberation, planning, and active involvement and consultation with civil society groups. And it will need to be done in a way that gives confidence to family members and others concerned with the welfare of the affected population.

So one reason for the focus on the right to live independently and be included in the community is the centrality of the right to

the lives of persons with disabilities. A second reason is the reality that here, at least, the EU can make a real difference. Many important issues and rights lie beyond the scope of competence of the EU. Most issues under the Convention reside within the more or less exclusive jurisdiction of its member states. Yet the Structural Funds are a classic example of an issue which, in a “mixed agreement”, engages the legal and moral responsibility of both the EU and its member states. Member states will not be spending monies unless and until the Structural Funds provide those monies. And the EU has at its disposal a powerful instrument to sculpt the right results – results which bring both itself and its member states into alignment with the CRPD. That is not to say that other issues are not important or indeed urgent. It is simply to say that in this domain the EU has a huge potential (as well as a legal obligation) to do good. This potential will not be achieved overnight – but, curiously enough, “progressive achievement” is what the CRPD demands and is also what the Structural Funds are peculiarly suited to.

3. Progressive Achievement and the EU Structural Funds – Rome Was Not Built in a Day – But It Was Built

International law distinguishes between obligations that take effect immediately and those that can be “progressively achieved”. The general prohibition against discrimination (which pervades the entirety of the CRPD) falls in the former category. It is at least arguable that the construction of new institutions (whether using EU monies or otherwise) is itself a form of discrimination. This is certainly the thinking of the US Supreme Court in its famous decision of *Olmstead*.²¹ In that case the Supreme Court held that in cases where it was determined that the persons in question could live indepen-

dently and wished to do so, institutionalisation of those persons was unlawful discrimination in the provision of public services.²²

It can certainly be argued that if, through silence in the underlying Regulations, the EU failed to condition the receipt of funds on compliance with Article 19, it could be found to have engaged in unlawful discrimination under the CRPD. A thorny issue arises with respect to the use of Structural Funds to refurbish existing institutions in order to make their living conditions more humane and tolerable. A purist answer would be that such a development would be similarly objectionable (to building new institutions) since refurbishment is likely to take the pressure off the need to develop genuine community alternatives and, in any event, does not satisfactorily address the overriding need to build bridges between the individual and the community. Furthermore, this class of violation is usually due to state action. Presumably the member state is individually and separately answerable to the UN monitoring process for these “violations”. However, since the EU has the means to mitigate the violations at its disposal, it might be reasonable to expect some ameliorative use of the Funds. In this instance, one might countenance a limited use of the funds to eliminate egregious conditions. However, in order to meet the spirit if not the letter of the Convention, such a use of the Funds should be made dependent on the recipient state demonstrating a deep and sincere commitment to move resources out of institutions and into the community. An extremely heavy onus of proof should be placed on the state to show that any such investment in institutions is strictly temporary (although it is never felt that way to the “residents”) and for the overriding purpose of eliminating inhumane and degrading treatment.

In general terms, it would be better for EU resources to be expended exclusively on a transition process away from institutions altogether and toward community living since primary responsibility and legal liability for existing human rights violations rests with the member states. If this is not possible, funding for improving conditions should be allowed only as part of a genuine plan (with a heavy onus on the state to demonstrate that it has one) for dismantling the institution and transitioning residents to settings with support in the community.

No matter how potent the non-discrimination weapon is, it will not drive the kinds of structural change needed to bring about substantive change. Indeed, the US Supreme Court could not order the re-allocation of funds. That had to await Congressional action. Twelve years later (in 2012) the US Congress established the US Federal Administration for Community Living – a body which oversees not just independent living for persons with disabilities but also independent living for older people.²³ The point is that the judgment of the Supreme Court was not self-executing. Europe doesn’t have to wait twelve years – it already has the Structural Funds to hand – provided they are animated appropriately.

It turns out that quite a lot of the change required by Article 19 will need to be “progressively realised”. States are therefore required to take all possible steps, using the resources available to them to their maximum ability, to fully realise the rights of persons with disabilities to live independently and be included in the community. Much therefore turns on what is meant by “progressive realisation” and whether, as a concept, it is robust enough to drive the change needed to transition to community living.

The concept of “progressive realisation” appears in Article 2.1 of the International Covenant on Economic, Social and Cultural Rights (ICESCR). It has no counterpart in the International Covenant on Civil and Political Rights (ICCPR). Long thought of as a weasel-like provision that undercut the status of economic and social rights as “real” rights, it lay in disuse until famously expounded by the UN Committee on Economic, Social and Cultural Rights in its General Comment No. 3 on the nature of states parties’ obligations. There the Committee stated:

“[W]hile the full realization of the relevant rights may be achieved progressively, steps towards that goal must be taken within a reasonably short time after the [ICESCR’s] entry into force for the States concerned. Such steps should be deliberate, concrete and targeted as clearly as possible towards meeting the obligations recognized in the [ICESCR].”²⁴

So just because change is long term does not absolve states from taking steps toward realisation. At a minimum that requires foresight, analysis and planning. In the context of securing the long term sustainability of a right to community living this requires a strategic vision – one in which due consideration is given to the optimisation of the Structural Funds.

The UN Committee amplified its position in relation to the progressive realisation of economic, social and cultural rights in the specific context of persons with disabilities when it stated in its General Comment No. 5 that:

“The obligation of States parties to the [ICESCR] to promote progressive realization of the relevant rights to the maximum of their available resources clearly requires Governments to do much more than merely

abstain from taking measures which might have a negative impact on persons with disabilities. The obligation in the case of such a vulnerable and disadvantaged group is to take positive action to reduce structural disadvantages and to give appropriate preferential treatment to people with disabilities in order to achieve the objectives of full participation and equality within society for all persons with disabilities. This almost invariably means that additional resources will need to be made available for this purpose and that a wide range of specially tailored measures will be required.”²⁵

Of course, the additional resources referred to here may come, at least in part, from the Structural Funds.

Implicit in the concept of “progressive realization” is some sort of balancing between a sense of the priority of the right and the state’s resource constraints. Resource constraints can take many forms. There may be resource constraints in terms of monies available for allocation. There may be resource constraints in terms of an underdeveloped public service capable of crafting new strategies and implementing them. There may be resource constraints that arise through the complexity of change and the need to reinvent budgetary and administrative processes. All such constraints apply especially in countries that have yet to acknowledge institutionalisation as in need of replacement. In a sense this places a premium on forward-planning.

Some states will be naturally tempted to delay a transition and progress toward achieving a transition plan because of the economic dislocation experienced across Europe since the on-going economic downturn that started in 2008. Of considerable relevance in this context are the findings of recent research

concerning the overall cost-benefit equation involved in any transition toward community living. Mansell et al,²⁶ in their comprehensive analysis of 2007 of the economic implications of the transition from institutional to community-based services, conclude that:

“There is no evidence that community-based models of care are inherently more costly than institutions, once the comparison is made on the basis of comparable needs of residents and comparable quality of care. Community-based systems of independent and supported living, when properly set up and managed, should deliver better outcomes than institutions.”²⁷

The authors also note that:

“In a good care system, the costs of supporting people with substantial disabilities are usually high, wherever those people live. Policy makers must not expect [these] costs to be low in community settings, even if the institutional services they are intended to replace appear to be inexpensive. Low-cost institutional services are almost always delivering low-quality care.”²⁸

The key point, however, is that the Structural Funds represent a major tool in ensuring that EU member states progressively achieve the requirements of Article 19. Rather than relying solely on national budgets to fund the transition from institutional to community-based resources and services, qualifying member states can use the Funds in a targeted manner in order to ensure a shift in policy and practice in line with the requirements of Article 19. This approach should be supported at an EU level by strong guidance on the use of the Funds in a manner consistent with the obligations of the CRPD. There is no inconsistency between the concept of “progressive achievement” and the appro-

priate use of the EU Structural Funds. To the contrary, the Structural Funds are precisely the kind of tool needed to “progressively achieve” the transition to community living and represent the very best added-value of the Union in a social policy field where innovation is key.

4. Anatomy of the EU Structural Funds – Key Tools for Social and Economic Innovation and Change

What are the Structural Funds and what purpose(s) are they intended to serve? How serviceable are they in the quest for ways to implement the CRPD?

The EU Structural Funds were created in order to address barriers to economic activity which might affect the functioning of the common market. It is hard to imagine an efficient – let alone a fair – common market that allows all losses to lie where they fall and that fails to correct for systemic or accumulated economic disadvantage.²⁹ The market alone will not correct for its “blind spots” and if no correction is found then the European market or economic integration project might itself be in jeopardy. Likewise, if wide disparities of the social situation in the member states are not corrected then the advantages of increased economic activity will continue to flow unevenly. Thus, for a combination of both economic and social reasons, the EU Structural Funds would have to be invented if they did not already exist.

The Structural Funds are distributed to (some) member states over a set programming period – usually seven years. Such programming periods are long enough to enable real change to occur and short enough to allow for appropriate adjustment as EU strategic priorities change. The Structural Funds are in fact part of the wider EU Cohe-

sion Budget reflecting EU Cohesion Policy during a particular programming period. Cohesion policy during the current period which is due to come to an end soon (2007-2013) had been focused on three priority objectives: convergence, regional competitiveness and employment. The convergence objective aims to help the least developed member states and regions that are lagging behind. The main fields of action are infrastructure (transport, environment, and energy), employment (training), innovation (research and development), information and communication technologies and improving the administrative efficiency of public administrations.³⁰

The strategic priorities for the next programming period (2014-2020) are taken directly from EU2020 strategy³¹ – something that dovetails very well with the CRPD. The Funds themselves are considerable. Approximately 35.7% of the EU budget 2007-2013 (equivalent to €347.41 billion over seven years at 2008 prices) was allocated to the various financial instruments which support Cohesion Policy.³²

From a legal point of view, the Structural Funds are traditionally governed by Regulations. A General Regulation is adopted which sets out the strategic priorities as well as management mechanisms and monitoring machinery. Fund-specific Regulations are then enacted to govern the relevant financial instrument in question. For our purposes there are two such relevant Regulations: Regulation of the European Regional Development Fund (ERDF) and Regulation of the European Social Fund (ESF). Unfortunately, legal literature and commentary on the Structural Funds is sparse which no doubt reflects their highly technical nature.³³ That is probably about to change as controversy over the (mis)-use of the Funds grows.

The Funds are not disbursed directly by the European Commission. Instead, qualifying states (mainly Eastern European states at this stage) put together national plans (Operational Programmes) which are reviewed and adjusted by the European Commission before the Funds are disbursed. The state then issues successive waves of calls to tender which are responded to nationally. The Funds are expected to bring “additionality” to bear on state action. That is to say, they are not intended as a replacement for state action that should otherwise occur. Further, they are designed to respect the principle of “subsidiarity”. So the strategic priorities of the EU must always be tailored to the circumstances of the state in question.

Despite the insertion of a novel provision prohibiting non-discrimination in the previous programming period (2007-2013), many commentators have noted that the Structural Funds have been used to open institutions, undermining the right to live independently and be included in the community.³⁴ The applicable generic non-discrimination provision is Article 16 of the General Regulation (2007-2013), which states that:

“The Member States and the Commission shall take appropriate steps to prevent any discrimination based on sex, racial or ethnic origin, religion or belief, disability, age or sexual orientation during the various stages of implementation of the Funds and, in particular, in the access to them. In particular, accessibility for disabled persons shall be one of the criteria to be observed in defining operations co-financed by the Funds and to be taken into account during the various stages of implementation.”

The limits of such generic provisions were graphically highlighted by a 2009 Study commissioned by the European Commis-

sion: *Study on the Translation of Article 16 of Regulation EC 1083/2006 for Cohesion Policy Programmes 2007-2013*, co-financed by the ERDF and the Cohesion Fund.³⁵ The Study was conducted by the Public Policy and Management Institute (PPMI, Lithuania) in partnership with Net Effect (Finland) and Racine (France). It concluded that there was a good overall awareness of the Article 16 requirements in programmes supported by the ERDF (explicit reference to it was made in 64% of the programmes analysed).³⁶ However, the study found that in most cases (70%), member states consider equal opportunities as horizontal or general priorities and do not devote attention to them in separate ground-specific strategies. In 22% of the examined programmes, the three examined themes (gender equality, non-discrimination and accessibility) appeared as declarative statements without clear targets, relevant selection criteria or obligations in terms of monitoring. Only 8% of the programmes integrated the three themes in a comprehensive strategy with clear identification of problems and quantified targets.³⁷ There has, therefore, been a lack of clear goal-setting and benchmarking by member states for the achievement of the non-discrimination requirements of Article 16 of the General Regulation.

In addition, the target groups for “non-discrimination” differed across member states: in EU12 (the 12 countries that became members of the EU by way of the enlargement on 1 May 2004) it was targeted mostly towards ethnic minority groups, particularly the Roma, while in EU15 (the 15 countries that were members of the EU before the enlargement on 1 May 2004) it was more about women, migrants and the elderly.³⁸ It is clear that this discrepancy in the understanding and application of the non-discrimination provision at member state level is something

which impedes the achievement of universal goals in relation to Article 19 of the CRPD.

Something more is needed to underpin the generic provision on non-discrimination to bring state behaviour in line with the CRPD. It is, therefore, clear that for the forthcoming programming period, a much more direct reference to the CRPD within the Regulations is needed both to avoid expenditures that create colourable violations of the CRPD and to optimise the positive potential of the Funds in enabling a genuine transition to take place. In all likelihood, this means building on but going beyond generic non-discrimination provisions.

4. Taking the CRPD Seriously – The European Commission’s Proposed Structural Fund Regulations for 2014-2020

Conscious of the ongoing criticism of the record of the Structural Funds in the field of disability and equally conscious of the need to bring the Funds into closer alignment with the only international human rights instrument the Union has ratified, the European Commission presented its long-awaited proposals for a new set of Regulations to govern the next programming period in October 2011.

Since the final regulations are to be adopted in the co-decision procedure, this means that the Commission’s draft will be the subject of intensive negotiations with the Council and the European Parliament. They are expected to emerge in final form in late 2012 or 2013. The European Commission’s proposals were quite strong. The Council has made it plain that it rejects some of the more positive elements in the Commission’s proposals. It remains to be seen if some of the more positive elements will survive. What follows is a brief description and analysis of the new elements.

(a) The Proposed General Regulation (2014-2020)

The proposed General Regulation gives explicit effect to the new EU strategic priorities as set out in EU 2020 (Article 4(1)).³⁹ Consequently, a set of eleven thematic priority objectives are set out in the draft Regulation. These rest on top of a transversal priority which is to avoid discrimination. Each Fund is expected to advance these thematic priorities in order to advance the goals of EU 2020 (Article 9).

Article 7 (within the rubric of “Principles of Union Support for CSF Funds”) sets out the overarching norm of equality and non-discrimination to suffuse all programming. It is to the effect that the member states and the Commission shall take appropriate steps to prevent any discrimination based on a number of grounds including disability. No specific mention is made of the CRPD.

Continuing with the general theme of equality and non-discrimination from the previous programming period, and giving it more operational effect at the beginning of the new programme drafting cycle, Article 87(3)(ii) of the draft General Regulation (which occurs within a chapter on the “General provisions on the Funds”) requires that each Operational Programme shall include:

“[A] description of the specific actions to promote equal opportunities and prevent any discrimination based on sex, racial or ethnic origin, religion or belief, disability, age or sexual orientation during the preparation, design and implementation of the operational programme and in particular in relation to access to funding, taking account of the needs of the various target groups at risk of such discrimination and in particular the requirements of ensuring accessibility for disabled persons.”

The specific mention of accessibility is to be greatly welcomed as this is essential for any meaningful strategy towards community living. However, the opportunity might have been taken to specifically cite institutionalisation as a form of discrimination that is specifically prohibited. It would certainly fit within the concept of discrimination and it would make sense to highlight it in a key provision dealing with embedding the principle of non-discrimination where it matters most – when Operational Programmes are being crafted.

Crucially, the proposed General Regulation contains new general ex-ante conditionalities which are essential pre-conditions for the receipt of Structural Funds. While they existed in the past (e.g., under a general rubric of avoiding discrimination), they are now systematised and given prominence in the draft General Regulation. They are set out in detail in Annex IV of the draft General Regulation entitled “Ex ante conditionalities”, which contains both thematic and general ex ante conditionalities. They are enumerated and aligned with the eleven strategic priorities of the new programming period (Article 9), with non-discrimination as an overarching priority (Article 7). In the table that sets out the eleven thematic goals (alongside the general non-discrimination criterion), a list of “fulfilment criteria” are specified and attached to each thematic priority to give an indication of the kinds of steps that should be taken by the member states.

In explaining the rationale for the inclusion of more particularised ex ante conditions for the next programming period of cohesion policy, the EU Commission stated that it must be ensured:

“[T]hat the conditions necessary for [the] effective support [of the funds]

are in place. Past experience suggests that the effectiveness of investments financed by the funds have in some instances been undermined by weaknesses in national policy, and regulatory and institutional frameworks. The Commission therefore proposes a number of ex ante conditionalities, which are laid down together with the criteria for their fulfilment in the General Regulation.”⁴⁰

In other words, the addition of the conditions is a way of reverse engineering into the architecture of state law and practice to optimise the chances that the Funds will meet their stated purpose. Member states are to assess whether the ex ante conditions are being met (Article 17(2)). They are expected to set out in their Operational Programmes “the detailed actions relating to the fulfilment of ex ante conditionalities including the timetable for their implementation”.⁴¹

If the conditions are not met at the time of the conclusion of their Partnership Contracts, the member states in question will set out clearly the actions to be taken to bring them into compliance within two years of the Contract (Article 17(3)).

Crucially, according to the draft Regulation, the European Commission shall assess information connected with the fulfilment of the ex ante conditions and:

“[M]ay decide to suspend all or part of interim payments to the programme pending the satisfactory completion of actions to fulfil an ex ante conditionality.

The failure to complete actions to fulfil an ex ante conditionality by the deadline set out in the programme shall constitute a basis for suspending payments by the Commission.”⁴²

This does no more than to just give reality to the ex ante conditionalities – something beyond rhetoric turns on their fulfilment which should concentrate the minds of national authorities.

Two sets of ex ante conditionalities are particularly important in the context of Article 19 of the CRPD.

The first important ex ante condition for our purposes focuses on the transversal thematic priority of combating discrimination. Within that rubric and in the specific context of disability (following the general provision as well as the provision on gender), this ex ante condition is to the effect of requiring member states to create “a mechanism which ensures effective implementation and application of [CRPD]”.⁴³

The reiteration of the need for Governments to set up these bodies is greatly welcomed in the draft ex ante conditionality. It is assumed that the overarching obligation to involve and consult with persons with disabilities will also be respected (and monitored in the relevant monitoring programme). It is also assumed that the national “focal point” and “coordinating” mechanism will explicitly bring the operation of the Structural Funds in their jurisdiction under their remit.

The “criteria for fulfilment” of this ex ante condition are highly specific and are stated to be:

“Effective implementation and application of the [CRPD] is ensured through:

- implementation of measures in line with Article 9 of the [CRPD] to prevent, identify and eliminate obstacles and barriers to accessibility of persons with disabilities;
- institutional arrangements for the imple-

mentation and supervision of the [CRPD] in line with Article 33 of the [CRPD];

- a plan for training and dissemination of information for staff involved in the implementation of the funds;
- measures to strengthen administrative capacity for implementation and application of the [CRPD] including appropriate arrangements for monitoring compliance with accessibility requirements.”

The reference to accessibility is quite important for the purposes of achieving the right to live independently and be included in the community. It applies particularly to infrastructural projects under the ERDF. Using the Structural Funds to ensure and enhance accessibility plays a major role in giving life to the right to live independently and be included in the community. The reference to institutional arrangements for the implementation and supervision of the CRPD is also greatly welcomed. Supervision in this context must be understood as including the monitoring requirements under Article 33(2) of the CRPD which, recall, has to contain a framework with one or more independent elements for the “protection, promotion and monitoring” of the Convention. Again, recall that Article 33(3) of the CRPD specifically requires the active involvement of persons with disabilities in this process.

The reference to training is also useful and most welcome. It stands to reason that, in any serious process of transition, the (re) training of human personnel is going to be a critical success factor. This applies both to staff involved in the administration of the Funds as well as personnel more generally in the field. As indicated earlier, the culture shift needed within services more generally will be quite significant. It will entail service providers seeing themselves less as meeting needs and more as building bridges into the

community and mending gaps in social connectedness. A mind-set change is needed and the Funds can play an enormously significant role in nudging this culture shift into place.

The reference to strengthening administrative capacity for implementation, application and monitoring of the convention is also a welcome and significant step forward.

The second draft ex ante conditionality of relevance falls under the 9th thematic priority of “Promoting Social Inclusion and Combating Poverty”. Rather confusingly this becomes the 10th “thematic objective” in the Annex (the 10th becoming the 9th). Falling thereunder there is an ex ante condition dealing with “active inclusion – integration of marginalised communities such as the Roma”. This calls for the existence of a national anti-poverty reduction strategy as well as a strategy for Roma inclusion. However, with respect to the relevant “criteria for fulfilment” covering the national strategy for poverty reduction there is a criterion that specifically calls for “measures for the shift from residential to community based care”.⁴⁴ This is very welcome as it sets the overall frame for the specific Funds and particularly the Social Fund, where social innovation is particularly required. Recall, this is an ex ante condition. In other words, it must exist in order to qualify a member state to receive funding.

In sum, the proposed inclusion of ex ante conditionality in the draft General Regulation is a welcome step forward. Indeed, it is hard to see how the EU could avoid ex ante conditionality if only to minimise its legal liability to the UN Committee on the Rights of Persons with Disabilities for member state actions that it could have avoided through better regulation of the Structural Funds. And the Declaration of Competence accompanying its “confirmation” of

the Convention made it inevitable that the ex ante conditions would include an express reference to the CRPD.

The ex ante condition of crafting measures “for the shift from residential to community based care” is particularly important. It provides a vital jump spark connection back to the CRPD. If it was not there it would have to be put in on account of the status of the CRPD. And the more particular reference to the implementation and monitoring mechanism required under the CRPD is also welcomed. The reality that the Convention engages the mixed competences of both the EU and the member states means that the relevant mechanisms have to be sensitised to the Structural Funds and how they operate. This is not just about ensuring a robust domestic implementation and monitoring mechanism in the abstract (which is required by Article 33(1) and (2) in any event). It is about tweaking those mechanisms to ensure that they avert their gaze appropriately to how or whether the Structural Funds are themselves contributing to or hindering the achievement of the CRPD.

On 24 April 2012, the General Affairs Council reacted strongly and negatively to the draft proposed by the European Commission. At that meeting the member states agreed on a “partial general approach” and adopted its own text. A “general approach” is a political agreement of the Council pending the adoption of a first reading position by the European Parliament. The general approach in this case is “partial” since some elements have not been broached including the exact sums to be devoted to cohesion policy and the eligibility of different regions which will be decided at a later stage in the process.

The Council text purports to remove all ex ante conditionalities. In the absence of such

robust conditionalities it is extremely hard to see how generic provisions on non-discrimination can do an adequate enough job of ensuring compliance with the CRPD. Furthermore, the Council’s text significantly weakens the role of the European Commission in monitoring compliance and withholding funds. Without the conditions the roadmap is gone. And without robust European Commission supervision the stick is gone.

The nature of the co-decision process means that further opportunities will arise to return to the position adopted in Council.⁴⁵ At the time of writing, the General Regulation is awaiting its first reading by the European Parliament.⁴⁶ It is understood that the European Parliament has presented over 4,000 amendments and is anxious to restore the relevant ex ante conditionalities. It is understood that some Members of the European Parliament (MEPs) have also tabled amendments that would expressly mention the CRPD in the recitals and also in draft Article 7 (the headline article on “Promotion of Equality between Men and Women and Non-discrimination”). It is unclear if the reference to the CRPD will (or can) be retained since it would give perhaps too much particularity to a headline norm on equality and non-discrimination and unbalance it in favour of disability. Against this, the additional and specific reference to the CRPD in draft Article 7 is defensible since this is the only international non-discrimination treaty that the European Union has ratified. It might also be said that the addition of the reference to the CRPD in a headline norm like Article 7 might prove problematical to the CJEU which cannot, as such, rule on such instruments since it is not a source of EU law. On the other hand, ratification by the EU has arguably conferred on the Convention a “quasi-constitutional” status hovering somewhere between primary treaty law

and secondary law. So although it does not – because it cannot – expand EU competence (and the law determining such), it is available to the CJEU as an interpretive tool. And it is certainly available to the Institutions as a source of norms according to which secondary law can be, and should be, developed.

With the support of the Commission (which is assumed) the matter will finally have to be resolved by tri-partite conciliation between the Commission, Council and Parliament.

It is fully appreciated that member states need a wide margin of appreciation in determining what mix of funds would be needed to best translate the majestic generalities of EU2020 into a domestic context. Subsidiarity is more than a slogan. However, it is submitted that the status of the CRPD as a legally binding instrument (binding both on the EU and its member states) converts what would otherwise be a matter of policy discretion into one of categorical imperatives. Removing the *ex ante* conditionalities will inevitably and predictably lead to a use of the Funds that cannot be squared with core obligations under the CRPD and hence merely stores up needless international legal exposure for the Union and its member states. It would be much better – and much more prudent from the perspective of avoiding international legal liability – to restore the conditionalities and other similar safeguards.

(b) The Proposed European Social Fund Regulation (2014-2020).

The European Commission's draft Regulation for the European Social Fund is important because it is a core instrument for enabling social innovation and change to occur. The Fund aims to promote, *inter alia*, "social inclusion thereby contributing to economic, social and territorial cohesion".⁴⁷

The focus on social innovation – a key theme of EU2020 – is mirrored in how the draft ESF Regulation references the new EU Programme for Social Change and Innovation (PSCI).⁴⁸ This is, in fact, a creative mix of long standing programmes including PROGRESS, EURES and European Progress for Microfinance Facilities.⁴⁹ The Programme for Social Change and Innovation will support policy coordination, sharing of best practices, capacity-building and testing of innovative policies, with the aim that the most successful measures could be up-scaled with support from the European Social Fund.

It may well be the case that elements of this new innovation programme can also be harnessed to help fertilise the transition process to community that is clearly needed. It is clearly relevant given that one of the PROGRESS strategies for the period 2007-2013 was ensuring that equality considerations, including disability accessibility requirements, were taken into account in all PROGRESS policy sections and activities.⁵⁰

The Explanatory Memorandum to the draft ESF Regulation specifically references the "European Platform against Poverty" which forms an integral part of Europe 2020 and which calls for social innovation for, *inter alia*, the transformation in the lives of persons with disabilities. Preambular paragraph 11 of the proposed ESF Regulation states:

"In accordance with Article 10 of the Treaty, the implementation of the priorities financed by the ESF should contribute to combating discrimination based on sex, racial or ethnic origin, religion or belief, disability, age or sexual orientation...

The ESF should support the fulfilment of the obligation under the UN Convention on the Rights of Persons with Disabilities with

regard inter alia to education, work and employment and accessibility. **The ESF should also promote the transition from institutional to community-based care.** [Emphasis added.]⁵¹

This preambular language is exceptionally useful in that it repeats familiar language on ending discrimination – surely an idea that precludes the building of new institutions. And, more to the point, it frankly concedes the need for a transition from institutional to community care and living. This is a crucial bridge back to the Convention and specifically Article 19 on the right to live independently and be included in the community. It shows a commendable awareness that a transition process is imperative and that social innovation will be called for to enable it to happen. The Social Fund will no doubt have a very important role in making this happen since the culture shift and related training need for human resources will be key.

Article 2 of the draft ESF Regulation follows through by including within the stated mission of the ESF into the next period the goal of benefiting people “including disadvantaged groups such as (...) people with disabilities (...) with a view to implementing reforms (...) in the fields of (...) social policies”. It also explicitly states that one of the key goals of the ESF in this regard is to:

“Provide support to enterprises, systems and structures with a view to facilitating their adaptation to new challenges and the implementation of reforms in particular in the fields of social policies.”

This too is greatly to be welcomed, particularly as it highlights the rights of persons with disabilities at the very outset in the mission statement of the ESF. And the direct mention of supporting adaptation to new challenges

and reform is highly relevant in the context of the transition set to take place in the move to community living.

The “scope of support” section (Article 3) deals more particularly with “promoting social inclusion and combating poverty”. It deals with the needs to: achieve “active inclusion”; combat discrimination on the grounds, inter alia, of disability; and encourage community-led development strategies. This, again, is greatly to be welcomed as it is exactly the kind of frame of reference needed in the context of the social innovation that needs to take place if community living is to become a reality.

More particularly, Article 8 of the proposed ESF Regulation states that:

“The Member States and the Commission shall promote equal opportunities for all, including accessibility for disabled persons through mainstreaming the principle of non-discrimination (...) and through specific actions within the investment priorities. (...) Such actions shall target people at risk of discrimination and people with disabilities, with a view to increasing their labour market participation, enhancing their social inclusion, reducing inequalities in terms of educational attainment and health status and **facilitating the transition from institutional to community-based care.**” [Emphasis added.]⁵²

Again, this draft language is commendable. And the specific reference to the transition from institutional to community-based care – which was already highlighted in the draft preambular language – is greatly welcomed.

Importantly, draft Article 6 deals with the “involvement of partners”. It is to the effect that the involvement of partners, “in par-

tical non-governmental organisations”, in the implementation of the relevant operational programme (as envisaged already in Article 5 of the draft General Regulation) may itself be supported using the ESF. Interestingly, the managing authorities are enjoined to set aside a sufficient amount to be allocated to “capacity building activities” such as training, networking and strengthening social dialogue. This is particularly relevant where social movements on disability are still in embryonic form and need support to develop to the point that they become constructive interlocutors in the dialogue for change.

Social transformation is the key. Usefully, Article 9 of the draft ESF Regulation is directed towards “social innovation”. The aim is the “testing and scaling up of innovative solutions to address social needs” (Article 9(1)). The member states are enjoined to identify themes for social innovation in their Operational Programmes. Since these programmes are to be designed with the relevant “partners”, this gives representative organisations of persons with disabilities considerable scope to ensure that the relevant innovation measures include those directed at moving the transition forward from institutional to community living. Furthermore, Article 10 of the draft enables states to enter “transnational learning” arrangements with the support of the Fund. The member states can pick from a list of themes to be proposed by the European Commission. It is strongly suggested that this list should include transnational learning platforms on the transition from institutions to community living.

The aforementioned meeting of Council did not remove or threaten to remove the abuse provisions. Hopefully they will survive the co-decision process intact.

(c) *The Proposed European Regional Development Fund Regulation (2014-2020)*.

The draft Regulation for the ERDF can support a range of projects and activities that may be of relevance in the context of disability. They include “investment in social, health and educational infrastructure” as well as “networking cooperation and exchange of experience between regions, towns and relevant social and economic actors”.

One of the “investment priorities” in the draft ERDF Regulation is stated to be:

“[I]nvesting in health and social infrastructure which contribute to national, regional and local development, reducing inequalities in terms of health status, **and transition from institutional to community-based services**”. [Emphasis added.]⁵³

Again, the specific reference to a transition from institutional to community based services is critically important.

Article 5.9(c) goes on to state that “support for social enterprise” is also a priority. This is also relevant in the disability context given that an entirely new social frame of reference will be needed to give life to the right to live independently and be included in the community.

The old 10% cap in the use of ERDF that applied to the purchase of land (with the on-going question mark over whether this also extended to the purchase of property on land) is carried forward in Article 59(3) (b) of the draft General Regulation. This of course applies to the ERDF as well as to the other Funds. This has been criticised by the European Coalition for Community Living.⁵⁴ The cap makes some sense on a theory of “additionality” whereby EU funds should

not be used to defray costs that states must themselves normally meet. But perhaps it need not be as inhibiting as suggested since the realisation of capital on the sale of institutions should provide states with sufficient assets to leverage the financial credit to enable more individualised housing options to be built in community settings. Put another way, the initiation of a serious transition process can be planned to successively capitalise on assets to be released from the sale of institutions perhaps aided by the 10% maximum allowable under ERDF.

Again, thankfully, the positive elements above in the European Commissions' draft ERDF Regulation were not displaced by the recent Council meeting.

(d) The Proposed Common Strategic Framework

Subsequent to the publication of its Regulation Proposals, the European Commission adopted a communication on a Common Strategic Framework (CSF) 2014-2020. This was published as a staff working document on 14 March 2012.⁵⁵ Its objective is to translate the general objectives and targets set out in the draft Regulations into key actions for the use of the cohesion funds. It thus aims to provide concrete direction of assistance to states in the programming.⁵⁶

The CSF will obviously have to reflect (and be consistent with) the content of the finalised Regulations. The Commission will launch a public consultation on the CSF at some point in 2012. Previously, it seemed likely that the finalised CSF would take the legal form of a delegated act after the finalisation of the Structural Fund Regulations in 2013.⁵⁷ However, MEPs have been calling for an adoption by co-decision procedure through making it an annex of the General Regulation based on the fact that, in their

opinion, the CSF is an "essential element" which expresses political views.⁵⁸ This latter approach seems to have gained more support in recent discussion.⁵⁹

There are many positive elements in the proposed CSF. Its utility, however, is in doubt given the current impasse over the final shape of the Regulations. Naturally, the two would fit better if the Regulations contained solid elements along the lines proposed by the Commission. In the absence of these strong elements (and if the Commission's monitoring role is diluted following the views of Council) it is hard to see how the CSF can gain real traction.

(e) The European Code of Conduct on Partnership

A much neglected aspect of the CRPD is its ambition to change process and not just substance. Of particular importance is Article 5(1)(c) of the draft General Regulation which stipulates, inter alia, that each member state will bring together different groups to sit on the partnership body including, specifically, "bodies representing civil society (...) and bodies responsible for promoting equality and non-discrimination". In line with the "partnership principle" (between states and civil society) contained in Article 5 of the draft General Regulation, the European Commission also published a Commission Staff Working Document in April 2012 on a European Code of Conduct on Partnership (ECCP).⁶⁰ It is intended to:

"[H]elp Member States to shape their partnership appropriately during the preparatory work before the regulations are adopted. In particular, it provides some examples of good practice on implementation of the partnership principle, based on the Commission's findings and various enquiries."⁶¹

It is further intended to outline:

“[T]he main requirements that the ECCP could contain as a basis for discussion with the European Parliament and the Council, in order to facilitate the on-going legislative procedure and to allow stakeholders to take part in this debate.”⁶²

The Commission has recommended that the ECCP be adopted as a delegated Act, as soon as the General Regulation for the period 2014-2020 enters into force.⁶³

It will be recalled that Article 4(3) of the CRPD requires that:

“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 organizations.”

The Commission Staff Working Document provides a useful suggestion for ensuring compliance with this provision by recommending that member states:

“[I]dentify, in their national context, the relevant stakeholders in the CSF Funds, the incentives and the legal and administrative barriers to partnership and possibly ways to address these obstacles. Member States are also encouraged to build upon the key existing national/regional/local partnership structures to minimise duplication and save time. Support for capacity-building might be necessary in order to help establish a representative and functioning partnership.”⁶⁴

The Commission goes on to suggest that:

“The ECCP could supplement the Common Provisions Regulation by requiring that the partnership includes the institutions, organisations and groups which can influence or be affected by implementation of the programmes. Specific attention will have to be paid to groups that might be affected by the programmes but find it difficult to influence them, in particular the most vulnerable and marginalised, such as the **persons with disabilities**, migrants, Roma (...) It is important to encourage pluralism in the partnership and to bring in the different relevant parts of the public sector alongside business, community-based and voluntary organisations, covering different types and sizes of organisations and including small innovative players.”⁶⁵ [Emphasis added.]

The specific recognition and mention of persons with disabilities as persons who will be affected by programmes financed by Structural Funds but who may not have previously had a voice within the national process is a notable progression and one which it is to be hoped will be maintained within the final ECCP.

Recognising the need to adjust partnerships in light of the programmes being undertaken, the document also states:

“For the ERDF and Cohesion Fund, partnerships will include (...) economic and social partners, representatives of NGOs having developed an expertise for cross-cutting issues, such as gender equality or **accessibility for persons with disabilities**, and for the relevant sectors where the funds are active ...

For the ESF, the involvement of economic and social partners in the partnership is es-

sential. Regional and local authorities will also be key partners, as will the chambers of commerce, business organisations, workers' education associations, education and training institutions, social and health services providers, NGOs and organisations having developed an expertise in the fields of gender equality, non-discrimination and social inclusion that have close ties with disadvantaged groups such as **persons with disabilities**, migrants, Roma ..." [Emphasis added.]⁶⁶

When engaging in this partnership process, member states are also reminded in the document that:

"Accessibility for persons with disabilities to the process both in terms of the physical environment and the information provided will also need to be taken into consideration."⁶⁷

Therefore, if this language is maintained in the final version of the ECCP, EU member states will have clear guidance in relation to the need to specifically structure their partnerships based on the nature of the programmes being undertaken. The potential impact of such an approach in the context of vindicating the rights of persons with disabilities to live independently and be included in the community is immense.

5. Conclusions

EU disability law and policy has come a long way since the early 1990s when people with disabilities were famously characterised as "invisible citizens". Advances in non-discrimination which have included both treaty changes and secondary legisla-

tion have anchored the rights-based perspective on disability in EU law. The landmark ratification by the EU of the CRPD copper-fastens this perspective at EU level. It augers well, or poorly, for future EU ratification of other international human rights instruments depending entirely on how the EU deals with this first real test of its sincerity and commitment.

EU commitment to the international rule of law was never going to be tested alone by laws and legislation. For the EU, unlike the Council of Europe, has real power which is transmitted through its various funding programmes. It would be ironic in the extreme if the EU Structural Funds, which are explicitly designed to bring about social innovation and facilitate development in lesser developed regions, were not consciously harnessed to help achieve some of the key goals of the CRPD.

We wrote at the outset of this essay that what really distinguishes the EU is its mix of power and principles. The addition of principles is not meant to simply add a list of side-constraints that, after the fact, can be used to question power. These principles can only be made real if they *inform* the use of the power. At the end of the day it is not really disability alone that is at stake. It is the very possibility of a Union based on the rule of law, human rights and democracy that is at stake. For this reason it is hoped that the EU will not fail its first serious test under the CRPD and that ways will be found to restore the conditionalities (or their equivalent) proposed by the European Commission to the Structural Fund Regulations.

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the authors on behalf of the United Nations Office of the High Commissioner for Human Rights (European Regional Office) entitled *Getting a Life – Living Independently and Being Included in the Community* which was launched at an event in Brussels on 7 May 2012.

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The European Union Structural Funds and the Right to Community Living

Camilla Parker and Luke Clements¹

Introduction

It is estimated that over 300,000 people with disabilities are housed in institutions across Central and Eastern Europe (CEE).² Traditionally, this has been the predominant, if not the only, form of “care” in CEE, with large, long-stay institutions housing hundreds, sometimes thousands, of people. This practice continues in many parts of CEE, despite the widespread acknowledgement that the institutionalisation of people with disabilities is an outmoded and unacceptable model of care in the 21st Century and leads to serious human rights violations.

This article is based on a report recently published by the Open Society Mental Health Initiative (MHI).³ MHI’s report considered whether the use of EU funds, known as “Structural Funds”, to build new, or renovate existing, long-stay institutions for people with disabilities, rather than developing alternatives to institutionalisation, is contrary to EU law in light of the EU’s ratification of the Convention on the Rights of Persons with Disabilities (CRPD). That some EU member states were using Structural Funds for such purposes was highlighted in a report published by the European Coalition for Community Living in 2010.⁴ This practice continues to be of concern.⁵

Importance of the Convention on the Rights of Persons with Disabilities

Both MHI’s report and the report of the United Nations Office of the High Commissioner on Human Rights (OHCHR), “Getting a Life: Living Independently and Being Included in the Community”,⁶ emphasise the importance of the CRPD in promoting the right of people with disabilities to live and participate in the community and the role of the EU in realising this goal. All member states of the EU have signed the CRPD, with 22 having ratified it.⁷ The CRPD was also ratified (referred to as “confirmation”) by the EU in December 2010.⁸ Accordingly, the CRPD has a significant impact on the responsibilities of the European Commission and member states in relation to the investment of Structural Funds for services for people with disabilities.

The CRPD and EU Law: Implications of the EU’s Ratification of the CRPD

The EU’s ratification of the CRPD means that the institutions of the EU and member states are under an obligation to implement the CRPD insofar as its provisions are within the scope of EU competence.⁹ Both “action

to combat discrimination on the ground of disability”,¹⁰ and the use of Structural Funds, fall within the area of shared competence between the EU and member states.¹¹

It is important to note that the CRPD provisions take precedence over secondary EU legislation. This is made clear by Article 216(2) of the Treaty on the Functioning of the European Union which provides that international agreements concluded by the EU are binding for the EU institutions as well as for member states.¹² As the Court of Justice of the European Union (CJEU) has stated:

“[T]he primacy of international agreements concluded by the Community over provisions of secondary Community [now Union] legislation means that such provisions must, so far as is possible, be interpreted in a manner that is consistent with those agreements.”¹³

Accordingly, it has been argued that the CRPD “will provide the basis for consistent interpretation of EC (now EU) secondary law” and:

“It can therefore be concluded that accession to the UN CRPD creates an obligation to interpret EU law in a manner that is consistent with the Convention. To this end, if the wording of EU law legislation is open to more than one interpretation, the ECJ [now CJEU] should adhere, as far as possible, to the interpretation that renders the provision most consistent with the UN CRPD. Similarly, and in line with Article 300(7) TEC, all European institutions and the Member States (for matters falling within EU competence) are required to apply EU law in a manner that is consistent with the UN CRPD.”¹⁴

Thus, to be lawful, the regulations governing Structural Funds must be interpreted consistently with the requirements of the CRPD.¹⁵

Relationship between the Strasbourg and Luxembourg Courts

The EU institutions, including the European Commission, are required to comply with the EU Charter on Fundamental Freedoms (“the EU Charter”), which is legally binding on member states when implementing EU law. Since December 2009 “the Charter has become the reference text and the starting point for the CJEU’s assessment of the fundamental rights which that legal instrument recognises”.¹⁶

There is a considerable overlap between the rights set out in the EU Charter and those contained in the European Convention on Human Rights (ECHR), and while the EU is not yet party to the ECHR,¹⁷ the ECHR has a special position in EU law.¹⁸ Much of the case law of the CJEU refers expressly to the ECHR and in practice it seeks, if at all possible, to make its judgments consistent with those of the European Court of Human Rights (“the ECtHR”) in Strasbourg.¹⁹

As discussed below, the ECtHR has emphasised the importance of the CRPD in protecting the rights of people with disabilities. Given the ECtHR’s influence on the CJEU, its approach to the fundamental rights of persons with disabilities is likely to be reflected in determinations by the CJEU.

Reflecting socio-legal change during the second half of the 20th century, the EU Charter, unlike the ECHR, is explicit in its protection of the rights of persons with disabilities. Article 21 specifically lists disability as one of the grounds on which discrimination must be prohibited, and Article 26 recognises the right of people with disabilities to “benefit from measures designed to ensure their independence, social and occupational integration and participation in the life of the community”.

Summary of Findings

MHI's report concluded that investing Structural Funds in institutional care, rather than developing community-based alternatives:

- Constitutes a breach of the EU's international legal obligations (in particular under the CRPD and the ECHR); and
- Amounts to disability discrimination under EU law.

These points, which are inter-related given the significance of the CRPD on EU law, are explored further in this article. This includes consideration of three broad areas: the relevance of the CRPD and in particular state parties' obligations under Article 19 of the CRPD, the development of case-law under the ECHR and disability discrimination under EU law. This legal analysis is preceded by an overview of the context for these discussions, namely the institutionalisation of people with disabilities in CEE and the potential role of Structural Funds.

Context: The Situation of People with Disabilities in CEE

Numerous reports have depicted appalling living conditions in institutions in CEE, such as poorly maintained buildings, lack of heating, malnutrition, inadequate clothing and unhygienic sanitation; physical and sexual abuse, lack of privacy, little to no rehabilitative or therapeutic activities as well the failure to provide procedural safeguards such as the review of involuntary placements.²⁰ Often these institutions are located in remote areas and residents have little to no contact with the outside world. In general, these are rigid regimes that take little or no account of individual needs or preferences.

A common response by governments presented with such concerns is to attempt to

improve living conditions, principally by renovating the institution. This may improve the physical environment, but it does nothing to address the fundamental issue that the segregation of individuals from society solely on the basis of a disability label is in itself a severe infringement of their human rights. Nor does such a response address the underlying problem of why people with disabilities are placed in institutions. A primary reason is the lack of alternatives to institutionalisation. In many CEE countries there is a severe lack of support in local communities that would enable people with disabilities to live in their own homes and participate in community life. The types of necessary services are wide-ranging and include housing (including supported housing), care in the family home, social work support, and supported employment, as well as access to mainstream services such as health care.

Structural Funds, namely the European Regional Development Fund (ERDF) and the European Social Fund (ESF), can be the catalyst for much needed change. They can be invested in financial and technical support to assist governments in planning and implementing their deinstitutionalisation strategies and in developing the community-based alternatives to institutionalisation.²¹ Indeed, the EU's "European Disability Strategy 2010-2020: A Renewed Commitment to a Barrier-Free Europe" envisages that the European Commission will promote the transition from institutional to community based care by using Structural Funds to support the development of community based services and raising awareness of the situation of people with disabilities living in residential institutions.²² It is therefore of serious concern that some member states are using Structural Funds to maintain the system of institutional "care" by financing the renovation

of existing institutions or the building of new institutions.²³

The Right to Community Living

The need for action to put an end to the institutionalisation of people with disabilities, by shifting the provision of care from institutions to community-based services (“deinstitutionalisation”), has been highlighted both at international²⁴ and European levels.²⁵ The introduction of the CRPD provides yet further weight to the calls for positive measures of this nature. By ratifying the CRPD, member states and the EU have made a commitment to ensuring that all people with disabilities can live and receive the support they need to participate in society as equal citizens (referred to as “the right to community living”). This right is now encapsulated in Article 19 of the CRPD which provides that people with disabilities have the right to live in the community, with the same choices as others.

Article 19 emphasizes the importance of providing support that enables people with disabilities to engage in community life, requiring states parties to take appropriate measures to facilitate their “full inclusion and participation in the community”. As the former Council of Europe Commissioner for Human Rights, Thomas Hammarberg, stated in his Issue Paper on Article 19, the right to live in the community applies to all people with disabilities, no matter how intensive their support needs:

“Time and again it has been demonstrated that people who were deemed too ‘disabled’ to benefit from community inclusion thrive in an environment where they are valued, where they partake in the everyday life of their surrounding community, where their autonomy is nurtured and they are given choices.”²⁶

The genesis of the right to community living can be traced back to various reports, comments by treaty bodies, and resolutions²⁷ and is supported by rights, such as Article 26 of the EU Charter (Integration of People with Disabilities) and Article 15 of the revised European Social Charter (the right of persons with disabilities to independence, social integration and participation in the life of the community). However, Article 19 of the CRPD is the first example of such an explicit right being included in a human rights treaty. It places obligations on states parties to take action to enable people with disabilities to realise this right. While included as a specific right in Article 19, the right to community living is integral to the CRPD with the themes of inclusion and participation referred to throughout the text.²⁸

Institutionalisation versus Community Living

There is a tendency for debates about the institutionalisation of people with disabilities and the action required to address it to focus on the size of the building. However, this is only one of a number of key factors. For example, an institution has been described as:

“[A]ny place in which people who have been labelled as having a disability are isolated, segregated and/or compelled to live together. An institution is also any place in which people do not have, or are not allowed to exercise control over their lives and their day-to-day decisions. An institution is not defined by its size.”²⁹

Similarly, the UN points out that “the size of the building is only one of a number of factors that create a culture of institutionalization”, other factors include residents having little, if any, control over their lives and day-to-day decisions and “rigidity of routine, such as

fixed timetables for waking, eating and activity, irrespective of individuals' personal preferences or needs".³⁰ The UN also notes that institutionalisation itself "can lead to serious and long-term adverse consequences" for people of any age, but particularly children, given that the "lack of emotional attachment is very damaging to their development".³¹

While these adverse factors are intrinsic to the traditional large, long stay institutions of CEE, they can exist in facilities of any size. Small community-based services can function as "mini-institutions" if residents have no choices or control over their lives. It is therefore essential to change the culture within services as well as the physical environment. The manner in which services and support are delivered must be based upon each individual's own needs, wishes and aspirations and be geared towards enabling people with disabilities to participate in their communities as equal members of society.

The CRPD and Community Living

Overview of the CRPD

The CRPD sets out a wide range of rights that address all aspects of disabled peoples' lives, such as respect for home and the family, education, employment, health, participation in political and public life, participation in cultural life, recreation, leisure and sport, the right to life, freedom from torture or cruel, inhuman or degrading treatment or punishment, and the right to equal protection and equal benefit of the law.³² It also emphasises the importance of the participation of people with disabilities, requiring governments to ensure the involvement of people with disabilities in both the development of legislation and policies that impact upon them³³ and the national monitoring of the implementation of the CRPD.³⁴ Unsurprisingly, the

principles of equality and non-discrimination are integral to the CRPD, not just being addressed specifically in Article 5 but running through the CRPD like a "red thread".³⁵

The adoption of the CRPD is the culmination of a growing acknowledgement and concern about the lack of attention given to the rights of people with disabilities.³⁶ In the relatively short time since it came into force (May 2008), the CRPD has taken on a significant role at the European level. For example, in *Glor v Switzerland* (2009)³⁷ the ECtHR emphasised the importance of the CRPD, noting that it reflects the international recognition of the need to protect the rights of disabled people.

Although some EU member states have as yet only signed the CRPD, the Vienna Convention on the Law of Treaties 1969 makes it clear that they cannot act in a manner which defeats the object and purpose of the CRPD.³⁸ In any event, following the EU's ratification of the CRPD, these states would be required to comply with CRPD treaty obligations in so far as these impact upon EU law. Furthermore, as was evident in *Glor*, the fact that a state had not ratified the CRPD (Switzerland had not even signed it) was not considered to be a material factor in limiting its relevance for the purpose of the ECHR.

Overview of Article 19

Article 19 is very broad in scope. It provides for "the equal right of all persons with disabilities to live in the community, with choices equal to others". States are required to "take effective and appropriate measures to facilitate" the right to live in the community and to promote "full inclusion and participation in the community". This right applies to all persons with disabilities, regardless of the degree of the disability or the level of sup-

port necessary. Article 19 has strong links to other CRPD rights. For example, the requirement in Article 19(a) that people with disabilities “have the opportunity to choose their place of residence” is linked to Article 12 (Equal recognition before the law) and that they are “not obliged to live in a particular living arrangement” links to Article 14 (Right to liberty and security of the person).

Obligations under Article 19

The Transition from Institutional Care to Community-based Services

Although Article 19 makes no specific reference to the need to close institutions, it is implicit that the closure of the long-stay institutions in CEE (together with the development of community-based services alternatives – i.e. a process of deinstitutionalisation) is a necessary consequence of compliance with its provisions. For example, the requirement that states parties ensure that persons with disabilities have access to community services that support their social inclusion and “prevent isolation or segregation from the community” cannot happen if they continue to be placed in institutions.

Given that the emphasis of Article 19, and indeed the whole CRPD, is on the full inclusion and participation of people with disabilities in the community, irrespective of the quality of care in long-stay institutions, the practice of isolating and segregating people with disabilities in institutions conflicts with the provisions under Article 19.

Progressive Realisation

While some obligations under Article 19 must be addressed by governments immediately, such as the requirement to recognise the right of people with disabilities to

live in the community, “with choices equal to others”, other obligations fall into the category of “economic, social and cultural rights” and are subject to the concept of “progressive realisation”, as described in Article 4(2) of the CRPD. This takes into account that the arrangements necessary to meet the realisation of such rights may take time to put into place and be subject to resource constraints. For example, it may take time for some states parties to develop a range of community-based services and supports that are geared towards the specific needs of people with disabilities as required by Article 19(b), particularly in those countries that have few community-based services and limited resources. However, the lack of resources does not justify inaction – states parties will be required to demonstrate that they are taking concrete and targeted steps towards realising the right to community living. Furthermore, the obligation to ensure that persons with disabilities can exercise their rights “without discrimination of any kind on the basis of disability”, including “reasonable accommodation”, takes immediate effect.³⁹

The CRPD Committee expects states parties to monitor their progress in realising the rights under the CRPD and report on such progress in their periodic reports.⁴⁰ For example in its concluding observations to the report submitted by Peru, the Committee raised concerns in relation to the implementation of Article 19 “at the absence of resources and services to guarantee the right of persons with disabilities to live independently and to be included in the community, in particular in rural areas”. The Committee urged the government to “initiate comprehensive programmes” to enable people with disabilities to access a whole range community support services “to support living and inclusion in the com-

munity, and to prevent isolation or segregation from the community, especially in rural areas".⁴¹

While the details of what action will be required to be taken will vary depending on the country context, it is argued the "progressive realisation" obligation under Article 4(2) of the CRPD requires all states parties to elaborate a "community living" plan.⁴² This must include a strategy and action plan for the closure of long-stay institutions and set out how the comprehensive review of law, policy and practice in relation to matters covered by Article 19 will be conducted.⁴³

Institutionalisation, Community Living and the ECHR

Although the ECHR contains no specific right to community living, its provisions unquestionably protect core components of this right. The freedom of individuals to exercise choice and control over their lives is, by way of example, integral to both the right to liberty (Article 5) and the right to private and family life (Article 8). The ECtHR has made this point explicit by emphasising that "the notion of personal autonomy is an important principle underlying the interpretation of its guarantees".⁴⁴

The Impact of Institutionalisation

Life in an institution is subject to substantial restrictions on a person's rights and freedoms. For example, an in-depth study of institutions in France, Hungary, Poland and Romania found:

"[I]n many respects, large residential institutions in these four countries are similar to those that have been studied elsewhere. Residents often live lives characterised by hours of inactivity, boredom and iso-

lation. Staff numbers are frequently too low to provide rehabilitation and therapy. The physical environment is relatively impersonal and does not provide the kind of privacy and homeliness that the general population expect. Contact with family and friends and community is limited."⁴⁵

Prohibition of Torture, Inhuman or Degrading Treatment or Punishment

In some cases the decision to institutionalise people against their wishes (or without informed consent) may not just interfere with an individual's personal autonomy, it may also amount to inhuman and degrading treatment. In *Stanev v Bulgaria*,⁴⁶ the ECtHR found the living conditions in a social care home, in which the applicant was required to live for nearly seven years, amounted to inhuman and degrading treatment in violation of Article 3. The Court highlighted its particular concerns:

"[I]t appears that the food was insufficient and of poor quality. The building was inadequately heated and in winter the applicant had to sleep in his coat. He was able to have a shower once a week in an unhygienic and dilapidated bathroom. The toilets were in an execrable state and access to them was dangerous, according to the findings by the CPT [Committee on the Prevention of Torture]. (...) In addition, the home did not return clothes to the same people after they were washed (...) which was likely to arouse a feeling of inferiority in the residents."⁴⁷

The ECtHR noted that despite being aware of a 2003 European Torture Committee (CPT) report which held that the living conditions in the Pastra care home (where Mr Rusi Stanev lived) amounted to inhuman and degrading treatment, the government failed to act on its undertaking to close down the

institution. The government had, in its 2004 response to the CPT's report, stated that the home "would be closed as a priority and that the residents would be transferred to other institutions".⁴⁸

The Right to Liberty

Article 5 of the ECHR (the right to liberty) is engaged where a person's placement in an institution amounts to deprivation of liberty. Although no definition of deprivation of liberty is provided by Article 5 or by the ECtHR, the jurisprudence in this area is extensive and continues to develop. The ECtHR has emphasised the importance of considering the particular circumstances of each case, taking into account a range of factors including the "type, duration, effects and manner of implementation of the measure in question".

In addition to determining whether an individual has been confined "in a particular restricted space for a not negligible length of time" (the "objective element"), the ECtHR must also be satisfied that the person "has not validly consented to the confinement in question" and that if there is a deprivation of liberty, it is "imputable to the State". These additional aspects of deprivation of liberty are relevant to the practice in CEE countries that permits individuals appointed as guardians of people deemed to lack capacity to make decisions for themselves to admit the person they are responsible for to social care homes, irrespective of the person's wishes.⁴⁹ This leads to serious human rights violations. A particular concern is that this system allows individuals subject to guardianship to be deprived of their liberty without any procedural safeguards.⁵⁰

*Shtukatorov v Russia*⁵¹ is illustrative for this purpose. The applicant was admitted to a psychiatric hospital on the authority of his

guardian. Even though, under domestic law, he was considered to be "voluntarily confined" (on the basis that his guardian had authorised the placement), the ECtHR considered that in reality he was objectively detained and even though legally incapable of expressing his opinion, the ECtHR was not satisfied that he had agreed to his continued stay in the hospital.⁵²

In the more recent case of *Stanev v Bulgaria*, the ECtHR noted that following its visits to Bulgaria, the CPT had found that "in most cases, placement of people with mental disabilities in a specialised institution led to a *de facto* deprivation of liberty".⁵³ A similar conclusion was reached by Interights in the light of its survey "of practices regarding placement of people with mental disorders in specialised institutions in central and east European countries".⁵⁴

The Right to Private and Family Life

Irrespective of a finding that the institutional placement amounts to a deprivation of liberty, the right to private and family life (Article 8) will be engaged. This is because the characteristics of institutions impair an individual's "physical or psychological wellbeing",⁵⁵ interfering as they do with social interaction, the ability to establish relationships, educational and other personal opportunities. These factors have all been recognised by the ECtHR as being important components of Article 8. The ECtHR has stressed that there must be a clear justification for an interference with one's ability to conduct one's life in a manner of one's own choosing.⁵⁶

Given such an approach, Article 8 has the clear potential to challenge "passive institutionalisation", such as the situation described by Interights (the third party intervener) in *Stanev v Bulgaria*.⁵⁷ Interights drew attention

to the dearth of community based alternatives to institutional care. Accordingly, “when faced with a choice between a precarious, homeless existence and the relative security offered by a social care home” people “might opt for the latter solution, simply because no alternative services were offered by the State’s social welfare system”.⁵⁸

To date the ECtHR has restricted its analysis of the inevitable institutional restrictions on social interaction to Article 5. In *Storck v Germany*⁵⁹ it held that the applicant’s complaint concerning such restrictions was in substance a repeat of her claims of a breach of Article 5 (which it had upheld). It took a similar approach in *Stanev v Bulgaria*, stating that his complaint concerning such restrictions raised nothing new to the arguments already considered under Articles 3, 5, 6 and 13 ECHR (all of which it upheld). However, this is an issue that may receive greater attention in the future. While agreeing with the majority on the findings of violations of these Articles, four of the judges considered that the applicant’s complaints concerning the infringements of his right to private and family life under Article 8 merited separate examination. In their partially dissenting judgment Judges Tulkens, Spielmann and Laffranque noted that one of the “genuine issues” requiring specific attention was Mr Stanev’s complaint that:

“[T]he fact of having to live in the Pas-tra social care home had effectively barred him from taking part in community life and from developing relations with persons of his choosing. The authorities had not attempted to find alternative therapeutic solutions in the community or to take measures that were less restrictive of his personal liberty, with the result that he had developed ‘institution-alisation syndrome’, that is, the loss of social skills and individual personality traits.”

Such comments reflect the view that Article 8 encompasses aspects of life that go beyond the limited parameters of Article 5. While the ECtHR has made clear that Article 5 requires consideration of the availability of less severe measures,⁶⁰ Article 5(1)(e) allows the detention on grounds of mental disorder,⁶¹ subject to three minimum conditions being met, namely: that objective medical evidence has shown that the person has a mental disorder; that this is of a nature or degree warranting compulsory confinement; and the person can be detained only so long as such mental disorder persists.⁶²

The threshold for meeting these criteria is low. For example, in the recent case of *DD v Lithuania*,⁶³ when determining whether the applicant’s detention was lawful under Article 5(1)(e), the ECtHR relied heavily on the report of a social worker who had not seen the applicant in person,⁶⁴ stating that it was ready to find that “the applicant has been reliably shown to have been suffering from a mental disorder of a kind and degree warranting compulsory confinement”. The ECtHR’s scrutiny of alternative measures was restricted to noting that there were no appropriate alternatives to the “compulsory confinement” because the applicant had escaped from her adoptive father’s apartment and been found by the police only three months later.⁶⁵

Article 8 demands a more careful consideration, particularly when viewed through the prism of Article 19 of the CRPD. This is discussed below.

The ECHR and Community Living

It is argued that ECtHR case-law in relation to Article 8 (right to private and family life) of the ECHR has shown that this right:

“[E]mbodies many (if not all) of the core components of the right to independent living: a right to positive measures to ensure ‘the development, without outside interference, of the personality of each individual in his relations with other human beings’,⁶⁶ a state obligation to avoid interferences with a person’s development of their ‘social identity’,⁶⁷ and a right (where the state bears responsibility for the applicants predicament,⁶⁸ or the applicant has significant impairments⁶⁹), to positive measures to address inappropriate living conditions.”⁷⁰

For example, in *Kutzner v Germany*⁷¹ the ECtHR considered whether the removal of the children of parents with mild intellectual disabilities was justified. The ECtHR held that Article 8 had been breached because there were insufficient reasons for such a serious interference with the family’s Article 8 rights. One of the factors taken into account by the Court in reaching this decision was its concern that the authorities had not given sufficient consideration to the additional measures of support that could have been provided as an alternative to the “most extreme measure” of separating the children from their parents.⁷²

While the ECtHR has stated that Article 8 is not “applicable each time an individual’s everyday life is disrupted”, it recognises that there are circumstances in which:

“[T]he State’s failure to adopt measures interferes with that individual’s right to personal development and his or her right to establish and maintain relations with other human beings and the outside world.”⁷³

In such cases the ECtHR has placed the onus on the applicant to demonstrate “the existence of a special link between the situation complained of and the particular

needs of his or her private life”.⁷⁴ In addition, the ECtHR tends to allow states a wide margin of appreciation when considering matters that involve the allocation of limited state resources.

However, there are cases in which the ECtHR is not prepared to take the financial implications of its findings into account. For example, in *Stanev v Bulgaria*,⁷⁵ having found that the living conditions in the social care home amounted to a violation of Article 3, the Court stated:

“[T]he lack of financial resources cited by the Government is not a relevant argument to justify keeping the applicant in the living conditions described.”

The allocation of resources will be relevant to arguments that Article 8 engages a positive duty to promote community living. While the ECtHR’s strong statement in *Stanev v Bulgaria* related to a violation of Article 3, it makes clear that providing inexpensive care to the detriment of the dignity and human rights of people with disabilities is not acceptable. In any event it has been shown that once the comparison is made on the basis of comparable needs of the residents and the quality of care provided, “there is no evidence that community-based models are inherently more costly than institutions”. The research also demonstrates that when properly set up, community-based systems of independent and supported living should deliver better outcomes than institutions.⁷⁶

Furthermore, given the Court’s approach to the CRPD, as highlighted in *Glor*⁷⁷ and *Kiss v Hungary*⁷⁸ (discussed below), it may take a more robust stance in cases where a person with disabilities argues that his or her right to private and family life has been unjustly interfered with because s/he has been placed

in an institution rather than being provided with appropriate support in a less restrictive setting. The obligations under Article 19 to provide access to a range of community based supports and avoid seclusion and segregation would be of direct relevance. It has been argued that:

“[W]here the Court seeks to identify which positive obligations derive from Article 8 in other contexts, it has taken into account other relevant international obligations of the State concerned. It has used an estoppel-like argument: how could a State possibly argue that it would be unreasonable to expect it to adopt a particular measure, if the State has already undertaken to adopt that measure by agreeing to other international agreements?”⁷⁹

Structural Funds and Disability Discrimination under EU Law

When determining how Structural Funds are to be invested, member states and the European Commission must ensure that they comply with their obligations to combat discrimination, which derive from the general principles of EU law and the CRPD. As discussed above, the EU’s ratification of the CRPD will require it to interpret secondary legislation consistently with its provisions, including regulations governing the use of Structural Funds. Similarly, the EU institutions and member states are under an obligation to act consistently with the provisions of the EU Charter, prohibiting discrimination, as well as the provisions of the regulations themselves.

In addition Article 16 of the general regulations governing the use of Structural Funds states:

“The member states and the Commission shall take appropriate steps to pre-

vent any discrimination based on sex, racial or ethnic origin, religion or belief, disability, age or sexual orientation during the various stages of implementation of the Funds and, in particular, in the access to them. In particular, accessibility for disabled persons shall be one of the criteria to be observed in defining operations co-financed by the Funds and to be taken into account during the various stages of implementation.”⁸⁰

In the absence of a definition of either “disability” or “disability discrimination” in the general regulations, and given the status of the CRPD in EU law, it is argued that the CJEU would be guided by the provisions set out in the CRPD. Whereas, in the past the CJEU (then the ECJ) applied a somewhat restrictive and medical model approach to the definition,⁸¹ it is likely to take the broader approach to disability, following the social model approach introduced by the CRPD.⁸² Article 1 of the CRPD provides a general description of “persons with disabilities” as including:

“[T]hose who have long-term physical, mental, intellectual or sensory impairments which in the interaction with various barriers may hinder their full and effective participation in society on an equal basis with others”.

Similarly, Article 2 of the CRPD defines “discrimination on the basis of disability” very broadly, stating that it includes “all forms of discrimination, including denial of reasonable accommodation”. Reasonable accommodation is defined as:

“[N]ecessary and appropriate modifications 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”.⁸³

As noted above, the ECtHR’s decisions are likely to have a strong influence on the CJEU in its deliberations.⁸⁴ In recent years the ECtHR has taken a strong line on what might amount to discrimination, and on what is expected of States to address discriminatory practices. In *D.H. and Others v the Czech Republic*⁸⁵ for example, it held that:

“[D]iscrimination means treating differently, without an objective and reasonable justification, persons in relevantly similar situations. However, Article 14 does not prohibit a member State from treating groups differently in order to correct ‘factual inequalities’ between them; indeed in certain circumstances a failure to attempt to correct inequality through different treatment may in itself give rise to a breach of the Article. The Court has also accepted that a general policy or measure that has disproportionately prejudicial effects on a particular group may be considered discriminatory notwithstanding that it is not specifically aimed at that group and that discrimination potentially contrary to the Convention may result from a *de facto* situation.” [case citations removed]

The ECtHR has commented that “the authorities must use all available means to combat racism”.⁸⁶ Similarly, in relation to sex discrimination, it has held that: “[V]ery weighty reasons would have to be put forward before such a difference of treatment [on grounds of sex] could be regarded as compatible with the Convention”.⁸⁷

The CRPD has already made a significant impact on the approach taken by the ECtHR to disability discrimination, with the Court referring to the important role played by this Convention in clarifying the protection

afforded by the ECHR to people with disabilities. When considering the CRPD and its impact on European equality law, Jarleth Clifford notes that the ECtHR “has pushed the issue of discrimination against persons with disabilities into focus”, setting an example “which the ECJ should look to follow”.⁸⁸

Thus, in *Glor v Switzerland* (2009)⁸⁹ the ECtHR confirmed that for the purposes of Article 14 (freedom from discrimination) and having regard to the “necessity to fight against discrimination towards disabled persons and to promote their full participation and integration into society,” that the “margin of appreciation” for states to establish different legal treatment for disabled persons is significantly reduced.⁹⁰ In finding a violation of the right to non-discrimination on the basis of disability, the Court emphasised that the adoption of the CRPD demonstrated a “European and universal consensus on the necessity to protect” people with disabilities from discriminatory treatment.⁹¹

The Court took a similar approach in *Alajos Kiss v Hungary*.⁹² In this case the applicant had been diagnosed as having “manic depression” (and was therefore considered to “suffer from a mental disability”) and had for that reason been placed under partial guardianship. Whilst acknowledging that states should enjoy a wide margin of appreciation in relation to determining whether restrictions on voting can be justified, the Court considered that an absolute bar, irrespective of the person’s “actual faculties” was not acceptable. The Court held unanimously that such an absolute ban violated the right to free elections of Article 3 of Protocol 1 ECHR. The Court observed that:

“[I]f a restriction on fundamental rights applies to a particularly vulnerable group in society, who have suffered consid-

erable discrimination in the past, such as the mentally disabled, then the State's margin of appreciation is substantially narrower and it must have very weighty reasons for the discrimination in question."⁹³

Institutionalisation as Discrimination

The comments by the ECtHR in *Alajos Kiss* are pertinent to the practice of institutionalising people with disabilities. Arguably, the ECtHR's view that consideration needs to be given to the history of prejudice and discrimination towards a group of people and the requirement in such cases for states to "have very weighty reasons for the restrictions in question" could be applied to situations where governments have decided to use available resources (such as Structural Funds) to maintain institutional care for people with disabilities, rather than develop community-based alternatives.

As discussed above, when considering rights under the ECHR, placement in an institution leads to substantial restrictions of a person's rights and freedoms. Further support for identifying institutionalisation in itself as a serious infringement of a person's rights is found in Article 19 CRPD. While it does not prohibit "institutions" *per se*, the range and manner of support expected under Article 19 is in direct contrast to the culture and environment found in institutions. Irrespective of the living conditions in institutions, if people with disabilities are excluded from the rest of society and prevented from participating in community life, this conflicts with Article 19.

The principle of non-discrimination is also highly significant. Article 19 of the CRPD requires that States Parties recognise "the **equal** right of all persons with disabilities to live in the community, with choices **equal** to others" [emphasis added]. This links to Arti-

cle 5 (Equality and non-discrimination) and also Article 4 which requires "the full realization" of the CRPD's rights and freedoms "for all persons with disabilities without discrimination of any kind on the basis of disability".

A decision by the United States Supreme Court is also worthy of note. *Olmstead v LC* (1999)⁹⁴ concerned the State of Georgia's funding arrangements that favoured institutional placements, rather than community-based independent living. The Supreme Court held that the arrangements in question contravened the Americans with Disabilities Act (1990) that includes the prohibition of discrimination in the provision of public services. The Court found that the complainants had the right to receive care in the most integrated setting appropriate and that their unnecessary institutionalisation was discriminatory.⁹⁵

As Gerard Quinn and Suzanne Doyle note, although limiting its finding to situations where "the placement could be reasonably accommodated by the State, taking into account the resources available to the State and the needs of others with mental disabilities," the thrust of the Supreme Court's decision that unjustified institutionalisation amounted to discrimination is of great significance.⁹⁶ It draws attention to the consequences of states' failure to provide appropriate care and support to people with disabilities and provides a mechanism for challenging this. The Supreme Court pointed to the negative impact of institutional care:

"Institutional placement of persons who can handle and benefit from community settings perpetuates unwarranted assumptions that persons so isolated are incapable or unworthy of participating in community life (...) confinement in an institution severely diminishes the everyday life activities of

individuals, including family relations, social contacts, work options, economic independence, educational advancement, and cultural enrichment.”

In a more recent case, a district court held that the New York State discriminated against people with mental illness by placing them in “Adult Homes” which had all the hallmarks of institutional care and were not “the most integrated settings appropriate to their needs” as “virtually all” of them “could be appropriately served in supported settings”.⁹⁷

As yet this issue has not been addressed by the Strasbourg Court. As we note above, it was raised in the *Stanev* proceedings by the Intervener,⁹⁸ but the Court declined to investigate it (having found violations of Articles 3 and 5). It is, however, inevitable that sooner or later the ECtHR will be called upon to address directly the nature and extent of the “community living” obligation inherent within Article 8.⁹⁹

Indirect Discrimination

Two common reasons for the institutionalisation of disabled people in CEE are the lack of community-based alternatives, and that in many parts of this region, the legal and financial systems are barriers to the development of services that are outside the institutional system. These factors raise the question of whether the institutionalisation of people with disabilities amounts to indirect discrimination by the state, particularly in circumstances where Structural Funds are available. Indirect discrimination occurs when an apparently neutral criterion “has the effect that members of a group protected by non-discrimination are disadvantaged compared to members of another group, and no objective justification (...) can be shown to exist to the applied criterion”.¹⁰⁰

The issue of concern is that a member state invests Structural Funds in renovating existing institutions and/or building new institutions rather than implementing a strategy for the development of community based services and ultimate closure of institutions. The impact of this policy, which may have no express intention of doing so, is that those already living in institutions are unlikely to be able to leave while others who are born with, or develop, disabilities are likely to be placed in institutions. In both cases the reason for institutionalisation is because there is insufficient community-based care and support available to the people with disabilities and their families. As discussed above, the consequences of institutionalisation may in some cases lead to severe human rights abuses, but in any event represents a serious infringement on individuals’ right to private and family life. Accordingly, the state’s decision to use Structural Funds in this manner has an adverse and disproportionate impact on disabled people (the placement in an institution constituting a severe restriction on their rights and freedoms which other non-disabled citizens do not face).

Such a situation is analogous to the circumstances considered by the ECtHR in *DH v Czech Republic*, which concerned the placement of children of Roma origin in special schools for children with learning disabilities. In that case, the ECtHR confirmed that the concept of indirect discrimination was covered by Article 14 of the ECHR.¹⁰¹ Clearly an important issue will be whether those seeking to pursue a claim of indirect discrimination can demonstrate a difference in treatment (which would then shift the burden of proof to the government to show that the treatment was justified). Given the paucity of data held by governments in CEE on the situation of people with disabilities,¹⁰² and the difficulty in getting information on

the use of Structural Funds,¹⁰³ this is likely to require independent research, for example to show the numbers of people with disabilities in institutions compared to the general population, those people with disabilities living in the community and of the latter, those receiving care and support other than from their families. In *DH v Czech Republic* the ECtHR was willing to accept the statistical evidence submitted by the applicants. Furthermore, the Court recognised that the quality of evidence required would depend on the circumstance of the case: that proof “might follow from the co-existence of sufficiently strong clear and concordant inferences or of similar unrebutted presumptions of fact”. It also noted that “where the events in issue lie wholly or in large part, within exclusive knowledge of the authorities, the burden of proof may be regarded as resting on the authorities to provide a satisfactory and convincing explanation”.¹⁰⁴

In relation to the justification for any proven differential treatment, states might argue that the renovation work was required to rectify the squalid living conditions in the institutions. It is arguable whether such work falls within the remit of Structural Funds, unless it forms part of a corresponding plan to develop community based services as alternatives to institutional care.¹⁰⁵ In any event, while a member state might be able to point to historic reasons for the institutionalisation of people with disabilities, such a position is difficult to sustain if the member state chooses to use the additional resources provided through Structural Funds to maintain a system which is recognised as being an outmoded form of care and places severe restrictions on the rights of people with disabilities. States would need to explain why they are taking such action rather than developing an alternative system of community based services that do not lead to such re-

strictions, when the transition to community based care forms part of EU disability policy. This argument is strengthened by:

- The widespread ratification of the CRPD, containing as it does an explicit obligation (in Article 19) to develop community-based alternatives;
- The ECtHR’s comments on discrimination generally, and in relation to disability discrimination in particular, and its strong statements on the need to take action to protect the rights of people with disabilities;
- Considering the impact of an EU member state having access to Structural Funds, particularly when the regulations require that this (substantial) additional funding is invested to prevent and combat discrimination.

Denial of Reasonable Accommodation

That denial of reasonable accommodation amounts to discrimination under the CRPD is “crystal clear”.¹⁰⁶ Reasonable accommodation is defined in the CRPD (Article 2) as:

“[N]ecessary and appropriate modifications 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 means that states parties must take all appropriate reasonable accommodation steps to promote equality in the enjoyment and exercise by persons with disabilities in all human rights in a wide array of areas that go beyond employment and occupation and include education, health and the provision of goods and services.¹⁰⁷

With the availability of additional funds it can be argued that investing Structural

Funds in institutions rather than developing community-based alternatives, amounts to a denial of reasonable accommodation. This conclusion springs from an appreciation of (a) the duty under the CRPD to promote equality and eliminate discrimination (see Article 5(3)); and (b) the definition of disability discrimination, which includes the denial of reasonable accommodation. It follows that a member state would be required to provide clear reasons why it decided to invest in maintaining the institutional system rather than developing community-based alternatives. Force is added to this analysis by an awareness of the obligations on member states and the European Commission to use Structural Funds to promote social inclusion (Article 3 of the General regulations) and improve quality of life (Article 4 of the ERDF regulations).

The CRPD requires states parties to take action to provide “reasonable accommodation” when a “necessary and appropriate modification and adjustment not imposing a disproportionate or undue burden” is needed “to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms”. In *HM v Sweden*,¹⁰⁸ the CRPD Committee found that the refusal to grant building permission for the construction of a hydrotherapy pool (considered to be an essential and effective means of meeting the complainant’s health care needs) amounted to a denial of reasonable accommodation. The Committee considered that such permission could have been given and would not have imposed a “disproportionate or undue burden” on the state party.

As discussed above, the ECtHR has set limits on the extent to which Article 8 might place obligations on states, particularly where there may be cost implications.¹⁰⁹ There are,

however, grounds for arguing that in the light of the CRPD the ECtHR might scrutinise the impact of the institutionalisation of people with disabilities more closely. In addition, there are at least three reasons why, in the context of Structural Funds, the ECtHR may take a less cautious approach:

- Structural Funds are additional external funds, not domestic and limited state resources;
- Where a person with disabilities has been institutionalised purely as a consequence of having no suitable services in the community, this has a direct and immediate impact upon that person’s life (interfering as it must with their “right to personal development and their relations with other human beings and the outside world”¹¹⁰); and
- Even where the margin of appreciation is wide, it is for the Court to determine whether a person’s ECHR rights have been curtailed:

“[T]o such an extent as to impair their very essence and deprive them of their effectiveness; that they are imposed in pursuit of a legitimate aim; and that the means employed are not disproportionate”.¹¹¹

In such circumstances, the ECtHR might well consider it necessary to examine the reasons why a state has not taken reasonable steps to establish community-based alternatives to institutions, especially when it had available funds to do so¹¹² and in light of the following:

- The general consensus on the need to move from institutional care to a system of community-based services;¹¹³
- The international recognition of the need to protect the rights of people with disabilities, as reflected in the adoption of the CRPD¹¹⁴ which includes the right to community living as articulated in Article 19 (and all EU member states have recognised the rights

set out in the CRPD, having signed, if not ratified it); and

- The state has access to funds that would enable it to shift its model of care to community-based services.

Conclusion

In its Press Release following the EU's ratification of the CRPD,¹¹⁵ the Commission Vice-President Viviane Reding referred to the EU's commitment to implement "concrete measures with a concrete timeline". In doing so, she specifically cited the EU disability strategy,¹¹⁶ which had identified eight main areas for action, the second of which concerned the use of Structural Funds to support the development of community-based services to promote the transition from institutional to community-based care.

However, the current misuse of Structural Funds frustrates their enormous potential to be a positive force in the transition from institutional to community-based care for disabled people. This misuse is something that the Commission can and legally must now tackle. As a case study, it also presents a paradigm example of how the CRPD, for all its "soft" soubriquets, can become a powerful vehicle that delivers practical change.

As we have discussed in this paper, over the last two decades several strands of European Law have been identified which bear upon the inappropriate institutionalisation of disabled people. These strongly suggest that such action: constitutes unlawful discrimination; violates the private and family rights of disabled people to "community living"; and engages the positive obligation on states to promote independent, non-institutional living opportunities for disabled people.

It is arguable that in the last decade a consensus has developed as to the validity of these legal principles, and the challenge is now to establish their justiciability: what substance should they be accorded when confronted by the "resource" argument? Rights and principles they may well be but (save in the most stark of circumstances) are they capable of being more – more than aspirational "wouldn't it be nice" rights?

As this paper demonstrates, in relation to the use of EU Structural Funds, there are two broad grounds for believing that these rights will become hard and justiciable. Firstly, the widespread ratification of the CRPD will act both as a powerful catalyst crystallising these disparate principles as well as providing a unifying philosophical basis for their use: ECHR jurisprudence, EU Law (including the Charter of Fundamental Rights) and the established principles of non-discrimination law in combination creating a powerful default position for any legal disputation concerning these issues.

Secondly, in relation to the use of Structural Funds, the resource argument must be a very weak one. The proper application of such funds is not one that is part of the "deference" debate – in the sense that it is not concerned with decisions by elected governments over the use of their scarce state resources. On the contrary, the question is about how the EU distributes what are in effect grants – "new" money, to which conditions are (indeed "must be") attached – made by an awarding body which has ratified the CRPD and is subject to EU and ECHR law and made to states that have (at the very least) signed the CRPD and are subject to the self-same laws.

The motives underlying a nation state's ratification of an international human rights treaty, are often open to conjecture – and specu-

lation over the reasons for the EU's "confirmation" of the CRPD is no less legitimate. Was this symbolic, rhetorical, synthetic – a grand gesture to a distant set of aspirational principles – a deed full of sound and glory, but signifying precious little of substance?

Whatever the motivation and however "soft" the CRPD may appear to be, it is difficult to en-

visage a more tangible, "concrete" example of how it will bind the EU and its member states, than the issue analysed in this article. Indeed, it could be said that the way the Commission responds to the challenges concerning the award of Structural Funds – whether these funds promote or undermine the right to community living – will be the litmus test, by which we measure its commitment to the CRPD.

1 Camilla Parker is Mental Health and Human Rights Consultant and Partner, *Just Equality*. Professor Luke Clements teaches at the Cardiff Law School. The authors would like to thank Israel Butler for his very helpful comments on an earlier draft.

2 This figure is based on the findings of a study covering the EU Member States plus Turkey. The figures for CEE countries were as follows: Bulgaria –13,269, Czech Republic –66,865, Estonia –22,421, Hungary –24,390, Latvia –10,053, Lithuania –45,464, Poland –73,741, Romania –32,783, Slovakia –12,252 and Slovenia – 821. (See Mansell J., Knapp M., Beadle-Brown J. and Beecham, J., *Deinstitutionalization and community living – outcomes and costs: report of a European Study*, Volume 2: Main Report, Canterbury: Tizard Centre, University of Kent, 2007, referred to hereafter as "the DECLOC report", p. 29.)

3 Open Society Foundations, *The European Union and the Right to Community Living: Structural Funds and the European Union's Obligations under the Convention on the Rights of Persons with Disabilities*, 2012 (referred to hereafter as "the MHI report"), available at: <http://www.soros.org/sites/default/files/europe-community-living-20120507.pdf>. This report was written by Camilla Parker and Luke Clements.

4 European Coalition for Community Living, *Wasted Time, Wasted Money, Wasted Lives – A Wasted Opportunity?*, 2010, available at: <http://community-living.info/documents/ECCL-StructuralFundsReport-final-WEB.pdf>. This report was written by Camilla Parker with input from I. Bulić.

5 See for example, presentation by Iorga, E., "Evaluating the effects of Structural Funds in new Member States – the case of Romania", IPP, 7 May 2012, available at: www.europe.ohchr.org/EN/NewsEvents/Pages/PresentationGettingLife.aspx, where it is stated that: "Despite having ratified the CRPD in 2010, Romania has extensively used EU money for investments in institutions, while independent living and development of community based services were not a priority for the social services system, neither under Structural Funds nor under the national budget."

6 United Nations Office of the High Commissioner on Human Rights, *Getting a Life: Living Independently and Being Included in the Community*, 2012. This report was written by Gerard Quinn and Suzanne Doyle.

7 As at 25 June 2012, 115 states have ratified the CRPD (see: <http://www.un.org/disabilities>). Out of the 27 EU member states, those yet to ratify are: Finland, Ireland, Malta, Netherlands and Poland.

8 Council Decision 2010/48 EC on 26 November 2009 permitted the EU to conclude the Convention, following the adoption, by the Council, of a Code of Conduct and the submission of an instrument of formal confirmation at the United Nations.

9 Pursuant to Article 44 CRPD, a declaration of competence was annexed to the Council of the EU's decision on the conclusion of the CRPD.

10 See Annex II of Council Decision of 26 November 2009 concerning the conclusion, by the European Community, of the CRPD (2010/48/EC), p. L 23/55.

11 *Ibid.* The regulations governing the use of Structural Funds are listed in the Appendix setting out "Community Acts which refer to matters governed by the Convention", p. L 23/58.

- 12 OJ C 83, 30.3.2010, p. 47. This is also true of mixed agreements (such as the CRPD). See Case C-239/03 *Etang de Berre*, Para 25.
- 13 Case C-61/94 *Commission v Germany* [1996] ECR I-3989, Para 52.
- 14 Quinn, G. et al, *Study on challenges and good practices in the implementation of the UN Convention on the Rights of Persons with Disabilities*, VC/2008/1214, European Foundation Centre, October 2012, p. 24, (“the EFC report”).
- 15 For further discussion of the legal framework for Structural Funds, see MHI report, above note 3, Chapter 4.
- 16 Case C-92/09 and C-93/09 *Volker and Markus Schecke*; Case C-236/09 *Association belge des Consommateurs Tests-Achats*.
- 17 Article 6(2) of the Treaty on European Union provides that the “Union shall accede to the European Convention for the Protection of Human Rights and Fundamental Freedoms”.
- 18 See, for example, *Opinion 2/94 Accession of the European Community to the European Convention for the Safeguard of Human Rights and Fundamental Freedoms*, 1996.
- 19 For a detailed account with numerous examples see Gordon R., *EC Law in Judicial Review*, Oxford University Press, 2007, Chapter 12.
- 20 See, for example, Mental Disability Advocacy Center, “Cage Beds, Inhuman and Degrading Treatment in Four Accession Countries”, 2003 (the countries were: Czech Republic, Hungary, Slovakia and Slovenia); Nowak, M., “Interim report of the Special Rapporteur of the Human Rights Council on torture and other cruel, inhuman or degrading treatment or punishment”, A/63/175, 2008, Paras 37–41.
- 21 Structural Funds provide the financial support for the implementation of the EU’s Cohesion Policy which is the EU’s strategy to promote and support the “overall harmonious development” of its member states and regions. The objectives for the current financing period (2007-2013) are to promote sustainable development by strengthening growth, competitiveness, employment and social inclusion and by protecting and improving the quality of the environment – see Article 3, Council Regulation (EC) No 1083/2006 of 11 July 2006 laying down general provisions on the European Regional Development Fund, the European Social Fund and the Cohesion Fund and repealing Regulation (EC) No 1260/1999 (referred to in this article as “the General regulations”).
- 22 European Commission, “European Disability Strategy 2010-2020: A Renewed Commitment to a Barrier-Free Europe”, COM(2010) 636 final, p. 6.
- 23 See above, note 4. In addition, see *Report of the Ad Hoc Expert Group on the Transition from Institutional Care to Community-based Care*, European Commission, Directorate-General for Employment, Social Affairs and Equal Opportunities, September 2009.
- 24 See, for example, Commission on Human Rights Resolution, 2005/24, Para 7.
- 25 See, for example, Council of Europe, Recommendation Rec(2006)5 3.8.1.
- 26 Hammarberg, T., “The Right of People with Disabilities to Live Independently and be Included in the Community”, Council of Europe, 13 March 2012, p. 7.
- 27 See, for example, Committee on the Rights of the Child General Comment No. 7 on implementing the rights of the child in early childhood, 2006, Para 36(b); Committee on Economic Social and Cultural Rights General Comment No. 6 on the economic, social and cultural rights of older persons, 1995, Para 33; and the Standard Rules on the Equalization of Opportunities for Persons with Disabilities, 1993.
- 28 See, for example, Article 3(c) and Article 26.
- 29 See above, note 4, p. 78.
- 30 United Nations Office of the High Commissioner for Human Rights Europe Regional Office, *Forgotten Europeans – Forgotten Rights: The Human Rights of Persons Placed in Institutions*, 2011, p. 5. This report was written by Camilla Parker.
- 31 *Ibid*, p. 6.
- 32 The CRPD and its Optional Protocol (which allows the Committee on the Rights of Persons with Disabilities (“the CRPD Committee”) to examine individual complaints) can be found on the United Nations Enable website at: <http://www.un.org/disabilities/>.
- 33 Article 4(3) CRPD.

34 Article 33(3) CRPD.

35 Waddington, L., "A New Era in Human Rights Protection in the European Community: The Implications of the United Nations' Convention on the Rights of Persons with Disabilities for the European Community", Maastricht Faculty of Law, 2007, p. 4. See also Articles 3 and 4 CRPD.

36 See, for example, Quinn, G., Degener, T. et al, "Human Rights and Disability – the current use and future potential of United Nations human rights instruments in the context of disability", Human Rights Commission, 2002, available at: <http://www.unhchr.ch/html/menu6/2/disability.doc>.

37 *Glor v Switzerland*, Application No. 13444/04. In this case the applicant had been deemed medically unfit to perform his military service due to his disabilities but the authorities decided that his diabetes was not severe enough for him to be relieved from paying the military exemption tax. The case is discussed below.

38 Article 18.

39 Lawson A., "The UN Convention on the Rights of Persons with Disabilities and European Disability Law: A Catalyst for Cohesion?", in Arnardottir, O., Quinn, G. (eds.) *The United Nations Convention on the Rights of Persons with Disabilities: European and Scandinavian Perspectives*, Martinus Nijhoff Publishing, 2009.

40 See Committee on the Rights of Persons with Disabilities, *Guidelines on treaty-specific document to be submitted by States Parties under article 35, paragraph 1, of the Convention on the Rights of Persons with Disabilities* (CRPD/C/2/3, 2009).

41 CRPD/C/PER/CO/1, 9 May 2012, Paras 32–33.

42 Adopting the approach taken in Hunt, P., "Promotion and protection of all human rights, civil, political, economic, social and cultural rights – Report of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health", A/HRC/7/11, 2008, which considers the obligations flowing from the right to health under Article 12 of the International Covenant on Economic, Social and Cultural Rights. This is discussed in more detail in the MHI report, above note 3, pp. 40-43. See also above note 6, pp. 19–20.

43 See Article 4(1) CRPD.

44 *Pretty v United Kingdom* (2002) 35 EHRR 1, Para 61.

45 Freyhoff G., Parker, C. et al (eds), *Included in Society, Results Recommendations of the European Initiative on Community-based Residential Alternatives for Disabled People*, Brussels, 2004.

46 *Stanev v Bulgaria*, Application No. 36760/06.

47 *Ibid.*, Para 209.

48 *Ibid.*, Para 82.

49 In many countries of Central and Eastern Europe and the former Soviet Union, a system of guardianship is still applied under which a guardian is appointed to make decisions on behalf of the person deemed to be incapacitated. Those subject to guardianship are prevented from making personal decisions in a wide range of areas such as employment, marriage, voting, and where to live.

50 United Nations, *Progress of efforts to ensure the full recognition and enjoyment of the human rights of persons with disabilities - Report of the Secretary-General*, A/58/181, Para 14–22, and see generally Lewis, O., "Advancing Legal Capacity Jurisprudence", *EHRLR*, Issue 6 (2011), pp. 700–714.

51 *Shtukatorov v Russia*, Application No. 44009/05 [2008] MHLR 238. See also *HL v UK* (2005) 40 EHRR 32 and above, note 46.

52 The ECtHR took a similar approach in the subsequent cases of *Stanev v Bulgaria* and *DD v Lithuania*, Application No. 13469/06.

53 See above, note 46, Para 83.

54 Interights third party intervention in *Stanev v Bulgaria* before the European Court of Human Rights, Para 112, available at: <http://www.interights.org/document/131/index.html>.

55 See, for example, *Tysiac v Poland* (2007) 45 EHRR 42, Para 107.

56 See above, note 44, Para 62.

57 See above, note 46.

58 *Ibid.*, Para 114.

- 59 *Storck v Germany* (2006) 43 EHRR. 6.
- 60 *Witold Litwa v Poland*, Application No. 26629/95.
- 61 No such provision is included in Article 14 (the right to liberty) of CRPD. See United Nations, *Thematic Study by the Office of the High Commissioner for Human Rights on enhancing awareness and understanding of the Convention on the Rights of Persons with Disabilities*, A/HRC/10/48, pp. 15–16.
- 62 *Winterwerp v the Netherlands*, Application No. 6301/73.
- 63 *DD v Lithuania*, above note 52.
- 64 Interights note on the judgment, available at: <http://www.interights.org/document/206/index.html>.
- 65 See above, note 64, Para 157.
- 66 *Botta v Italy* (1998) 26 EHRR 241.
- 67 *Mikulic v Croatia* [2002] 1 FCR 720.
- 68 *Moldovan v Romania* (No. 2) (2007) 44 EHRR 16, Para 105.
- 69 *Marzari v Italy*, Application No. 36448/97.
- 70 Parker C., and Clements L., “The UN Convention on the Rights of Persons with Disabilities: a New Right to Independent Living?”, *EHRLR*, Issue 4(2008), pp. 516-517. See also above note 57, Para 50.
- 71 *Kutzner v Germany*, Application No. 46544/99.
- 72 *Ibid.*, Paras 69 – 81; and see also *Saviny v Ukraine*, Application No. 39948/06, where on similar facts (the parents being blind in this case) a violation of Article 8 was also found, the Court observing (Para 57) that there had been insufficient analysis by the domestic courts of whether the “purported inadequacies of the children’s upbringing were attributable to the applicants’ irremediable incapacity to provide requisite care, as opposed to their financial difficulties and objective frustrations, which could have been overcome by targeted financial and social assistance and effective counselling”.
- 73 *Sentges v The Netherlands* Admissibility Application No. 27677/02.
- 74 *Ibid.*
- 75 See above, note 46.
- 76 The DECLOC report, above note 2, p. 97.
- 77 See above, note 37.
- 78 *Alajos Kiss v Hungary*, Application No. 38832/06, [2010] *MHLR* 245.
- 79 De Schutter, O., “Reasonable Accommodations and Positive Obligations in the European Convention on Human Rights”, in Lawson A. and Gooding C. (eds), *Disability Rights in Europe: From Theory to Practice*, Hart Publishing, 2005, p.48.
- 80 See the European Disability Strategy, Para 10, which states that: “EU action will support and supplement national efforts to improve accessibility and combat discrimination through mainstream funding, proper application of Article 16 of the Structural Funds General Regulations.”
- 81 *Sonia Chacón Navas v Eurest Colectividades*, C-13/05, 2006, Para 43.
- 82 EFC Report, above note 14, p.42. See also European Commission comments on the social model approach in “Communication from the Commission to the Council and the European Parliament – Towards a United Nations legally binding instrument to promote and protect the rights and dignity of persons with disabilities”, COM 2003 16 final, p. 7.
- 83 EFC Report, above note 14, p. 54, which notes that the definition includes “direct, indirect, structural, multiple or other, as well as discrimination by association and discrimination based on assumed or future disability”.
- 84 It should be noted that different forms of discrimination are recognised in other areas of EU law. For example, Article 2 of the Employment Directive includes “direct discrimination”, “indirect discrimination” and “harassment”. The Directive also recognizes that, in relation to people with disabilities, the failure to provide “reasonable accommodation” can constitute discrimination (Article 5).
- 85 *D.H. and Others v the Czech Republic* (2008) 47 EHRR 3, Para 175.

- 86 Ibid., Para 176.
- 87 *Schuler-Zgraggen v Switzerland*, 16 EHRR 405, Para 68.
- 88 Clifford, J., "The UN Disability Convention and its Impact on European Equality Law," *The Equal Rights Review*, Vol. 6, 2011, p.19.
- 89 See above, note 37.
- 90 Ibid., Para 84.
- 91 Ibid., Para 53.
- 92 See above, note 78.
- 93 Ibid., Para 42.
- 94 *Olmstead v LC*, US Supreme Court 527 US 581, 1999, pp.98-536.
- 95 For further discussion see Kanter A., *There's no place like home: The right to live in the community for people with disabilities under international human rights law and the domestic laws of the United States and Israel - DRAFT*, 2011, available at: [http://law.huji.ac.il/upload/Kanter\(1\).pdf](http://law.huji.ac.il/upload/Kanter(1).pdf).
- 96 See above, note 6, p. 36.
- 97 *DAI v Paterson*, 653 F. Supp. 2d 184 (EDNY 2009) (Memorandum of Findings of Fact and Conclusion of Law). See also discussion in Kanter, A., above note 96, pp. 31-33.
- 98 Interights, above note 54, Para 114.
- 99 The issue has been pleaded by MDAC as Intervener in the pending case of *Stanislaw Kedzior v Poland*, Application No. 45026/07, available at: http://mdac.info/sites/mdac.info/files/Kedzior_v_Poland_amicus_brief_MDAC.pdf.
- 100 Hendricks, A., "The UN Disability Convention and (Multiple) Discrimination", in Waddington, L. and Quinn G. (eds), *European Yearbook of Disability Law*, Intersentia, Volume 2, pp. 12-13.
- 101 See above, note 85, Para 184.
- 102 DECLOC report, above note 2, p. 94.
- 103 See above, note 4, p. 35.
- 104 See above, note 85, Para 179.
- 105 The MHI report argues that while in very limited circumstances Structural Funds might be capable of being used to ameliorate the poor living conditions in institutions, these are restricted to cases in which: (a) there is a clearly identified and competing case to take limited action (for example to prevent an urgent and life threatening risk to the resident); and (b) their use forms part of a wider strategic program for community living. See MHI report, above note 3, Chapter 6.
- 106 See above, note 6, p.35.
- 107 See Clifford J., above note 88; and the EFC report, above note 14, p.55.
- 108 *HM v Sweden*, CRPD/C/7/D/3/2011.
- 109 See, for example, above note 73.
- 110 See above, note 66, Para 32.
- 111 *Hirst v UK* (2006) 42 EHRR 41, Para 62.
- 112 Parker C. and Clements L., above note 70, p. 516.
- 113 See, for example, *Report of the Ad Hoc Expert Group on the Transition from Institutional Care to Community-based Care*, above note 23.
- 114 See above, note 37, Para 53.
- 115 "EU ratifies UN Convention on disability rights", 5 January 2011, available at: <http://europa.eu/rapid/press-ReleasesAction.do?reference=IP/11/4>.
- 116 See above, note 22.

Deinstitutionalisation – A Human Rights Priority for Children with Disabilities

Georgette Mulheir¹

The United Nations Convention on the Rights of the Child (CRC) clearly outlines a range of children’s rights that, taken together, suggest that most children should live with and be cared for by their birth families (articles 9 and 7). It is the primary responsibility of parents to raise their children and it is the responsibility of the state to support parents in order that they can fulfil that responsibility (article 18). Children have the right to protection from harm and abuse (article 19), to an education (article 28) and to adequate healthcare (article 24). But they simultaneously have the right to be raised by their family. Where their family cannot provide the care they need, despite the provision of adequate support by the State, the child has the right to substitute family care (article 20).

Despite this, across the European region, it is likely that between 600,000 and 1,000,000 children are separated from their families and live in large residential institutions that cannot meet their needs.² There is a shortage of accurate statistics, but existing research suggests that children with disabilities are significantly over-represented in these institutions.³ Research also demonstrates that the institutionalisation of children harms their health, development and future life chances.

It should be noted that the intentions behind this institutionalisation are usually good. Children with disabilities are often institutionalised as a way of providing “specialised” care. They are either considered to be ill,

therefore requiring constant medical care in long-stay hospitals, or are assessed with special education needs, which are provided for in centralised, residential special schools, often sited at a considerable distance from the family home. The logical intention of these institutions is to provide care and services to children. However, this results in the arbitrary separation of children with disabilities from their families and communities, and their isolation from society.

This article sets out some of the evidence of the impact of institutionalisation on children in Europe. It explores the human rights legislative and policy framework underpinning institutionalisation and outlines areas that require development. It assesses some of the most recent advances in policy and action to address the issue and makes recommendations for transforming systems of health, education and social protection services for children and families, in order to end the institutionalisation of children. In addition to published academic research, the article draws on the results of Lumos’ research into placements of children in residential institutions in a number of countries.⁴

The Picture of Institutionalisation across the European Region

Over the past fifty years, most countries in the European region have begun to reform systems of care. In most cases the reform was triggered by a growing understanding



Photo credit: Lumos/Chris Leslie

of the harm caused by institutionalisation. In many Northern and Western European countries, reform efforts have resulted in a significant reduction in the numbers of children in institutions. However, in these countries, children with disabilities are still significantly over-represented in residential care. Furthermore, the picture across Northern and Western Europe is not uniform. Some countries continue to place even young babies in institutions of considerable size.⁵

The countries of Central and Eastern Europe (CEE) and the Commonwealth of Independent States (CIS) share a common history that includes decades of heavy reliance on the placement of children in large institutions. In these countries (with some exceptions), major efforts to reform systems of caring for children began in earnest over the past decade. This delay in reform is due to a number of factors, including:

- relative isolation, during the communist era, from international research evidence demonstrating the harm caused by institutionalisation;
- a lack of family- and community-based services, including sufficiently accessible health and education services;
- economic turmoil following the collapse of planned economies and the subsequent increase in poverty;
- a lack of professionals with specialised skills to address the needs of children with disabilities;
- The current global financial crisis, which, according to the World Bank, hit CEE/CIS countries harder than any other part of the world.⁶

Definition of an Institution

Most attempts to define institutions for children tend to focus on the number of children living together in one building. This does not

always provide a complete picture: a small group home with 15 children might have a staffing structure and ethos which means it functions in a family-like and inclusive way, whilst another with eight children might maintain an isolated, rigid and regimented system similar to that in a large institution.

Instead it is perhaps useful to focus on the definition of “institutional culture”. The recent report by the Ad Hoc Expert Group on the Transition from Institutional to Community-based Care,⁷ known as the Spidla report, defines institutional culture through an examination of specific institutional characteristics. These include the precedence of the requirements of the organisation itself over the users’ individualised needs, and the use of a medical model of care, which carries the risk of reducing individuals to their diagnoses.

Using the Spidla report’s approach to the definition of institutional culture, institutions for children with disabilities are therefore defined as those residential facilities that:

- are isolated from the mainstream community, providing little opportunity for inclusion in normal everyday life and experiences;
- house relatively large groups of non-family members who are compelled to live together;
- result in prolonged periods of separation from the child’s family, friends and community;
- are organised according to a regimented routine that cannot respond to the individual needs and wishes of the children; and
- segregate children from the community owing to a diagnosis of disability and/or chronic illness.

The Difference between Institutionalisation and Residential Care

Residential care does not automatically result in institutionalisation. Countries that

have moved away from the use of large institutions have found that some children with very complex needs or challenging behaviours benefit from a placement in highly specialised, therapeutic residential care. This is ideally provided in small groups, living in normal houses, integrated into the community. A highly trained, professional workforce supports these children and, wherever possible, strong relationships with the birth and extended family are maintained. Where deinstitutionalisation has been successful, these residential placements account for a small percentage of the care provided to children with disabilities.

Most importantly, the difference between institutionalisation and good quality residential care can be demonstrated by the impact on health and developmental outcomes, as well as life chances and quality of life, for the children who live there.

The Impact of Institutionalisation on Children’s Health, Development and Well-being

Over the past sixty years, research across Europe has demonstrated the harm caused by institutionalisation. In the 1950s and 1960s, studies in Britain and the former Czechoslovakia noted that children in institutions struggled to form healthy emotional attachments to their carers.⁸ This was due to the number of carers working shifts in the institutions, and the regimented regime that could not respond to the individual needs and demands of children. The lack of emotional and physical contact, together with a lack of regular stimulation and interaction, resulted in specific developmental delays and challenging behaviours common to both the British and Czech children studied.

More recent research has found significant impairment of brain development among

infants raised in institutions, with the first six months of life being the most crucial.⁹ Most babies removed from institutions and placed in families before the age of six months recovered completely from this impairment. Those who remained longer than six months recovered only partially and demonstrated continued developmental and emotional difficulties throughout their childhood and adolescence.¹⁰

There is considerable evidence that children living in institutions are at a significantly higher risk of being abused or neglected than their peers raised in families. One Romanian study found a high prevalence of physical and sexual abuse of children in institutions.¹¹ Studies in the UK have found that children in residential care are at very high risk of sexual exploitation¹² and that disabled children are more likely to live away from home in residential care or in state-funded residential education.¹³ Additionally, a report for the Council of Europe found that:

“[A]buse in institutional settings is regarded by many to be endemic and can take place against a pervasive culture of depersonalisation, lack of privacy, inactivity, inadequate food and heating, poorly trained and supervised staff and isolation from community activities.”¹⁴

One of the most comprehensive studies to make comparisons across European countries in recent years found a disturbing pattern in the outcomes for young children with disabilities in institutions. It compared the movement of children from social care institutions to the movement of children from institutions for children with disabilities:

“Children under three from social care institutions were most likely to leave the institution and be returned to their biological family (32%) or be adopted nationally (24%). The most common reason for children to leave an institution for children with disabilities was because of death. For children under three leaving institutions, 28% of those children with disabilities had died in comparison to 0.29% of children in social care institutions.”¹⁵

Experience of early institutionalisation continues to have a negative impact as children grow into adults. One Russian study found severely reduced life chances for adults who had spent their childhoods in institutions: 20% had a criminal record, 14% ended up in prostitution and 10% committed suicide.¹⁶ A study in Moldova by the International Organisation for Migration found that young women raised in institutions were ten times more likely than their peers to be trafficked for the purposes of sexual exploitation.¹⁷

Children with a moderate to severe intellectual disability face an even bleaker future. Analysis of admissions to and discharges from children’s institutions in a number of countries demonstrates that the majority of these children, once they reach adulthood, are transferred to an institution for adults. The majority remain institutionalised – with all that implies – until their death.¹⁸

In summary, the harmful effects of institutionalisation include:

- impaired early brain development, leading to delayed cognitive and physical development and, in some cases, resulting in the onset of an intellectual disability;

- attachment disorders, which may result in the development of autistic behaviours, self-stimulation, self-harming, aggression to others or cruelty to animals;
- poor cognitive processing, resulting in educational under-achievement;
- poor physical health, including chronic infections;
- non-organic failure to thrive;
- unusually raised anxieties, specifically the fear of being abandoned and the fear of being alone, resulting in nightmares and sleeping disorders;
- eating disorders;
- enuresis;
- difficulty understanding right from wrong, resulting in behaviour such as lying and stealing;
- difficulties in forming healthy emotional relationships as adults;
- increased risk of child abuse and neglect; and
- significantly reduced life chances and, in some cases, life expectancy.

Reasons for Institutionalisation

Orphaned and Abandoned Children – Dispelling Myths

Lumos carried out an analysis of admissions to, and discharges of, 1,600 children aged 0-18 years, from residential institutions in two European countries. This study confirms, and sheds further light on, the findings of previously published research. There are many myths associated with the reasons for institutionalisation of children in Europe. Firstly, it is commonly understood that many of these children are “orphaned” or “abandoned”. Yet true “orphanhood” and “abandonment” accounts for a very small minority of children in institutions.

In relation to “orphanhood”, Browne et al found that across Europe, less than 6% of children in institutions under the age of three were actually orphaned.¹⁹ Lumos’ study of 1,600 children in two countries found that only 9% were actually orphaned.

In relation to abandonment, Browne’s study concludes that, in countries that were EU member states prior to 2003, only 4% of children under three in institutions were abandoned. Yet in new member states and other countries across Europe, 32% of the children were considered to have been abandoned. It is likely that this significant differential is in part due to a difference in the legal definitions of abandonment and in social work practice. In English law, for example, abandonment is defined very restrictively as a matter of criminal law. Under the Offences Against the Person Act (1861), it is a criminal offence to abandon a child under two, endangering its life or health; this is an extremely rare practice. In a number of countries in CEE, a child can be “declared abandoned” if a parent has expressed a lack of interest for a period of months. This means a parent has not contacted or visited the child in that period. Yet there is no obligation on the part of the state actively to encourage parents to maintain contact with their children. It is likely therefore that these figures on abandonment disguise motivations related to poverty and other social issues. A recent study on abandonment in several European countries confirms that the lack of a definition of “abandonment” results in groups of children with very different circumstances being grouped together, and in parents having been labelled as abandoning their children when they had no intention of doing so.²⁰

Lumos' analysis of children in institutions confirms Browne's findings on the subject of abandonment. In the Lumos' study, 11% of the children reviewed were defined as abandoned. Significantly however, children with disabilities appear to be over-represented in this group: in one country children with disabilities accounted for 63% of children in institutions defined as abandoned and 52% of those who had been orphaned.

Abuse and Neglect – a Varied Picture

Another striking difference among states found in Browne's research related to abuse and neglect as a reason for placing children in residential care. In the EU countries that were member states prior to 2003, overall rates of institutionalisation were generally lower than in other countries in the region. Of those children who were removed from their families, 69% were removed due to abuse and neglect. In the new member states and other countries in Europe, abuse and neglect accounted for only 14% of admissions. In these countries, as we have seen, socially-related "abandonment" accounts for 32% of admissions. A further 23% of admissions are children with disabilities.

This is a significant finding, since it is clear that abuse and neglect are at times legitimate grounds for separating a child from the family. Under the CRC, while factors such as poverty and disability should never be the primary reason for separating a child from the family, abuse and neglect may be such reasons. It should be noted, however, that where children are separated for reasons of abuse and neglect, placement in an institution is likely to exacerbate the trauma suf-

fered. This is of even greater concern when child victims of abuse are placed together with children who have perpetrated abuse. In a number of countries, Lumos has found that children in such institutions face increasing vulnerability and a greater risk of further abuse. For this reason, Lumos concludes that child victims of abuse should, as a priority, be placed in substitute families.

There is a tendency on the part of society and professionals to fail to detect the abuse of children with disabilities. Communication difficulties can act as a barrier to children disclosing abuse. But studies have consistently shown that children with disabilities are more likely to be abused than their peers:

"Sullivan et al (1997) found that disabled children were 1.8 times more likely to be neglected; 1.6 times more likely to be physically abused and 2.2 times more likely to be sexually abused. Cross et al (1993) found that disabled children were 2.8 times more likely to be emotionally neglected; 2.1 times more likely to be physically abused; 1.8 times more likely to be sexually abused and 1.6 times more likely to be physically neglected. Overall they were 1.7 times more likely to be abused or neglected than non disabled children."²¹

Lumos' research found that in a number of countries children and adults with disabilities are placed together in so-called "social care" institutions. In some of these institutions, a great effort has been put into separating children and adults. In others, however, children and adults may even share bedrooms. When discussing such practices with professionals, in some cases there is little understanding of the risks to children. A number of profession-

als and policy makers appeared to view adults with disabilities as “eternal children”, who would therefore not pose a risk to children. The research indicates a clear need for the implementation of appropriate child protection policies and training programmes in all services that care for children. In addition, training is required to change attitudes towards, and understanding of, the needs and rights of adults with disabilities.

Poverty, Disability and Ethnicity

In addition to the considerable over-representation of children with disabilities in institutions, a number of studies also suggest that there is an over-representa-

tion of children from ethnic minorities in institutions. However, it should be noted that data on ethnicity of children in care is often not available in the central databases of governments, or at times the individual files of children, and it is necessary to carry out in-depth research in the institutions themselves to provide an accurate picture. Where such research has been carried out, the results demonstrate a significant over-representation of ethnic minority children.

For example, Table 1, drawn from a recent European Roma Rights Centre study across six EU member-States, illustrates the dramatic over-representation of Romani children in institutions.²²

Table 1: Romani Children in Institutions

	Bulgaria	Czech Republic	Hungary	Italy	Romania	Slovakia
Percentage of Romani children in children's homes visited	63.0%	40.6%	65.9%	10.4%	28%	82.5%
Share of Roma in the total population	10%	3%	7%	0.23%	9%	9%

The study demonstrates however that the picture is not uniform and there are significant differences between countries. Lumos' studies in a number of countries have produced similar findings to the above data in some countries, however in others, the over-representation was not so significant: for example 6% of children in institu-

tions being Roma compared to 2% in the general population.

Grounds for Admission to Institutions

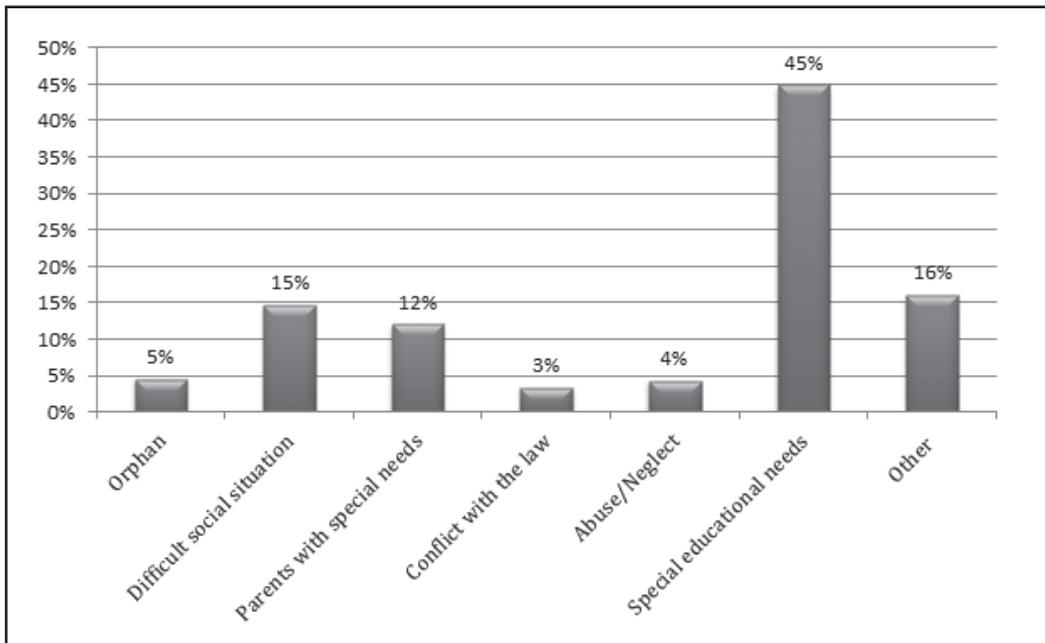
The reasons for admitting children to institutions identified by Lumos' study paint a complex picture of the inter-relationship between poverty, disability and ethnicity.

A Range of Reasons for Admission

Graph 1 represents a range of reasons given to Lumos for the admission of children within one country over one year.

These findings demonstrate that a relatively low percentage of children were admitted to institutions as they were orphans; there are three times as many children who are in institutions due to social

Graph 1: Reasons for Admission

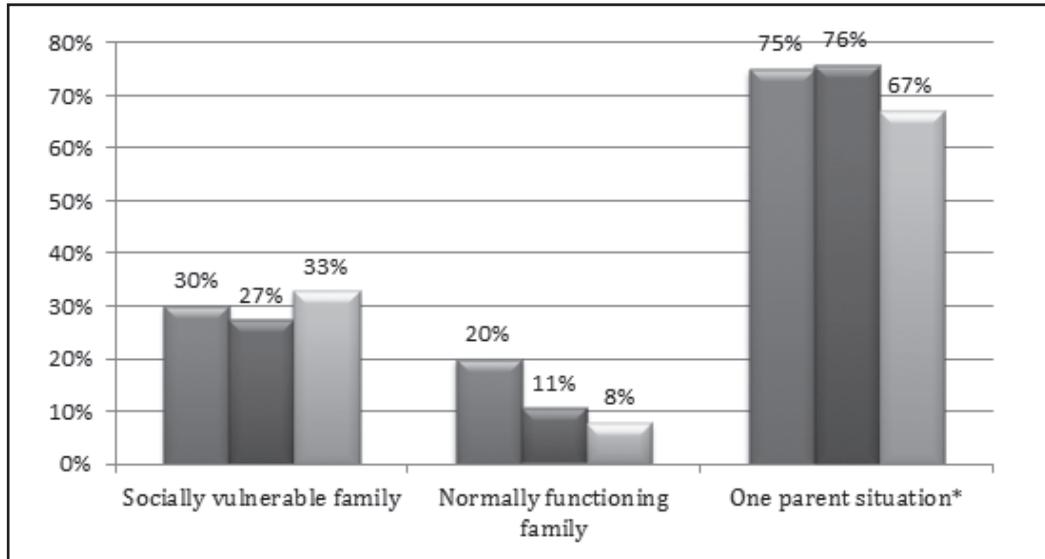


reasons as there are orphans. The “parents with special needs” include parents with special health needs, some of whom are likely to be able to look after their children if provided with some additional support. The prevalence of “special educational needs” highlights the need for a focus on inclusive educational services. Further, it demonstrates that in this country, nearly half of children in institutions are those with disabilities, placed for educational purposes.

Social Status of the Family - A Comparison between Three Different Children’s Homes

Graph 2 provides a comparison of the family backgrounds of children within three institutions in **one country** as identified by Lumos’ research.

A comparison of three institutions from another country demonstrates that a significant percentage of children come from situations of some kind of breakdown of

Graph 2: Family Backgrounds

* One parent situation includes divorced parents, single parent, one parent in prison and one parent deceased.

the parents' relationship (single-parents, one parent deceased, divorced parents). It would appear that a breakdown in the relationship between the parents is a predictor of social vulnerability that may require additional services for single parents in order to prevent separation of children from their families. It is common knowledge that single parents are more likely to be living in poverty than those in couples. Furthermore, a number of studies demonstrate that disability can be a cause of breakdown of the relationship of the parents.²³

Length of Stay Correlated with Disability and Ethnicity

Lumos' analysis has confirmed that not only were Romani children over-represented in institutions, but they also tended to stay for

longer periods of time than children from the majority ethnic group. In the most extreme example of one institution, 69% of Roma children stayed for a year or more but only 18% of the majority population stayed longer than a year.

Similarly, children with disabilities or special health needs are generally more likely to stay longer in institutions. In one institution for babies where 50% of children had a disability, 90% of children who stayed for only up to three months did not have a disability. In another institution 57% of children with no special needs stayed for six months or less, whereas those with a sensory disability always stayed at least a year and 46% of those with an intellectual disability stayed for two years or more.

In the disability institutions most stays are long term, frequently 3.5 years and more.

This is a very long time to be separated from the family and the community. Lumos' research also highlights that once children are admitted to residential homes for disabled children, for the most part they stay there and later go on to another institution. Once admitted, children are not likely to be placed elsewhere, be it with the birth family, a foster family or in a better care facility.

Taking account of the negative impact of institutionalisation on a child's health, development and well being, it is evident that children with disabilities and those from ethnic minorities are likely to experience a greater impact of institutionalisation. This is likely to result in more severe developmental delays or disturbed behaviours than their peers.

Article 2(1) of CRC states that:

"States Parties shall respect and ensure the rights set forth in the present Convention to each child within their jurisdiction without discrimination of any kind, irrespective of the child's or his or her parent's or legal guardian's race, colour, sex, language, religion, political or other opinion, national, ethnic or social origin, property, disability, birth or other status."²⁴

It is clear therefore that the over-representation of children with disabilities and those of ethnic minorities in institutions, coupled with their extended stays, represents a contravention of Article 2 of the Convention.

The Link between Poverty and Disability

The relationship between poverty and disability has been well researched. It is a complex two-way relationship, in that disability causes poverty and poverty causes disability. A recent study in the UK found that:

"[W]ealthy families are a third less likely to have a disabled child. Families with a disabled child were on average £50/week worse off than others; despite the fact that **extra costs for raising a disabled child** means families need an extra 18% of income". (Emphasis added)²⁵

Although the available research data in the CEE/CIS countries has been insufficient, a UNICEF study in 2005 found that:

"In Moldova, one third of households that have a child with disabilities fall into the lowest-income quintile, while only 8 per cent were in the highest quintile. In Romania, households that have children with disabilities have 65 per cent of the per capita income of those without."²⁶

These figures are not surprising, since the additional care needs of a child with a disability often limit its parents' ability to undertake paid employment. Research also demonstrates that, particularly in lower and middle-income countries, poverty is a direct cause of disability, where:

"[T]he proportion of disability caused by communicable, maternal and perinatal diseases and injuries and the proportion of childhood disability are higher than in developed countries. Much of the disability in developing countries stems from preventable impairment, and a large part of the disability could be eliminated through treatment or alleviated through rehabilitation. Nutrition is particularly important."²⁷

The impact on individual children of this poverty-disability axis is much greater in lower income countries, where the consequences can include high infant mortality rates and widespread lack of access to ad-

equate nutrition. Therefore, where children in lower income countries with a disability are more likely to live in poverty, the results of that poverty are more likely to harm the health and development of a child.

As children with disabilities grow into adults, they are more likely to live in poverty than their peers:

“Disabled people have lower education and income levels than the rest of the population. They are more likely to have incomes below poverty level, and less likely to have savings and other assets than the non-disabled population. These findings hold for both developing and developed countries.”²⁸

Thus it is evident that poverty is significantly more likely to affect the entire lives of children with disabilities than the lives of their peers. When planning support structures and services, this should be taken into account.

The Link between Poverty and Ethnicity

Recent research also demonstrates a strong link between poverty and ethnicity in Europe. For example, a survey conducted by the World Bank in Serbia found that 60.5% of the Roma population were considered “very poor,” as compared to 6.1% in the general population.²⁹ A study by UNICEF also presented a very high poverty level for Romani children: 66.6% of children from Serbian Roma settlements and 83% of those living in slums were considered to be under the poverty line.³⁰

In 2010, the World Bank found that approximately one third of the wage gap between Roma and majority populations was a result of discrimination and other factors beyond differences in education, experience,

and place of residence.³¹ Other studies have shown a link between unemployment and the number of children in care.³²

Lumos’ study of 1,600 children admitted to institutions showed significant over-representation of Roma children and those from socially vulnerable families, reinforcing the World Bank findings which link poverty and unemployment with the separation of children from their families and their placement in institutions.

The Challenges for Children with Disabilities in Some Ethnic Minority Communities

Research indicates that there have been specific challenges for children with disabilities in specific ethnic minority communities. For example, amongst Roma populations in some European countries, discrimination appears to have led to the systematic misdiagnosis of Roma children as having special educational needs. Research in Hungary showed that the percentage of children in care categorised as having an intellectual disability was significantly higher among Romani children; one estimate was as high as 90% of the children with disability. The study indicated that the information provided by some of the children’s home directors showed a higher percentage of Roma children with intellectual disabilities and it was suggested that at times the testing of these children was a matter of “social deprivation, diagnosed as disability”.³³ There is evidence to suggest that such diagnoses were influenced by “scholastic aptitude tests”, which were designed to reflect the dominant culture and language.

At the same time, Lumos’ research found a lack of available evidence regarding Romani children with disabilities. A number of international organisations have written about the misdiagnosis of Romani children as having in-

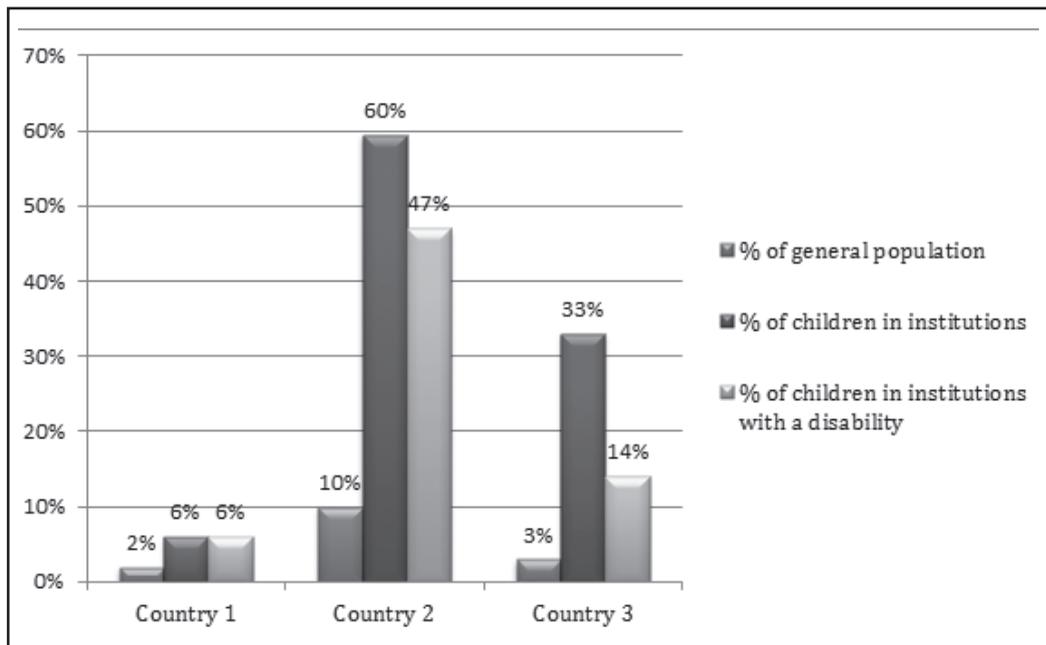
tellectual disabilities.³⁴ However, the specific topic of disability among Romani children and in the Roma community in general seems to be under-researched. Lumos' research suggests that some non-governmental organisations (NGOs), governments and communities may be reluctant to address the issue of disability among Romani children for fear of reinforcing the attitudes that have led to the misdiagnosis of many Romani children and their arbitrary separation from their families. However, this may result in Romani families of children with disabilities not accessing the services they require and is likely to delay interventions that might ameliorate the impact of disabilities on children's life chances.

Lumos' findings reflect those of a Council of Europe report, which demonstrates the links between disability and ethnicity and the sub-

sequent social disadvantage and lack of access to support.

"People with disabilities from ethnic minorities are doubly disadvantaged in their dealings with social and welfare institutions and in their vulnerability to racially motivated abuse and discrimination. These "extra" disadvantages are not separate entities, running in parallel, but act as multipliers of difficulty and create a unique identity for disabled individuals who may be resisting hostile attitudes to disability within their own communities at the same time as they are struggling with the effects of social and economic discrimination due to racism from the dominant community."³⁵

Graph 3: Romani Children with Disabilities in Institutions



However, despite a significant over-representation of Roma children in institutions, in some countries this was less of an issue among children with disabilities. This is shown in Graph 3, presenting the proportion of Roma in the general population, compared with the proportion of Romani children in institutions and disabled Romani children in institutions.

In addition, Lumos' research suggests that Roma families were more likely than the majority ethnic population to maintain relationships with their disabled children placed in institutions.

Poverty-Disability-Ethnicity Nexus

Many ethnic minority communities have higher levels of poverty and are therefore likely to have higher levels of disability among children. Yet discrimination suffered by some communities may result in under-reporting of disability. As a result, children with disabilities from some communities are likely to access services later than their peers in the majority community. Early intervention is crucial to ameliorating the impact of disability and maximising children's potential. It is, therefore, evident that planning services for children with disabilities should take these complex relationships into account.

Thus it would appear that in some European countries poverty and discrimination based on disability and ethnicity intersect to reinforce and exacerbate each other. Unpacking the reasons for admission to institutions and the practices that result in the over-representation of certain groups of children is essential to correcting these practices and implementing reforms that ensure all children, irrespective of background, can enjoy all the rights provided for by the CRC.

In this regard, Lumos' research found a number of factors common across many countries that still rely heavily on large residential institutions to look after vulnerable children. The findings summarised below are drawn from:

- the analysis of 1,600 admissions to institutions;
- the analysis of 102 cases of children referred to social services (through a process of considering each case, from the point of referral to case closure);
- the assessment of 1,388 families of children with disabilities in institutions.

Lack of Sufficient Support Services for Families in Poverty

In our study, social workers cited unemployment, housing and lack of access to basic material necessities as a primary cause of many cases of children referred to social services. Most social workers felt they had little or no options to offer these families other than an institutional placement.

Stigma and Discrimination Attached to Disability

Families cited frequent occasions when health, education or social work professionals had advised them to place their children in an institution. Professionals expressed a belief that most families of children with disabilities did not want their children and cited a lack of contact with children as evidence. However, many parents involved in the family assessment stated that when they tried to find out more about their children, they were informed that the child had severe disabilities and there was no point in coming to disturb and upset them (or, for that matter, upset themselves). Some parents were also informed that it was best for their child if they did not visit and did not enquire after them, as the child would get upset after each visit.

The family assessment found that 53% of families who had lost contact with their children with disabilities expressed a desire to re-establish contact and for their children to be placed close to them to facilitate this contact.

Discriminatory Assumptions about Romani Families

The misdiagnosis of Romani children as having special educational needs appears to be based on rigid and discriminatory approaches to assessment and has resulted in high levels of Romani children without disabilities admitted to residential special schools. In addition, Romani families frequently faced discrimination when attempting to access services for their children (such as health care).

Lack of Sufficiently Accessible and Supportive Universal Health and Education Services

The lack of inclusive education services for children with disabilities in many countries results in continued arbitrary separation of children from their families and placement in residential special schools, often sited a considerable distance from the child's home.

Lack of Sufficient Investment in Frontline Social Work

Common findings in most of the social work cases studied include:

- All social workers had high case loads and were over-stretched, making it difficult to allocate sufficient time to each case.
- In many cases, this resulted in an inability to intervene early; as a result, many cases were referred several times to social services before action was taken. This usually resulted in deterioration in the case and action being taken once the situation had reached crisis point. In these cases,

the most common result was removal of the child from the family and their placement in an institution.

- Once children were placed in institutions, social workers felt these children were "safe" and therefore focused on other pressing or crisis cases; as a result there was little follow up or review of children's placements. Children then spent long periods of time in institutional placements.
- Social workers cited insufficient training and a lack of regular supervision and professional support. Many social workers were taking significant levels of responsibility for decision-making in challenging cases without appropriate guidance.
- A lack of tools for systematic assessment, decision-making, monitoring and follow up of children was identified by the researchers among social workers from a number of countries. Where assessments existed, these often focused on material welfare and rarely involved direct discussion with, or observation of, the children involved.
- A lack of alternatives to institutional placements meant that, faced with cases of severe risk to children, social workers felt they had no alternative but to place children in institutions. In a number of countries, foster care was under-developed. Where it existed, it tended to operate as quasi-adoption, where placements were considered permanent and foster parents were reluctant to facilitate contact with birth families. Foster care is still not available for children with disabilities in many countries. In addition, some countries are reluctant to place young babies in foster care, despite the fact that the greatest harm caused by institutionalisation occurs in the first six months of life.

Legal and Human Rights Framework

Previously published academic research and Lumos' analysis presented in this article

demonstrate that the rights of children separated from their families and placed in institutions are infringed on a number of levels. This raises questions regarding the human rights legislative framework, including:

- Are the human rights instruments sufficiently understood by governments and communities involved in reforming and providing services?
- Are there sufficient resources for governments to make the changes necessary to implement the human rights framework for children with disabilities?
- Is the human rights legislative framework sufficiently robust to ensure all children, including those with disabilities and the most complex needs, receive the support and services they need to develop to their full potential?

A number of international human rights instruments are relevant to the care and protection of children with disabilities. The strengths and limitations of three key instruments are considered here.

The UN Convention on the Rights of the Child (CRC)

As outlined at the beginning of this article, the CRC provides a clear framework regarding the care and protection of children, including the following principles:

- Parents have the primary responsibility for raising their children;
- The state should support parents to fulfil their responsibilities;
- Where, despite support, parents are unable to care properly for their children, children have a right to protection from harm and abuse;
- If that protection involves removal from the family, placement in a substitute family is the preferred option; and

- All these rights apply to all children, including children with disabilities.

However, references to disability in the CRC could be interpreted in ways that are contrary to the rights framework outlined above. Disability is only mentioned in two articles throughout the whole Convention: articles 2 and 23. The specific article on disability (article 23) does not mention the child's right to family life. Instead, it focuses on children's development of independence and their access to health, education and other services. This, coupled with article 20, which allows placement in "suitable institutions", appears to have been interpreted in some countries as a justification for institutionalisation. Since there are inadequate community based specialised health and education services, institutionalisation in residential special schools or special hospitals is seen as a way of ensuring children's rights to access those services. But this is at the expense of the right to family life.

The UN Convention on the Rights of Persons with Disabilities (CRPD)

The welcome advent of the CRPD begins to address the lack of detail on disability in the CRC. The Convention sets up a framework to ensure the fullest possible independence and integration in the community of persons with disabilities. Article 19 is widely cited by Disabled Persons Organisations (DPOs) and other NGOs to argue for an end to institutionalisation of disabled adults. The focus of article 19 is the right to "live independently and be included in the community". However, in many respects this article is predominantly focused on adults. In fact, children need to be cared for in families, in order to grow into independent adults.

Article 7 of CRPD, which is the article specific to children, states:

“1. States Parties shall take all necessary measures to ensure the full enjoyment by children with disabilities of all human rights and fundamental freedoms on an equal basis with other children.

2. In all actions concerning children with disabilities, the best interests of the child shall be a primary consideration.

3. States Parties shall ensure that children with disabilities have the right to express their views freely on all matters affecting them, their views being given due weight in accordance with their age and maturity, on an equal basis with other children, and to be provided with disability and age-appropriate assistance to realize that right”.

This article is important, but it is quite general, reflecting the essence of articles 2, 3 and 12 of CRC. Specifically, it does not emphasise disabled children’s right (and need) to be raised in a family environment. As with the CRC, the concept of “best interests of the child” is open to interpretation.

Article 23 of CRPD guarantees respect for home and the family. Article 23 (3) states that:

“States Parties shall ensure that children with disabilities have equal rights with respect to family life. With a view to realizing these rights, and to prevent concealment, abandonment, neglect and segregation of children with disabilities, States Parties shall undertake to provide early and comprehensive information, services and support to children with disabilities and their families.”

However, article 23 does not explicitly prohibit the use of arbitrary separation under the guise of providing children with health and education services,

which research has shown is the primary reason for institutionalisation of children with disabilities in Central and Eastern Europe. Article 24 of CRPD is of some value in this regard as it emphasises the right to inclusive education.

The European Convention on Human Rights (ECHR)

This Convention is of great importance, since it is legally binding for all member states and sanctions can be applied if it is contravened.

Article 8 of ECHR guarantees the right to respect for private and family life and requires that any interference with this right by a public authority be justified as being in accordance with the law and necessary in a democratic society. But this Convention has no specific references to children, for whom interference in private and family life has a different meaning compared to that of adults.

In summary, the Convention on the Rights of the Child has little focus on disability and the Convention on the Rights of Persons with Disabilities appears to be drafted primarily with adults in mind. The European Convention on Human Rights contains no reference to children at all. This lack of reference does not automatically mean lack of protection, since children are rights holders under ECHR. However, there is a risk that the potential of the ECHR, and its case law, to act as a living instrument that protects children with disabilities, will not be fully realised. Unless all the Conventions are interpreted holistically and purposefully by governments and judicial authorities, there is a risk that children with disabilities may fall between the gaps of the human rights legal framework.

Cost Effectiveness and Cost Benefit of Deinstitutionalisation

Removing children from their families due to poverty or social reasons represents a violation of their rights. As argued above, it has a negative impact on their health and development and reduces their life chances. However, it is also a relatively expensive way of looking after children. Often one of the greatest challenges faced by governments in trying to fulfil their obligations under international Conventions is the financial cost involved. The deinstitutionalisation process does require investment, but in the long run proves to be cost effective for governments.

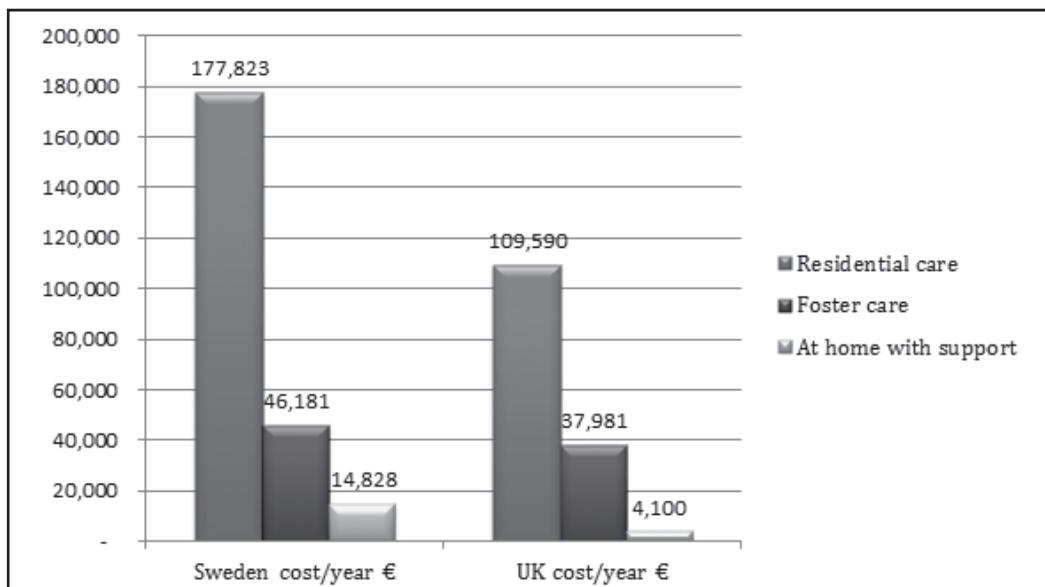
In most cases, the cost of supporting a child to remain in their family is significantly lower than the cost of placing a child in residential care, whilst outcomes are considerably better.

Graph 4 presents examples from two European countries, Sweden and England, outlining the costs per child per year to place them in residential care, in foster care or to support them in their family.

Although the residential care provided is extremely expensive, very few children with disabilities require this service and most are cared for at home. For example, in one county in England, only 0.7% of children with disabilities lived in residential care. In one county in an Eastern European country, that rate was 7%: the government of a much poorer country was paying for ten times as many children with disabilities to live in residential institutions.

The process of moving from heavy reliance on large institutions to a system of family and community based care should be an exercise in the reinvestment of resources. By reducing

Graph 4: The Cost of Supporting a Child



the numbers of children in residential care, money can be freed up to support much larger groups of children to live in families. This can also make increased funding available for the small minority of children with highly complex needs, for whom the provision of high quality care requires significant investment.

A number of studies have demonstrated the cost benefit of investment in good community support services for children with disabilities.³⁶ Early intervention in particular ameliorates the impact of disability and improves children's chances of completing education, gaining employment as adults and contributing to the economy. This approach also reduces the amount the state needs to spend on provision of support services throughout the life of a person with disabilities.

Key Developments in Policy and Advocacy

In recent years, a number of advocacy and policy developments have taken place at the international level that are paving the way for deinstitutionalisation of children with disabilities. A number of key examples follow.

Better Health, Better Lives

The World Health Organisation's Better Health, Better Lives Initiative was launched in 2008. The initiative aims to:

“[E]nsure that all children and young people with intellectual disabilities are fully participating members of society, living with their families, integrated in the community and receiving health care and support proportional to their needs.”³⁷

The Initiative takes a holistic approach to the health, development and well-being of children with intellectual disabilities and the role of different agencies to achieve this.

As a next step, in 2010 the European Declaration and Action Plan on the Health of Children and Young People with Intellectual Disabilities and their Families was signed on behalf of 53 Ministers of Health of the European region and endorsed by a group of international NGOs at a conference in Bucharest. The Declaration was formally endorsed as a Resolution in 2011.

The Declaration goes some way to bridging the potential gap on the rights of children with disabilities and in particular, by making explicit the implied inter-connected rights of children to live with their families *and* access appropriate health and education services *and* participate fully in the community, live with dignity and achieve independence. Moreover, it provides a framework for ensuring these rights are realised.

The Spidla Report

In 2009, EC Commissioner for Employment and Social Affairs, Vladimir Spidla, asked a group of experts to produce a report on deinstitutionalisation in Europe. The report covered the situation of four groups of people – children, adults with disabilities, people with mental health problems and older people. The Expert Group represented a range of NGOs, DPOs and service providers across Europe.

The report made a range of specific recommendations to EU member states and to the EC itself. Key recommendations included: all countries to develop national action plans for deinstitutionalisation; the EC to ensure deinstitutionalisation is factored into its work with countries outside the EU; the development of a set of Common European Guidelines on deinstitutionalisation that could be used by EU member state governments to plan reform, but could also be used by EC desk officers in assessing reform projects and allocating funding.³⁸

Common European Guidelines and Toolkit

On the basis of the recommendations of the Spidla report, the European Expert Group on the Transition from Institutional to Community Based Care is currently developing a set of Common European Guidelines on deinstitutionalisation and an easy-to-use Toolkit for assessing financing programmes and initiatives in the context of the use of EC Structural Funds.

Recommended Priorities for Future Action

It is evident that children with disabilities face multiple disadvantages throughout their lives. There are strong links between disability and poverty, abuse, social exclusion, and lack of access to adequate health care and education. Investing to ensure equal rights in most cases requires the direction of additional funds towards these children and their families, in order to:

- Lift them out of poverty;
- Protect them from harm and abuse;
- Ensure they can live with and be cared by their families, included in their community;
- Ensure they receive the healthcare and therapy they need to develop properly; and
- Ensure they receive education that gives them the opportunities to learn and develop to their full potential.

The institutional system should be seen as a resource to be reallocated to community based services and to strengthen and make more accessible universal healthcare and education services, in order to ensure full access to rights for all children with disabilities.

With this in mind, the following recommendations are made:

- Countries that still have significant numbers of children living in large residential institutions should develop national action plans for complete reform and deinstitutionalisation.
- These plans should prioritise young babies and children with disabilities, since they tend to be the most vulnerable children in institutions. In addition, it is often the case that children with disabilities are left until last in reform programmes, as authorities tend to focus first on children who are considered to be “easier to place”.
- Plans for reform should ring-fence resources from the institutional system and reallocate them to family and community services.
- The next programming period for EC funding should prioritise deinstitutionalisation, in order to fulfil the EU’s responsibilities under the CRPD. Regulations should be developed to avoid the investment of EC funds in renovating large institutions or the development of other services that would continue to isolate or segregate children with disabilities.
- Other donors should coordinate their efforts to support the deinstitutionalisation process. Donors should be discouraged from investing in the “improvement” of institutions, as this often results in a reluctance to reform them.

With concerted efforts, it is possible to ensure that all children with disabilities can enjoy their rights to be raised in their families, included in their communities, provided with education and healthcare, have their voice heard and develop to their full potential.

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ity Lumos, which works to put an end to the systematic institutionalisation of children within the next 20 years, ensuring that all children have the opportunity to grow up in a safe and caring family environment or, where there is no alternative, in specialist services that meet all their needs, respect their rights and ensure they can fulfil their potential.

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Moving from the Norm to Practice Towards Ensuring Legal Capacity for Persons with Disabilities in Kenya

Lawrence Mute¹

I. Introduction

Article 12 of the Convention on the Rights of Persons with Disabilities (“the Convention” or “CRPD”) covers the legal capacity of persons with disabilities. This, perhaps, is the most profound article in a human rights instrument full of other insightful articles. States across all global divides including Kenya are just now beginning to appreciate the significance of that article. While Article 12’s affirmations are resounding, the practical approaches for legislating its provisions into national law are far less easy to grasp. This article offers a reflection on the options available to Kenya and indeed other common law jurisdictions, particularly in Africa, as they seek to make Article 12 of the Convention operational. The article explores the possibility of passing an omnibus law on capacity subsequent to which all legislation which undermines the legal capacity of persons with disabilities would be repealed.

II. Summation of the Convention on the Rights of Persons with Disabilities

Article 1 states the Convention’s purpose as to: “promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity”.² Yet the Convention

“is not primarily about disability – it is about a theory of justice as applied to disability”.³ The Convention’s approach to the exercise of human rights offers amazing opportunities for persons with disabilities globally. It also provides policy- and law-makers, as well as implementers, with advanced tools for ensuring the rights of persons with disabilities. The Convention is a truly revolutionary human rights instrument. The paradigm shift which it heralds entails three fundamentals:

“[T]he shift away from treating people with disabilities as ‘objects’ to be managed or cared for to honouring and respecting them as ‘subjects’ (...) restoring voice, power and authority to the self over him or herself (...) and (...) respecting this power and authority by forging pathways to independent living and participation.”⁴

In other words, what the Convention does is to affirm that persons with disabilities are human beings with personhood and dignity. It replaces the theories which in the past have been used to engage persons with disabilities: where persons with disabilities in the past were **objectified**, now they are **subjects with human rights**; where before they did not have legal capacity, now they do; where before persons with disabilities

were forced to live in institutions or hidden away from the community, now they have the right to live independently in the community; where before persons with disabilities were educated in segregated settings, now they are educated along with their non-disabled peers in inclusive settings; and, now, persons with disabilities are no longer asexual or infertile – they have the right to retain their fertility, to have intimate relations and bring up a family.

III. The Concept of Legal Capacity

Prior to 2006 when the CRPD was adopted by the United Nations General Assembly, laws by and large approached people with disabilities assuming that they had no legal capacity. Following adoption of the Convention, laws now are required to be crafted with the basic assumption that persons with disabilities have legal capacity.

Legal capacity is what a human being can do within the framework of the legal system. It allows one to enjoy the right to access the civil and juridical system and the independence to speak on one's own behalf. Legal capacity means a capacity recognised by law which would make a person capable of having rights and obligations. In other words, it makes a person the subject of law. This subject of law enters into social relations which with the backing of law are transformed into legal relations.

Legal capacity is fundamental to human "personhood" and freedom. It protects the dignity of persons as well as their autonomy – their ability to take charge of their own lives and to make their own decisions. These decisions span a broad range including the development of personal relationships, medical treatment, and finance and asset management.

Possession of rights without legal capacity is impossible: being declared incompetent to manage one's personal affairs means that an individual no longer has the legal right either to make any personal decisions or to participate in activities otherwise taken for granted. Depriving someone of legal capacity often also deprives them of the legal right to enter into contracts, instruct a lawyer, to vote or own property, to marry or even to bring up children. If you are deemed legally incapable then your legal "personhood" is stripped away – your destiny is placed in the hands of others: you are dead.

An illustration of legal incapacity relates to women who for many centuries were denied legal capacity to own property and to vote. It is no wonder that Article 15 of the Convention on the Elimination of All Forms of Discrimination Against Women makes the following affirmation:

"2. States Parties shall accord to women, in civil matters, a legal capacity identical to that of men and the same opportunities to exercise that capacity. In particular, they shall give women equal rights to conclude contracts and to administer property and shall treat them equally in all stages of procedure in courts and tribunals. 3. States Parties agree that all contracts and all other private instruments of any kind with a legal effect which is directed at restricting the legal capacity of women shall be deemed null and void."⁵

IV. How the Law Has Construed Incompetence

There are three models on the basis of which law attributes legal incapacity on persons with disabilities.⁶

Under status attribution, the law declares that a person with a particular disability can-

not perform a specified legal task. The law declares that you cannot adopt a child if you have an intellectual disability; or that you cannot drive a car if you are deaf; or that you cannot operate a bank account.

Under functional attribution, the law treats disability as a threshold condition under which a person is incapable if by reason of such disability he is unable to perform a specified function. So you are stripped of legal capacity if you cannot understand the nature of a contract; or if you cannot understand that an act is wrong or contrary to law.

Under outcomes attribution, incompetence is determined on the basis of the quality of decision at which a person with disability arrives. If you decide to discontinue psychiatric treatment, then you are incompetent because that is a bad decision. In other words:

“[W]hile we may not make assumption about the lack of capacity based on one’s status as, say, a person with an intellectual disability, we can certainly make them by inference from bad decisions or a pattern of bad decisions or a flawed process of decision-making.”⁷

V. Meaning and Essence of Article 12 of the Convention

Article 12 of the Convention has midwived a significant paradigm shift for the way in which persons with disabilities exercise their human rights. Whereas before the assumption was that persons with disabilities did not have legal capacity, the assumption now is that all persons with disabilities have legal capacity and that wherever they may not be able to exercise that capacity effectively they shall be provided with appropriate supports to make their own decisions. In other words,

before the Convention the supposition was the bottle was half empty. Now the assumption is the bottle is half full.

The aim of Article 12 is to ensure that persons with disabilities are “subjects” of the law capable of determining their own destinies and deserving of equal respect, and not “objects” of the law to be managed and cared for by others.⁸ They should not be patronised, paternalised or treated like children. It provides as follows:

- “1. States Parties reaffirm that persons with disabilities have the right to recognition everywhere as persons before the law.
2. States Parties shall recognize 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.
5. Subject to the provisions of this article, States Parties shall take all appropriate and effective measures to ensure the equal right of persons with disabilities to own or inherit property, to control their own finan-

cial affairs and to have equal access to bank loans, mortgages and other forms of financial credit, and shall ensure that persons with disabilities are not arbitrarily deprived of their property.”⁹

What are the key elements of the paradigm shift from substituted decision making to supported decision making that are pronounced in this Article? First, the personhood of all persons with disabilities is reaffirmed: that the law recognises them everywhere as persons. This recognition is not undermined by their cognitive abilities. Second and following from that affirmation, the Convention requires the autonomy of persons with disabilities to be respected on an equal basis with others: that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life. Third, Article 12 recognises that persons with disabilities may have decision-making deficits which require to be supported in exercising their legal capacity. The state therefore is required to take appropriate measures to provide access by persons with disabilities to the supports they may require. Fourth, the Article requires safeguards to be put in place to ensure that measures for facilitating supported decision making are not abused.

What, then, is the distinction between substituted decision making which Article 12 ousts and supported decision making which it introduces? Substituted decision making assumes that decision-making deficits must be replaced by plenary guardianship or partial guardianship. Under plenary guardianship, a third party assumes the right to make all decisions for the disabled person with total disregard for the person’s views. Under partial guardianship, a third party assumes the right to make certain kinds of decisions

for a disabled person. Supported decision-making assumes that decision-making deficits are just that: deficits which can be augmented, developed, understood. Existing capacities can be developed and capabilities can grow.

VI. The Approach of Kenyan Legislation

Kenyan legislation is full of situations where the legal capacity of persons with disabilities is constrained and either partially or wholly handed over to third parties. In a few instances, though, some legislation endeavours to move towards supported decision making for persons with disabilities.

Participation in the Political Process

Article 83 (1) of the Constitution of Kenya (2010) provides that:

“A person qualifies for registration as a voter at elections or referenda if the person— (a) is an adult citizen; (b) is not declared to be of unsound mind; and (c) has not been convicted of an election offence during the preceding five years.”¹⁰

Three essential questions are relevant here. First, who is a person of unsound mind and who makes that determination for purposes of elections? Second, what is the relationship between Article 83 (1) (b) of the Constitution and Article 12 of the Convention? Finally, what does Article 83 mean when it is read alongside Article 38 of the Constitution?

Article 38 (3) of the Constitution provides that:

“Every adult citizen has the right, without unreasonable restrictions – (a) to be registered as a voter; (b) to vote by secret ballot in any election or referendum; and (c)

to be a candidate for public office, (...) and, if elected, to hold office.”¹¹

Article 83 (1) (b) of the Constitution is informed by the outcomes model of determining incapacity. Indeed, Kenya’s judiciary did agree with that formulation when it stated in 2010:

“A person who is in prison and is of unsound mind is not in control of his faculties and may not be able to know the magnitude of any election let alone the referendum. The exclusion of that class of inmates is therefore obvious and self-explanatory.”¹²

Yet, it has been noted thus:

“The assumption is that mad people will cast irrational votes. It hilariously follows therefore that people without labels of mental disorders/disabilities cast rational votes. What is rationality anyway? Since when have people without labels of mental disorders/disabilities had to take a rationality test at the polling station? What would such a test look like? And since when did we discount irrational votes? If we think racism is irrational, did we discount those votes which were cast solely because of the ethnicity of the candidates? Doesn’t rationality in voting boil down to agreement with the person who is conducting the rationality test, just like consenting to medical treatment boils down to agreeing with the doctor?”¹³

And I have noted:

“It is a common adage that: ‘every village has its mad man’. If the residents of a village chose to elevate their ‘mad-man’ to be their chief, would there be anything essentially wrong in that? In other words, if the villagers were so mad they crowned a mad-man their leader, what objective test of san-

ity (rationality) could the law use to invalidate that? With what legitimacy? Why, then, does the law forbid persons of unsound mind from standing for elective office? Is Kenya so ‘mad’ it would actually elect them, and if so, are our leaders not as good (or bad) as the electors who choose them?”¹⁴

Restrictions to Civil Life

Civil death is a condition common to many persons with disabilities. The law far too often places a disabled person under the legal guardianship of another instead of providing measures and safeguards to support such person to make decisions. The central basis for ousting legal capacity in particular for persons with intellectual or psychosocial disabilities is framed under the rubric of suffering from mental disorder.

Section 16 of the Mental Health Act (Cap. 248) provides that a police or administrative officer may take into custody and hand to a mental hospital a person with mental disorder; one who is dangerous to himself or others or who on account of the mental disorder is likely to offend public decency; or one not under proper care and control or who is being cruelly treated and neglected by a relative or guardian.¹⁵ Section 2 of the Act defines a “person suffering from mental disorder” as:

“A person who has been found to be so suffering under this Act and includes a person diagnosed as a psychopathic person with mental illness and person suffering from mental impairment due to alcohol or substance abuse”.¹⁶

Section 107 of the Children Act (No. 8) of 2001 provides that if a child suffers from a mental or physical disability or illness rendering him or her incapable of maintaining

himself or herself or managing his own affairs and property without a guardian's assistance, the court may order extension of guardianship for such a child. Such order, though, should be made with the consent of the child if he is capable of giving such consent. Such an order may be accompanied by conditions on duration and how the order should be carried out. This provision proceeds in type when it provides that an application to vary or revoke its order may be lodged by such person's guardian or, if he or she marries, their spouse.¹⁷ In similar fashion, section 26 of the Mental Health Act provides that the court may make orders for the management of the estate of a person with a mental disorder or for the guardianship of such a person.¹⁸ Under section 5 of the Law of Succession Act (Cap. 180), a person who is not of sound mind has no capacity to dispose of his or her free property by will. A person who alleges that another was not of sound mind when he or she made a will has the burden of proof to confirm the allegation.¹⁹ Under section 8 of the Matrimonial Causes Act (Cap. 152), being of unsound mind is also a ground for a petition for divorce.²⁰

The Civil Procedure Act (Cap. 21) recognises that a guardian or next-of-friend may oust the capacity of a person with disability to litigate a suit (section 93).²¹ The express expectation in such instance is that suits are litigated by non-disabled persons. Order 10 Rule 1 and Order 32 introduce partial guardianship in cases where a person of unsound mind is a litigant. In particular, Rule 15 of Order 32 extends provisions on suits against minors to cover:

“So far as they are applicable (...) persons adjudged to be of unsound mind, and to persons who though not so adjudged are found by the court on inquiry, by reason

of unsoundness of mind or mental infirmity, to be incapable of protecting their interests when suing or being sued.”²²

Section 31 of the Traffic Act (Cap. 403) restricts the legal capacity of persons with disabilities to be licensed to drive: deaf persons in Kenya have in particular found it extremely hard to be granted drivers' licenses. One condition for the grant of a driving license is a declaration by an applicant that he or she is not “[s]uffering from (...) physical disability which would be likely to cause the driving by him of a motor vehicle (...) to be a source of danger to the public.”²³

Even the possibility of a disabled person to purchase ordinary goods is limited. Section 4 (1) of the Sale of Goods Act (Cap. 31) distinguishes general capacity to buy and sell goods from that of persons with intellectual disabilities. It states that:

“Capacity to buy and sell is regulated by the general law concerning capacity to contract, and to transfer and acquire property; provided that where necessaries are sold and delivered to an infant or minor, or to a person who by reason of mental incapacity or drunkenness is incompetent to contract, he must pay a reasonable price therefor.”²⁴

Criminal Justice

The criminal justice system has far too often been a portent of injustice for persons with disabilities. The law has made it exceedingly difficult for persons with disabilities to be active participants in the justice system either as witnesses or as victims when they wish to seek redress. For example, a court may institute a declaration that a person is of unsound mind during criminal proceedings. Sections 162-164 and 280 of the Criminal Procedure

Code (Cap. 75) establish the procedure via which a court may determine that a person is of unsound mind and the arising consequences, including that once so declared a person may be consigned to a mental hospital or, in the phrasing of section 280, a “lunatic asylum” until such time as the medical officer or the court or the Attorney General deem such person to be of sound mind.²⁵ Section 165 of the Criminal Procedure Code provides for the defence of insanity which when reached by a court eventuates in the accused being detained by order of the President in a mental hospital until such time as a determination of soundness of mind is made.

Another illustration is in relation to persons with disabilities who are victims of sexual crimes. The probative value of their evidence has in the past been so discounted as to be worthless, either because it was assumed they did not see or hear their violator or because it was assumed they were so dim-witted as not to be able to recognise their attacker. This has been the case too where such persons have witnessed crime. This approach which negates instead of affirming the capacity of persons with disabilities is reflected by provisions such as section 146 (now repealed) of the Penal Code (Cap. 63) which referred to a person with intellectual disability as an “idiot or imbecile”.²⁶

It is this substituted decision making that the Sexual Offences Act (No. 3) of 2006 rather mitigates by introducing aspects of supported decision-making. Section 31 of that Act²⁷ introduces a raft of support measures and safeguards to ensure that a victim of sexual abuse with disability may as necessary communicate effectively with the court. These measures and safeguards include that:

- A court may declare as a vulnerable witness a witness who has a mental disability.²⁸

- A witness with psychological, intellectual or physical impairment may apply for the court to declare him or her as a vulnerable witness.

- The court may seek advice from an intermediary on the vulnerability of a witness. An intermediary is “a person authorized by a court, on account of his or her expertise or experience, to give evidence on behalf of a vulnerable witness and may include a parent, relative, psychologist, counselor, guardian, children’s officer or social worker.”²⁹

- The court may, having regard to all the circumstances of the case including the witness’s views, direct that a vulnerable witness give evidence via an intermediary; but such direction may be varied or revoked.

- An intermediary may communicate the essence of a question to the vulnerable witness and may also communicate to the court on the well-being of the witness.

One doubtful provision in section 31 of the Sexual Offences Act is subsection (10) which provides that an accused shall not be convicted solely on the uncorroborated evidence of an intermediary. Even more worrying is the fact that section 31 applies to a witness and not an accused person. Section 31 therefore does not rectify the draconian provisions of section 280 of the Criminal Procedure Code which could sorely punish persons with disabilities in the dock as accused or witnesses. That section provides that:

“If an accused person being arraigned upon an information stands mute of malice, or neither will nor by reason of infirmity can, answer directly to the information, the court may order the Registrar or other officer of the court to enter a plea of ‘not guilty’ on behalf of the accused person. A plea so entered shall have the same force and effect as if the accused person had actually pleaded it;

or else the court shall thereupon proceed to try whether the accused person be of sound or unsound mind, and, if he is found of sound mind, shall proceed with the trial, and if he is found of unsound mind, and consequently incapable of making his defence, shall order the trial to be postponed and the accused person to be kept meanwhile in safe custody in such place and manner as the court thinks fit, and shall report the case for the order of the President.”³⁰

This provision fails to cater for situations where the accused may have a disability making it impossible for him to hear or communicate with the court.

Providing for what it refers to as “dumb witnesses”, section 126 (1) of the Evidence Act (Cap, 80) allows a deaf witness to give evidence “in any other manner in which he can make it intelligible”.³¹ This for example may be by writing or signing so long as this is done in open court. Such signing or writing is deemed as oral evidence.³² Section 135 of the Act confers as privileged communications communications between interpreters and their clients.

VII. Conclusion: Towards a Model for Ensuring Legal Capacity for Persons with Disabilities in Kenya

Thus far, society through the instrumentality of law has been fixated with problematising disability. If the logic of this fixation had been allowed to run its course each time, it would have excluded Stephen Hawkins from being a top physicist; and, astounding as it may sound, mental illness would have excluded Winston Churchill from being British Prime Minister (he had what he referred to as “the black dog” – depression) and so too American Civil War President Abraham Lincoln.³³

In Kenya, persons with disabilities rather relish the fact that Mwai Kibaki was sworn to the presidency of Kenya on 30 December 2002 while wheelchair bound.³⁴

The CRPD revolution demands focus on ability, capability and performance. Yet, legislation passed since Kenya promulgated its new Constitution in 2010 has fallen back to type: continuing to pigeon-hole, exclude and patronise people with disabilities. For example, section 21 of the National Land Commission Act (No. 5) of 2012 provides that the Secretary of the National Land Commission may be removed from office, among other things, for: “inability to perform the functions of the office of the secretary arising out of physical or mental incapacity”.³⁵ In this instance, surely, the law’s focus should be on performance: that if the Secretary does not perform she will be removed from office. Provisions with the above effect have also been legislated in among other statutes, e.g. section 11 (1) (c) of Commission for Implementation of the Constitution Act (No. 9) of 2010.³⁶ Section 9 of the Elections Act (No. 24 of 2011) affirms the constitutional provision that persons of unsound mind cannot be registered as voters. But, admittedly, sections 109 (1) (n) and (o) of the Act anticipate regulations to provide for assisted voting for voters with disabilities.³⁷

By dint of Article 2 (6) of the Constitution, the Convention is part of Kenyan law.³⁸ It is incumbent on Kenya, therefore, to take policy, legislative, judicial and administrative measures for enabling Article 12 of the CRPD. Kenya, too, should repeal all policies, laws and administrative procedures which undermine the letter and spirit of Article 12. As a very last resort, Kenya’s judiciary would expectedly provide proper interpretation if a person with disability sought legal remedy against viola-

tion of their legal capacity. But it is far better if the executive and legislature pass legislation to make Article 12 operational.

This leads us to a suggestion on the way forward. Presently, whenever a new law is being drafted, the country is spending far too much misdirected energy working out how to respond to arising legal capacity questions. The variety and large number of statutes discussed in the preceding section show how law-making is obsessed with reacting to the assumed legal incompetence of persons with disabilities. The logic of reacting singly to each legal capacity circumstance as it arises is not smart in view of the probability that different legislators will respond differently to similar issues. Kenya requires deploying a model whose overall aim would be to ensure that future laws would legislate legal capacity not to target persons on account of their disability but rather as laws of general application to all individuals. This would also eschew the need for drafting legal capacity provisions statute by statute.

Under the model, Kenya would pass a legal capacity statute. That law would declare that all adult individuals including those with disabilities have legal capacity in all aspects of life. The statute would then identify and detail the contexts and circumstances under which supported decision-making measures would be available to persons with disabilities. The law would also establish safeguards for ensuring that such support measures are not abused.

The project of preparing a single legal capacity law is weighed down by the obvious

danger that Article 12 remains an extremely mysterious norm which does not lend itself easily to practical nuts and bolts interpretation. Perhaps the most certain issue in all this discussion is that everything remains extremely fluid and challenging. Multiple questions remain unanswered and ideas for making Article 12 remain untested so much that any legislation will bear the tag of pioneering trail blazer with the consequence that trail-blazing carries: the baggage of error and missed steps. The Committee on the Rights of Persons with Disabilities is just now cutting its teeth by beginning to prepare a general comment or recommendation on Article 12. In the meantime, on 23 May 2012, Kenya's national human rights institution, the Kenya National Commission on Human Rights, convened a meeting of state and non-state actors at which initial discussions were had on how to make Article 12 operational. Multiple institutions at the global and national levels will continue to work on this for a fair while.

In conclusion, then, we have shown that legal incapacity in Kenya is legislated over far too many statutes. Repealing or amending all those laws will not be an easy task. Even more difficult are the realities of bias and stereotype imprinted in key national institutions such as the bench and the bar and the practice of medicine. For many years it will remain difficult for Kenya's professional classes to accept that they should treat persons with disabilities and particularly those with psychosocial disabilities equally and without patronising them. Yet, the dignity and personhood of each disabled person is guaranteed and it must be ensured.

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key roles in negotiating the Convention on the Rights of Persons with Disabilities and seeking its domestication in Kenya. Mute is a member of the Working Group on the Rights of Older Persons and Persons with Disabilities established by the African Commission on Human and Peoples' Rights to prepare protocols on the rights of older persons and persons with disabilities.

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- 10 Constitution of Kenya 2010.
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- 13 Lewis, O., "How Can Strategic Litigation Play a Role in Nudging States towards Legal Capacity Utopia?", preliminary ideas paper for discussion on 13 November 2009 at the seminar on disability litigation in Washington DC, organised by Mental Disability Rights International, Open Society Institute and the American University.
- 14 Mute, L., "Shattering the Glass Ceiling: Ensuring the Right to Vote for Persons with Intellectual Disabilities in Kenya", *Thought and Practice: a Journal of the Philosophical Association of Kenya*, Vol. 2, No. 2, December 2010.
- 15 Mental Health Act (Cap. 248).
- 16 Ibid.
- 17 Children Act (No. 8 of 2001).
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- 19 The Law of Succession Act (Cap. 180).
- 20 The Matrimonial Causes Act (Cap. 152).
- 21 Civil Procedure Act (Cap. 21).
- 22 Civil Procedure Rules 2010.
- 23 The Traffic Act (Cap. 403).
- 24 Sale of Goods Act (Cap. 31).
- 25 Criminal Procedure Code (Cap. 75).
- 26 The Penal Code (Cap. 63).
- 27 Sexual Offenses Act (No. 3 of 2006).
- 28 Section 2 of the Sexual Offenses Act (ibid.) defines "person with mental disability" as: "a person affected by any mental disability irrespective of its cause, whether temporary or permanent, and for purposes of this Act includes a person affected by such mental disability to the extent that he or she, at the time of the alleged commission of the offence in question, was – (a) unable to appreciate the nature and reasonably foreseeable consequences of any act described under this Act; (b) able to appreciate the nature and reasonably foreseeable consequences of such an act but unable to act in accordance with that appreciation; (c) unable to resist the commission of any such

act; or (d) unable to communicate his or her unwillingness to participate in any such act.”

29 See above, note 27.

30 See above, note 25.

31 Evidence Act (Cap, 80).

32 *Ibid.*, section 126 (2).

33 See “The Black Dog”, *CBS/AP*, available at: http://www.cbsnews.com/2100-500164_162-239704.html.

34 See “Kenya’s New President Kibaki Sworn In”, *CTV News*, available at: http://www.ctv.ca/CTVNews/CanadaAM/20021230/kenya_new_president_021230/.

35 National Land Commission Act (No. 5 of 2012).

36 Commission for Implementation of the Constitution Act (No. 9 of 2010).

37 Elections Act (No. 24 of 2011).

38 Article 2 (6) of the Constitution provides that international treaties to which Kenya is a party form part of Kenyan laws. See above, note 10.

Limiting Autonomy? Mental Capacity to Refuse Treatment in the UK

Case Note: *Re E (Medical treatment: Anorexia)* (Rev 1) [2012] EWHC 1639 (COP)

Joanna Whiteman¹

On 15 June 2012, the full judgment of the Court of Protection of England and Wales in the case of *Re E (Medical Treatment: Anorexia)*² was published. The case was the result of an urgent application made by a local authority requesting guidance as to whether it should take steps to force-feed, against her wishes, a 32-year-old woman, E, who was suffering from extremely severe anorexia nervosa and was on the verge of death. The Court granted an order permitting the force-feeding, finding that E did not have capacity to make a decision about life-sustaining treatment and that feeding E against her will was in her best interests.

The case highlights the challenges faced when an attempt to respect the freedom and autonomy of an individual (howsoever disabled or otherwise) to make their own choices appears to come into conflict with the perceived need to preserve the life of a vulnerable person, in their “best interests”. It appears to indicate that, when faced with this dilemma, the court is inclined to come down on the side of preserving life. This note summarises the case, focusing in particular on its discussion of E’s capacity, before considering the right to equal enjoyment of legal capacity of persons with disabilities, as prescribed by the UN Convention on the Rights of Persons with Disabilities 2006 (CRPD).³

Background to the Case

E’s eating disorder began in her early teens following years of serious sexual abuse. Over the years prior to the case she had, at various times, been institutionalised for treatment. In addition to her severe anorexia nervosa (acknowledged to be a pervasive psychiatric illness), E had been diagnosed with alcoholism and an unstable personality disorder. At the time of the hearing, E had not taken solid food for a year, was refusing to eat and was only taking a small amount of water.

E had, for a number of years, consistently expressed the wish that she not be given life-sustaining treatment. She was described as “intelligent and articulate” and “fully aware of her situation”⁴ and simply desirous of being “allowed to act as she wants”.⁵ In July 2011, E signed an “advance decision” in which she stated that she did not want to be resuscitated or given any medical intervention to prolong her life. In October 2011, she signed another such decision having gone so far as to willingly raise her body weight in order to seek to ensure that she be deemed to have the capacity to make the decision valid. No formal assessment of her capacity to make either decision was carried out contemporaneously.

By April 2012, after 18 years of unsuccessful treatments, E had been placed on a palliative care regime whose purpose was to allow her to die in comfort. It was only after five weeks of such care that the local authority decided to seek the Court's view on whether it should go against her wishes and force-feed her. The proposed treatment – which included admitting E into intensive care and force-feeding for a year or more (until her weight stabilised) before offering her therapies for her eating disorder and other problems – was acknowledged by the Court to amount to “a wholesale overwhelming of [E's] autonomy for a long period whose exact period could only be measured in hindsight once it was known whether the treatment had succeeded or failed”.⁶ Expert medical opinion before the Court as to the treatment's prospects for success varied but overall, the view at the hearing was that E's prognosis for recovery if the course of treatment was carried out was poor.⁷

Law Applied by the Court

Under the Mental Capacity Act 2005 (MCA) a person is presumed to have the capacity to make a decision in relation to their treatment unless it is established otherwise.⁸ A person lacks such capacity if “at the material time he is unable to make a decision for himself because of an impairment of, or disturbance in the functioning of, the mind or brain”.⁹ Making a decision requires a person, amongst other things, to understand the relevant information and weigh that information when making the decision.¹⁰

The MCA also enables a person, in anticipation of any future incapacitation, to make an “advance decision” to refuse treatment if they have capacity to do so at the time of making the decision.¹¹ However, in the ab-

sence of a valid “advance decision,” if a person lacks capacity a court may authorise action to be taken for them if that action is in their best interests.¹²

Under the Human Rights Act 1998 (HRA), in giving effect to the MCA, the court must, where possible, do so in a way which is compatible with the European Convention on the Protection of Human Rights and Fundamental Freedoms 1950 (ECHR). This includes respecting E's right to life (Article 2), not torturing E or subjecting her to inhuman or degrading treatment (Article 3) and respecting her private life (Article 8).

Issues

On the basis of its above legal analysis, the Court sought to establish:

- (a) Whether E had, at the moment of the hearing, the mental capacity to make decisions about her treatment;
- (b) If not, whether she had mental capacity when she had made either of her advance decisions, and whether either decision was valid and applicable; and
- (c) If she lacked capacity and her advance decisions were not valid, whether it was in her best interests to receive life-sustaining treatment in the form of force-feeding.

In making its decision the Court relied on the opinions of a number of medical experts, including some who had worked with and treated E over the years as well as a court appointed expert who had not. The Court also listened to the views of E's parents. All parties involved acknowledged that it was a difficult case and stated that they would support the implementation of the decision of the Court either way. On the question of legal capacity, the views of the medical experts were mixed, with some (notably those who had worked

with and treated E previously) considering that she had at least had capacity when she made her advance decision and others disagreeing. On the question of E's best interests, E's parents had serious misgivings about the potential outcome of further treatment and, on balance, were of the view that it was in their daughter's interests for her wish not to be treated to be respected.

Decision

Before ruling on the issues, the Court stated that the case should have been brought before it much earlier and noted that those involved were aware of the ethical concerns raised by the case as early as 2009. However, the Court did not discuss and it does not appear that the issue was raised as to whether this delay had constituted a violation of E's rights under Articles 3 and/or 8 of the ECHR.

On the matter of E's mental capacity at the time of the hearing, the Court noted her condition as anorexic and held that her obsessive fear of weight gain meant she was unable to weigh the advantages and disadvantages of eating in any meaningful way. Secondly it held that she was also currently sedated. For these reasons, the Court held that she did not have capacity to make a decision to refuse treatment which involved being fed. The Court acknowledged E's parents' comment that:

"It seems strange to us that the only people who don't seem to have the right to die when there is no further appropriate treatment available are those with an eating disorder. This is based on the assumption that they can never have capacity around any issues connected to food. There is a logic in this but not from the perspective of the sufferer who is not extended the same rights as any other person."¹³

The Court admitted that a person with severe anorexia was in a "Catch 22" situation "namely, that by deciding not to eat, she proves that she lacks capacity to decide at all".¹⁴ However, it did not consider, nor was it apparently asked to consider, whether this raised any concerns as to discrimination against people with anorexia in relation to their right to respect for private life.

In relation to E's mental capacity at the time of her "advance decisions," rather than applying a presumption in favour of capacity, the Court held that the decision would only be valid and applicable if there was "clear evidence establishing on the balance of probability that the maker had capacity at the relevant time".¹⁵ It held that this threshold was not met in the case and stated that in case such as E's, it would want to see a "full, reasoned and contemporaneous assessment evidencing mental capacity".¹⁶ Although not expressly acknowledged by the Court, the effect of this decision is that a person who makes an "advance decision" when they in fact have capacity, may well have their wishes overruled by a court at a later date if, through no fault of that person's own, the state negates to carry out a full, contemporaneous assessment of their capacity at the time so their capacity may be proved in the future. Furthermore, the Court did not expressly consider the impact of section 1(3) of the MCA, which states that: "a person is not to be treated as unable to make a decision unless all practicable steps to help him to do so have been taken without success".

On the question of what was in E's best interests, the Court held that "at its simplest, the balance to be struck places the value of E's life in one scale and the value of her personal independence in the other, with these transcendent factors being weighed in the light of the reality of her actual situation".¹⁷ In

weighing this balance, the Court stated that “all human life is of value”¹⁸ and that there is a “presumption in favour of the preservation of life”.¹⁹ Despite the court’s recognition that “intelligent and articulate” E’s “views are entitled to respect” and its acknowledgment that arguments in favour of trying all new treatment options, if taken too far, run the risk of discriminating against the incapacitated,²⁰ the Court held that “the balance tips slowly but unmistakably in the direction of life-preserving treatment”.²¹

CRPD: Legal Capacity of Persons with Disabilities

As Mute explains, “legal capacity is fundamental to human ‘personhood’ and freedom”.²² Accordingly, it is particularly imperative that legal capacity is assured without discrimination on any grounds, including disability. The matter of legal capacity is not dealt with expressly in the human rights convention referred to by the court, the ECHR. However, Article 12 of the CRPD clearly emphasises the primacy of the need to respect the legal capacity of disabled persons. In reaffirming the right of disabled persons to equal recognition as persons before the law, Article 12 provides that:

“States Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life...[and]...States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.”²³

It goes on to require that safeguards are in place to ensure that any measures relating to the exercise of legal capacity “respect the rights, will and preferences of the person” and are “proportional to the degree

to which such measures affect the person’s rights and interests”.²⁴

These elements of Article 12 of the CRPD give reason to think again about a number of aspects of the *Re E* judgment. Firstly, can it be anything other than a breach of a person’s right to legal capacity on an equal basis for her to be incapable of making a “capacitous” decision as to the prolonging of her life, regardless of how articulate and considered she has been, on the basis that she has a disability? Perhaps the Court’s acknowledgement of E’s parents’ point that only a person with severe anorexia is always deprived of legal capacity in relation to an “advance decision” of this kind is a sign that the current system falls short of Article 12(2) CRPD. Secondly, does the current system provide adequate support to such a person to help enable her to make a “capacitous” decision as required by Article 12(3) CRPD? There appears to have been a distinct lack of involvement by the local authority at the times when E sought to make her “advance decisions”. Finally, although the Court did not agree, there are certainly strong arguments to be made that the prolonged force-feeding of an intelligent woman against her will amounts to a violation of her dignity and constitutes inhuman and degrading treatment. With such a serious violation of a person’s rights at the very least a real risk, the need for strong safeguards is clear. Perhaps the case indicates the need for the UK to take a considered view of the current process for making determinations as to capacity to refuse treatment, in light of Article 12(4) CRPD.

In summary, whilst cases such as that of E are inherently extremely difficult for any court to decide, and whilst the ECHR does not deal with the issue of capacity rights expressly,

Article 12 of the CRPD provides useful guidance as to the approach to be taken. Courts should use this guidance in future, when dealing with such challenging cases.

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- 1 Joanna Whiteman is Legal Officer at the Equal Rights Trust.
 - 2 [2012] EWHC 1639(COP).
 - 3 Despite its ratification by the UK in 2009, the CRPD was not discussed in *Re E (Medical Treatment: Anorexia)*. E's severe anorexia nervosa alone makes her a person with a disability under Article 1 CRPD.
 - 4 See above, note 2, Paras 5 and 132.
 - 5 *Ibid.*, Para 76.
 - 6 *Ibid.*, Para 117.
 - 7 The estimated prospects of success were placed between 10% and 30%.
 - 8 S1(2) MCA.
 - 9 S2(1) MCA.
 - 10 S3(1) MCA.
 - 11 S24 MCA.
 - 12 S1(5) MCA.
 - 13 See above, note 2, Para 52.
 - 14 *Ibid.*, Para 53.
 - 15 *Ibid.*, Para 55.
 - 16 *Ibid.*, Para 65.
 - 17 *Ibid.*, Para 118.
 - 18 *Ibid.*, Para 119.
 - 19 *Ibid.*, Para 140.
 - 20 *Ibid.*, Para 132 and 134.
 - 21 *Ibid.*, Para 140.
 - 22 Mute, L.M., "Moving from the Norm to Practice: Towards Ensuring Legal Capacity for Persons with Disabilities in Kenya", *The Equal Rights Review*, Vol. 9, 2012.
 - 23 Convention on the Rights of Persons with Disabilities, G.A. Res. A/RES/61/106, (2006), Article 12(2) and (3).
 - 24 *Ibid.*, Article 12(5).

TESTIMONY

"My teachers did very little to help and would quite often encourage the stigmatisation.

On one occasion, a teacher told another pupil: "If you don't stop talking, I'll make you sit next to Josh." The girl almost started crying and said, "I would rather stand outside." That will be ingrained in my memory for the rest of my life."

Joshua Hepple

Just Like One of the Others:

Testimony of a British Student Living with Cerebral Palsy

In the United Kingdom, disabled people are disproportionately affected by the reform of the NHS and the massive cuts in public spending undertaken by the Coalition government after it came to power in May 2010. Joshua Hepple, 21, is a young man with a physical disability who is one of the hundreds of thousands people with disabilities in the UK who are on the receiving end of the cuts. In February 2011 he wrote to David Cameron, the UK Prime Minister, but received no reply. ERT spoke with him about publicising his concerns and asked him to provide further information about the position of people whose circumstances are similar to his own. He provided the following testimony, part of which is based on a letter he published in the Times, in October 2011.

I am Joshua, a 21 year old currently studying law at Stirling University in Scotland. I have cerebral palsy and am a keen disabled rights activist. In the past I have been heavily involved in the National Union of Students as well as other organisations, but now I concentrate on human rights campaigning with my student Amnesty International group.

However, I speak now purely from my own experience and not as affiliated with any organisation. I hope I echo the voices of the many disabled students that I have represented, but I want you to know how much social work funds mean to me: a very intellectually capable, but severely physically impaired young man. I wrote to David Cameron in February 2011. I imagined that as his son had cerebral palsy and died at the age of

six, David Cameron saw the role social work played for people with learning disabilities too. It is difficult for me to speak on their behalf, but I hoped he would understand my experience and see how critical social work funds are to disabled individuals. I received no reply.

One of my worst experiences that related to my disability was in high school.

Throughout my five years at school, I was not bullied. I was ignored by everyone, which I think is worse – at least when you are bullied, you get some kind of attention, which I craved. I used to go weeks at a time with no one even making eye contact with me, let alone having a conversation. I am aware that young teenagers are very image-conscious and anxious about being able to fit in – and



Photo credit: J. Hepple

Joshua Hepple

because I was different, my fellow students wanted nothing to do with me.

As if it wasn't hard enough to be disabled at school, I also found I was questioning my sexuality and was appalled by the lack of support my school gave me. I remember telling my guidance teacher that I thought about being gay: her response was "Oh dear", and she then walked out of the room. Two days later, she had a flyer for LGBT Youth Scotland, a fantastic organisation which I cannot applaud enough and have been in contact ever since. The flyer had a "post-it" note with my name on it, so during her drop-in session every person who came in saw this on her desk, which automatically outed and stigmatised me even more.

During the summer, when I returned home from university, my younger sister brought some of her friends over and they looked at me as if I was some kind of alien. This brought back so many memories from school and it really saddens me that these people are almost being taught to hate disabled people. I don't know why this is. My school was

known as a pond socially, which means you were either in the gang or not. If you weren't, you had no friends.

My teachers did very little to help and would quite often encourage the stigmatisation. On one occasion, a teacher told another pupil: "If you don't stop talking, I'll make you sit next to Josh." The girl almost started crying and said, "I would rather stand outside." That will be ingrained in my memory for the rest of my life.

There was not one day of school that I looked forward to, and I don't think there was ever a day in the five years I was there that a teacher ever told me to stop talking. It wasn't that teachers were frightened to discipline a disabled student, but rather that I never spoke in class.

I endured five years in my high school in Edinburgh before things eventually became too much for me and I left to join a local further education college. Thankfully, I found attitudes were very different there. At college, the tutors included me in classes, I made so many friends and no one seemed to care about my disability. I think I made more friends in my first week there than I ever did at school. After the isolation of school days, a move into further education helped me to leave a world of prejudice far behind.¹

I have kept in contact with around five people from college, but not one from school. My grades were so much better at college, even though I was doing more Highers, because I was having a great time.

I am now studying law at Stirling University and have lots of friends. I do not feel that my disability is having a huge impact on my life. At university, academia is only a small part of

the whole package; university is more about finding out who you are as a person as well as making great friends and learning skills for life. This is also what secondary school should be about.

If you are a teacher and have disabled pupils in your class, I would really like you to think about whether they are included. And there isn't just one way to include disabled people in a classroom. What really helped me was being treated just like one of the others; being shown a positive attitude; and being kept an eye on to see whether I was being ignored in activities involving group work. Being asked questions in class is an excellent way of being included and stretched intellectually.

I have been so frustrated with people's perceptions of

disability that I am now working with the Edinburgh Festival Fringe and training all front-of-house staff on how to interact with disabled customers. I was also the disabled students' officer at Stirling University, which involved helping students with individual problems, as well as working with presidents of clubs and societies and training them to make the effort to involve disabled students in their clubs. I have also been the LGBT officer at Stirling and loved to challenge perceptions of sexuality



Photo credit: J. Hepple

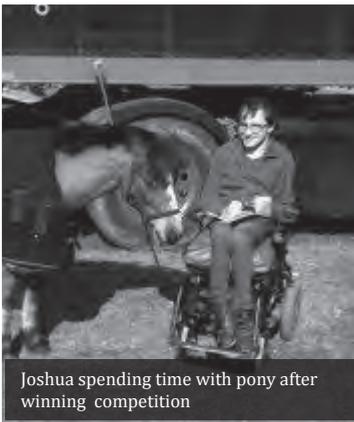


Photo credit: J. Hepple

Joshua spending time with pony after winning competition

Joshua winning a carriage driving competition

and gender. I faced the exact same problems through having a different sexuality, as being disabled, with my classmates.

I wish there was a way of teaching young people not to be afraid to talk to people who are different. I would love to see a new breed of people leaving school who are open-minded, able to talk to new people and not care about differences.



Photo credit: J. Hepple

Joshua with a dog at the stables

Teachers of any subject need to think about how to welcome diversity in their classroom, whether it's disability, sexuality, gender or race. We are all people and no one should be treated less favourably than anyone else in any situation, especially not in school.

Up until three years ago, I did not have any interaction with social work, as my parents provided me with all the care that I needed. A friend told me about his personal assistants

that supported him and asked me why I did not have any myself. To begin with, I was very reluctant to have to pay people to support me with personal care, etc.

The money that I now receive from social work has had an extremely positive impact on my life. I don't know what the system is exactly in England, and around the world, but in Scotland I receive "Direct Payments", which are given to me by the government. This is a set amount of money every month with which I can pay for my own support in the way I choose to. At the moment I have around ten fellow students who support me, many of whom are in my university's hockey or rugby teams. These assistants allow me to do what I want and let me live a life which I do not feel is inferior to that of a non-disabled person. I am able to do anything that I wish when I am with them, be it horse riding, typing emails, or going to conferences in London. I am very lucky and grateful that I have assistants, but I do not feel that I should have any guilt for requiring them as they do not make my life any more superior to that of a non-disabled person.

If I didn't have these funds there would be no way that I could be at university or have any sort of life which did not heavily rely on my parents. Similarly, it has only been recently that my mother has been able to go back into work. It is not fair that she has had to wait so long. I am her son and I would like to hope that a parent should not have to make drastic changes to their life if they have a disabled child compared to a non-disabled child.

You may be aware that the Independent Living Fund is slowly being reduced and in a few years it will cease to exist and has closed already to new applicants. This fund provides me with half of my income for my personal assistants. I do not even want to think about

what will happen when this money is withdrawn. It is no one's fault that I have to pay for support and I really do not feel this should be something that I have to be concerned about. For instance, my parents live in Edinburgh and I am at university in Stirling. Quite often there will be a big event at the weekend in Stirling which I want to attend, but to save money I go home and rely on free support from my parents. This may seem trivial to you; however, no other students who aren't disabled would have to make a decision like this which automatically segregates me from the rest of my peers because of my disability. It also puts quite a lot of pressure on my parents to be there for me. If anything happened

to them and they were unable to support me, I would hate to think of the consequences.

If the proposal of a residential home ever came up, this would make me absolutely disgusted as I could not lead the independent life I am entitled to have and I would see this as a breach of my human rights. I am aware that the state has limited funds for social services; however, I feel they are the most important funds in the UK today. Without them, I could not have access to personal care such as eating or washing and could not live my life to the potential that I am able to do. I feel that without this money it would be degrading and easily count as a violation of the prohibition



Joshua on the top of The Empire State Building June 2012

Photo credit: J. Hepple

of degrading treatment under Article 3 of the European Convention on Human Rights.

Independent living is something that I feel extremely strongly about. I have many issues and concerns with the whole social work setup, from the way individuals are assessed to the way social workers treat their clients.

Regarding assessment, the process to receive direct payments is problematic. A request is made to social work for an assessment. This assessment is then made after around two months with a dedicated social worker and someone from the funding team. The assessment is dreadful. The individual is required to reel off everything they cannot do for an hour or two. Basically, the more the individual cannot do, the more money he or she will receive. This assessment is checked over by different people and goes to a board and then after a couple of months wait the money starts to go in to the individual's bank account. Some people decide to pay an agency that demands slightly more an hour to sort out their needs and gives them the support which they have been assessed for. The individual has very little say in who comes to help. I could never do this. I feel it is absolutely essential to get on with the person who is supporting me. In fact, 90% of the people I interview do not make it and when they do many of them do not make it past a month.

Regardless of the process for receiving direct payments and my criticisms above, I do want to reiterate how positive they are, I don't know where I'd be without them.

I feel that social workers treat their clients very much as numbers and make no effort to under-

stand their clients' needs or spend time getting to know them. The whole concept of reasonable adjustments is ironically non-existent within social care. For example, I cannot use a telephone due to my speech impairment but have no problem on e-mail. Not only do social workers phone up periodically to discuss my case, they also proceed to discuss extremely confidential matters with whoever answers the phone, normally my mum. At meetings, when social workers cannot understand me, they will automatically look at my PA (or "carer", as they insist on calling them even though I have explained my numerous problems with the term on many occasions) to translate instead of asking me to repeat myself which is much more empowering. If I could give disability equality training to one group of people it would be social workers, though they would never accept they needed it.

As you will know, I receive 12 hours a day support and unlike most disabled people, I employ my own staff instead of hiring an agency to provide me with people I don't know to help me with very personal care, which I think is very un-dignifying and very costly.

I don't think it's fair to limit the amount of funds any disabled person requires at all, as I feel it would be an Article 3 (with 14) breach of the ECHR. I need my staff for anything from helping with the toilet to giving me food. I don't think it would be difficult to argue that lack of food and personal care would amount to degrading treatment. I know it would not be as easy as this, as social work have very tight budgets which they keep unnecessarily reminding me about. I think this is an area which needs a lot of work done to it.

¹ A version of the above paragraphs was published in: Hepple, J., "From school to college was a journey out of exclusion", TESS, 21 October 2011.

INTERVIEW



"Should all institutions be abolished? Yes, all institutions - certainly those funded by governments - should be abolished and care should be replaced with individual support. We can't stop private entities from setting up institutions and having their residents cover the costs, but if people have resources on an individual basis, they would be able to choose whether to pay for institutional care or go for community living with personal assistance."

Kapka Danayotova

Breaking down the Barriers: Current Challenges to Disability Equality

Propelled by the adoption of the UN Convention on the Rights of Persons with Disabilities (CPRD) in 2006, the movement for equal rights irrespective of disability has made remarkable progress in many parts of the world. At minimum, there is more visibility. There is more awareness of the human rights of persons with disabilities, including their rights to equality and non-discrimination. At the level of legislative and policy frameworks, the disability equality movement is grappling with a number of challenges in translating the principles of the CRPD into practice. Among the most serious of those are issues around legal capacity, independent living, and access to information and communications technologies (ICT) on an equal basis.

ERT spoke with Mr Hiroshi Kawamura, Founder and President of the DAISY Consortium, Japan, which is a leading assistive technologies developer, and Ms Kapka Panayotova, Director of the Centre for Independent Living based in Sofia, Bulgaria.

ERT: You are widely recognised as a leading expert on the rights of persons with disabilities. Can you begin by telling us how you developed into one of the most prominent authorities in this area? What life experiences and major influences played a role on the way to your present position?

Hiroshi Kawamura: When I was working at the largest library system in Japan – the University of Tokyo Library – as a professional librarian in late 1970s, I had three incidents that opened my eyes on issues of persons with disabilities, and that they could be encouraged to focus on what they have rather than what they lost. Firstly I lost my mother in law who lived with my family, who suc-

cumbed to cancer after three years of terminal care at home. My wife and I did our best to enrich her life. Not long after the funeral of my mother in law, one of my colleague librarians who won the table tennis championship of the University of Tokyo lost one of his legs due to sarcoma. I thought about him and proposed to make the library accessible for wheelchair users as soon as possible. The University Union, the library chapter in particular, immediately picked up my proposal and agreed to establish a library committee on accessibility to work on the physical accessibility of the library building. While, as a committee member, I was planning to make our library accessible for wheelchair users, we were informed that the first blind candidate had successfully passed the examina-



tions in Braille. It was surprising that I could not find any accessible titles, in Braille or in audio tape, among six million titles of the library holdings. So, a 19 year old blind student opened my eyes on the issues faced by people with disabilities. Since then, I have been collaborating with this man, to change the library, the publishing industry and the society in order to guarantee access to human knowledge for everybody.

Kapka Panayotova: I guess I should start with my parents – they made me the way I am: strong, stubborn, curious about things around me and eager to be free. When I was seven months old – it was in 1957 – I got polio. I was one of the last victims of this nasty virus; it was a short while later that the Communist Government of Bulgaria got the vaccine and started its application on children. My situation was really bad at the beginning. Lots of surgeries, rehab, and doctors and nurses around in my childhood made me hate hospitals and medical centres but also helped to recover my body as much as it was possible. I walk with crutches now and as I get older things deteriorate – the Post-Polio Syndrome is after me. But I’m not complaining about that – other things drive me mad.

I was raised as a normal child, and a regular family member – with a lot of love and support but also with all the duties and obligations to the family as everybody else. I had to clean my room, go shopping, and throw out the rubbish. Neighbours were often appalled – “what kind of parents can make the poor kid do these things?” I started reading and writing at the age of four and my mother – she was a teacher – tried to get me to school earlier. The school entry age at that time in Bulgaria was seven. Due to my disability I was referred to a special school, which was nothing like the special schools in Britain or Germany, it was, and still is, a sort of warehouse where kids learn nothing but parents are told that both teaching and rehab are provided. I was taken to Momin Prohod – a place 100 km away from Sofia – and left there. Apparently, as we left the house I started crying and didn’t stop for days, declined food and didn’t sleep. The staff at the rehab centre couldn’t cope and called my parents to come and take me home. That was the end of institutional care for me. My mum arranged to get me enrolled in the school she was teaching at and thus – being educated with my non-disabled peers in a mainstream school – I managed to graduate from an English Language School in Sofia and Warsaw University later on. My



parents always encouraged me to stand firm for what I believe in, to speak for myself and to be as independent as possible.

In 1993 I got a chance to study at the Johns Hopkins University in Baltimore, Maryland. There I met many disability leaders running independent living operations. And I realised that this was what I wanted to do myself. When I got back home in Sofia, I set up a Centre for Independent Living (CIL). We were registered in 1995 and here we are still, a trouble maker for governments when they do not do the right thing. We advocate for disability rights and provide support for those disabled people who want to be independent and manage their own lives.

ERT: The UN Convention on the Rights of Persons with Disabilities which was adopted in 2006 has been celebrated as a powerful instrument that has shifted the paradigm of thinking about disability at the international level. Has this Convention contributed to shifting the paradigm on disability at the national and local levels in your countries, Japan and Bulgaria (even though Japan has signed but not yet ratified it)? If yes, in what way? If not, why not?

Hiroshi Kawamura: Yes, the CRPD has triggered a discussion to change the paradigm. I expect a revision of the Basic Law for Persons with Disabilities by the end of this year. This will allow the National Diet to ratify the Convention.

The Japanese disability community contributed a lot to CRPD, in particular ICT accessibility in which I was involved. Our journey to CRPD in Japan started with the UN ESCAP¹ Decade of Persons with Disabilities in Asia and the Pacific, 1993-2002. I established and

took the chair of the ICT Working Group of the First Decade which contributed to the ICT accessibility part of the Biwako Millennium Framework of the Second Decade of Disabled Persons of ESCAP, 2003-2012. Since 2002, I participated in the WSIS² process representing the DAISY Consortium and the ICT accessibility initiatives in Asia and the Pacific. I took the responsibility of the Disability Focal Point of the WSIS Civil Society on behalf of the DAISY Consortium which is legally established in Switzerland, although actually I have been based in Japan. Our major contribution to the CRPD is the inclusion of language on “universal design” in the disability context,³ to reflect the united one voice of persons with disabilities formulated by the Global Forum on Disability in the Information Society in 2003 and in 2005. If you closely trace the WSIS 2003 preparatory process, until the last prep-com, you will see that needs and demands of persons with disabilities were not reflected in the strategic documents in an appropriate language because of the absence of disability in the Millennium Development Goals. Our struggle was around putting proper language on ICT accessibility issues and solutions in place in the context of WSIS strategic documents to solve the Digital Divide. Speaking of my own role, my contribution to CRPD is seamlessly connected to WSIS. Likewise, it is very common for Japanese active contributors to contribute a lot to CRPD through international channel, but we have done less through national channels.

Although Japan has not yet ratified CRPD, we have achieved a major revision of the Copyright Law in 2008 reflecting the new paradigm set out by the CRPD. So far, more than one hundred laws have been revised to meet the requirements of CRPD.

Last month, the Prime Minister appointed the Disability Policy Committee which is chaired

by a blind professor – the same man who opened my eyes on disability 35 years ago.

Kapka Panayotova: As far as Bulgaria is concerned, the Convention is just a token thing, even though Bulgaria has ratified it earlier this year. No change whatsoever. Frankly, I personally expected to see more human rights related changes in the process of EU accession. Politicians highjacked the language of the social model of disability and maintained the same old practices of parallel public systems for disabled people: institutions, special schools, etc. Even physical accessibility is not provided for – sidewalks, buildings, buses, everything is inaccessible for disabled people, not to mention services like education, or employment. Physical accessibility is easy – you build stairs and a ramp next to them: as simple as that! It serves the elderly, baby pushchairs, everybody. I still keep asking why it doesn't happen. And my answer is it has to do with POWER: no one wants to give up power and control over disabled people's lives. Accessibility would be the first step to independence; people will go out and see the world, the opportunities, a different future for themselves, and will start demanding. I've seen it happening with the guys who started coming to CIL, sharing our vision for independent living. Once you take them out of their houses, parents, therapists, you can't stop the process. However, everybody is scared: parents are worried about their "sick" children; service-providers think of their business; policy makers worry about the political routine; administrations don't know how to do things differently... And here we are: saying the right things while doing what we are used to.

But to have the UN Convention is a brilliant thing: it is the main tool in the hands of active disabled people who want change and do not agree with the traditional percep-

tions of being "sick", "vulnerable", or "objects of care". Bulgaria has not ratified the Optional Protocol, so we can't file a case with the Committee, but we can sue the government or any entity for discrimination on the ground of disability using the Convention in the Bulgarian courts of law, no matter how unreliable they are.

CIL is very active in promoting the Convention, addressing both disabled people and the public at large. Politicians and public servants will be forced to learn about it from the pressure we put on them. I guess this is how democracy works – and I believe nothing better has been invented so far.

ERT: From the point of view of non-discrimination and equality, what most important norms have been incorporated in the national laws of your country to ensure equal participation of persons with disabilities in all areas of life? Where are the most important challenges that remain to be addressed?

Hiroshi Kawamura: "Equal access" and "reasonable accommodation" are key norms incorporated in Japan's national laws to ensure equal participation. The challenges are dissemination of the concept of equal rights among both the general public and persons with disabilities, in particular those with intellectual disabilities, psycho-social disabilities, learning disabilities and older persons with disabilities. In addition, budget is another most critical challenge.

Kapka Panayotova: Regretfully, the Bulgarian legislation does not even promote equal participation of disabled people. The definition of disability still refers to diagnosis and health condition, and there is no mention of barriers. Special facilities for disabled people enjoy good funding and charity contri-

butions all the time. Assistance allowance is worth €25 a month – worth not much more than to buy bread for the family. Family members were made personal assistants for a minimum monthly salary; social assistance is available as an annual service offered on a project basis by service providers. Wheelchair users ride their “vehicle” for ten years before they are entitled to a new one, while accessibility adjustments of the living space are supported with up to €300 paid by the government – anything above that must be covered by the person concerned. Poverty among disabled people is huge. Briefly, the whole approach to disability policies should be changed in Bulgaria, but there are not many drivers of change. Therefore, the process is slow.

ERT: Can you explain, for an audience of non-experts on disability, what is Augmentative and Alternative Modes of Communications (AAC) and are there minimum standards of access to AAC for persons with different types of disabilities?

Hiroshi Kawamura: Everybody has different abilities. The communication methods a person may use are determined by persons in the community. In most cases, speech and writing are dominant methods of communication. Stored information for knowledge is the basic asset of our civilization which has been transferred to contemporary communities.

AAC is a concept to bridge the mismatch between the communication abilities a person with disabilities has and the dominant communication methods in the community. One most popular AAC example must be Dr Stephen Hawking’s communication device. Dr Hawking manipulates a word processor with an adapted keyboard attached to his electric wheelchair to write

his speech and generate a synthetic voice to present his speech. Another example of AAC is a set of symbols for communication in place of speech or written language and this can be used by persons with intellectual disabilities. A sign or a body language is often used among people with different languages. Current ICT development opens up opportunities to bridge the gap above mentioned. To make the most of the potential of ICT development in the AAC arena, it is crucial to develop international standards and guidelines to avoid fragmentation of AAC.

Kapka Panayotova: I wouldn’t dare – being paired up with Hiroshi – to elaborate on that. But I know that AAC is today’s tool to overcome barriers in communication between people, to compensate the deficit of the body caused by the impairment. This is what Bulgarian disabled people are deprived of. Let me give you an example. A young fellow with cerebral palsy and speech problems has been diagnosed with mental disability at the age of five because “he can’t speak, and is incommunicable”, according to his disability document. This “diagnosis” took him to a special school where no one even tried to communicate with him. Now he is 22 years old and really incommunicable, with a severe social disability. This is what AAC could have prevented.

ERT: Persons with disabilities are particularly vulnerable during political and humanitarian crises, such as the post-electoral violence in Kenya in 2008, or the Somali refugee crisis in the same country in the summer of 2011, as well as in disasters, such as the catastrophic tsunami and nuclear disaster in Japan in 2011. What legal and policy measures should be in place to safeguard persons with disabilities in these cases?

Hiroshi Kawamura: The vulnerability of persons with disabilities lies in both physical access and information and knowledge access. Essentially, in mass casualty natural disaster situations, the rescue operation has extremely limited ability to save the lives of the most vulnerable people due to the fact that the first responders must ensure their safety before they operate in the disaster zone. In addition, as we have learned again and again, most of the victims are killed within one hour of the incident. Following the first hour, neighbours in the community who have survived may save lives of others in the disaster area. Legal and policy measures to save lives of vulnerable people including persons with disabilities during disasters should focus on empowering those vulnerable people, with effective enforcement to encourage persons with disabilities to take part in the disaster risk reduction, from the planning stage through preparedness drills and the reconstruction process. The law should require accessibility guidelines for disaster risk reduction documentation, evacuation routes and shelters, and disaster alerts to be set out and the necessary budget should be provided. Use of copyrighted materials for disaster risk reduction documentation needs to be guaranteed legally as a fair use in an accessible format so that all vulnerable people may have access to the information and knowledge necessary to save their lives during disasters. Regarding political and humanitarian crises, I have no actual expertise, but I suppose that an empowering approach to accessing information and knowledge is valid in this area too.

Kapka Panayotova: We had an earthquake in Bulgaria, too. It was in the night of 22 May 2012. Luckily, there were no casualties, just ruined buildings. Last year we had floods in several areas of the country. No one knows how to handle disabled people in such cases.

You know what, I think they'll let us die – sorry for being so cynical, but this is the reality here. And I think we can learn a lot from our Japanese brothers and sisters.

ERT: What are the most important global issues within the area of mental capacity? What are in your view the major challenges in the enactment of mental capacity legislation?

Hiroshi Kawamura: The methods of access to information and knowledge as well as of communication methods are diverse. Accessible interactive multimedia development has great potential to bridge the current gap between readily available methods and methods that are required by a person with disabilities who cannot make or cannot communicate his or her decisions. We must re-examine the way to deliver knowledge, in particular legislation, contracts and scientific information that are currently delivered only in written language, and must promote publications in accessible multimedia which guarantee alternative methods of understanding the contents, such as reading aloud, sign language, enlarged text or easy-to-read versions. In this respect, it is strongly recommended that scientists and engineers work in close collaboration with disability communities such as those with CP⁴, dyslexia, autism, dementia and psycho-social disabilities. The DAISY community learned a lot from a self help group of persons with severe psycho-social disabilities in Japan and the autism community in the USA. In addition to above mentioned technology development, legal measures should be established to protect the rights of persons with disabilities who are not able to make decisions or not able to communicate their decisions.

Kapka Panayotova: We have a heated debate in Bulgaria on legal capacity and sup-

ported decision making. It has been triggered by Article 12 of the Convention and Bulgaria is among the countries that fall far behind in their compliance with this Article. In Bulgaria, it is quite easy to declare a person legally incompetent – a diagnosis and doctor’s opinion before a court that the person cannot be responsible for his/her actions are enough. Once being declared legally incapable, the person has little chance to have such a ruling reviewed and repealed. Thus people are deprived of their basic human rights – to make choices, to own and manage property, to have a family, etc. And this is often for life. If a family member is granted guardianship, there is a slight possibility that they may request a review of the position. This happens, albeit very rarely. However, once a person with intellectual disabilities or mental health problems is institutionalised, and the guardian functions are placed with the director of the facility, even that slight possibility of reversal is gone. These people will never enjoy their rights to vote, to choose where to live and whom to live with, or what kind of assistance to have. The situation in Bulgaria is in severe violation of the whole Convention because legal capacity is the key to all other rights.

ERT: What are the most important global issues in the area of information and communication technologies aimed at persons with disabilities? What is your vision for the future of these technologies?

Hiroshi Kawamura: Implementation of CRPD and WSIS plans of action in standard development, i. e. development of universal design in combination with assistive technologies, is the key issue. For cutting off the chain of the newly developed digital divide, and for the development of technologies that create digital opportunities in the inclusive human

centred society, the role of standards that guarantee accessibility for diverse categories of persons with disabilities is crucial. Accessible ICT will stimulate participation of persons with disabilities in the R&D process that will result in better meeting their demands and increasing their participation. I do believe that if all stakeholders respect and implement the CRPD, we will be successful in developing one of the pillars of the inclusive society.

Kapka Panayotova: I do believe that technologies are a powerful tool for the independence of disabled people – I wouldn’t walk without crutches, and wheelchair users can’t make it without their wheelchairs. You know, it was entirely unthinkable for a disabled person to drive a car just 20 years ago. Nowadays you can see people with quite severe impairments sitting in the wheelchair, steering the wheel with a finger, and driving their cars. It would have been impossible to have Adolf Ratzka, a severely disabled Swedish man, at a conference in Vidin, Bulgaria, talking about his studies in the U.S., his work in Latin America, and about independent living and peer support. This would have never happened without technologies being so advanced as to help compensate for the deficit caused by the impairment.

I don’t think though that we need “information and communications technologies aimed at persons with disabilities”. We are talking about universal design and this means technologies and products that are useful for everyone. For example, I communicate by Skype with both disabled and non-disabled people in Bulgaria and around the world.

Crucially, no amount of sophisticated technology can replace self-esteem and self-confidence – technical aids can make happen what people want for themselves but they need to make their decisions in the first

place. My disabled fellows need to believe that they can make it through life despite the disability, that they have the same rights as other members of society, and that they are as valuable as every other human being. Technologies will be useless if there is no political will to make a policy change.

ERT: In this issue of *The Equal Rights Review*, several articles deal with the right to independent living enshrined in Article 19 CRPD. Do you think that caring for persons with disabilities in institutions violates the right to independent living? Should all institutions be abolished and replaced with other forms of care?

Hiroshi Kawamura: The right of choice is always important. As long as the right to choose to live independently is guaranteed, some persons with disabilities may choose well designed institutions that may meet their specific needs.

Kapka Panayotova: Institutional care constitutes – by all means – a severe violation of basic human rights as defined nowadays. It takes away the control of one’s life and places the decision-making power into the hands of the institution’s staff – management, therapists, social workers, etc. People have to obey the rules of the institution, and those rules shape their daily life, schedule, diet, everything. An institution doesn’t contribute to any personal development whatsoever. It is oppressive and a terrible invasion of privacy. Disabled people need support and services, not care. This need exists irrespective of age, even though age is a factor in defining the nature of the support and services themselves. For example, children may need more or different support compared to adults. Care means a degree of control, whereas support means respect for one’s wishes and aspirations, gentle guid-

ance, contribution to the efforts made by the supported person. Should all institutions be abolished? Yes, all institutions – certainly those funded by governments – should be abolished and care should be replaced with individual support. We can’t stop private entities from setting up institutions and having their residents cover the costs, but if people have resources on an individual basis, they would be able to choose whether to pay for institutional care or go for community living with personal assistance. Briefly, the key words are individual support, including help from peers more than from experts and professionals, barrier-free environment in and outside the living space, societal acceptance, equal treatment, and finally, proper technical aids, which *inter alia* can compensate for the deficit caused by the impairment.

ERT: How can new and emerging technologies contribute to independent living? Can you give us some examples of promising experiments, or good practices?

Hiroshi Kawamura: Tele-working or working at home and remote participation are good examples while equal access to transportation and the built environment is also crucial. Remote caption and other relay services are another good practice to support persons with sensory disabilities. Penetration of accessible low cost networking including mobile telephone networks and digital TV broadcasting will make it possible for more and more persons with disabilities to live independently.

Kapka Panayotova: Both existing and emerging technologies can contribute to independent living – any item that gives control to the individual is helpful. But I keep insisting that individual and group empowerment of the disabled should be given as high a priority as technologies and indeed

higher, in order to have disabled people aware and educated to use them for independent living, not just for fun or fashion. I don't know of any experimental work in Bulgaria but, honestly speaking, Bulgarian disabled people have no access even to the existing technological solutions, not to mention new inventions.

Instead of an example of a good practice, a "bad practice" comes to mind. A new parking regulation will enter into force in September this year in Sofia. It has to do with the disability cards and special parking spaces – it's called preferential parking regulation. However, if you are a disabled person, it will not be enough for you to find a disability-marked parking space and make sure you have displayed your disability card. You will have to sit and wait for someone to come over in person to certify that you, the car user, are the same person who is in possession of the disability card. They will then place a paper inside your car next to your plastic disability card. If you are in a hurry and can't wait, your car will be clamped or towed away. This whole regulation is a step backwards. The right thing to do here would be to introduce a technology making it easier for everyone including persons with disabilities, and increasing independence and control over our lives by enabling communications.

ERT: If you were in charge of the national budget of your country, what priorities would you include with a view to improving the position of persons with disabilities?

Hiroshi Kawamura: Firstly, I would put priority on the implementation of CRPD through government investment on R&D and government procurement policy to ban new buildings, transportation, ICT products and services that are not accessible. Secondly,

I would procure accessibility guidelines of government publications and websites, guaranteeing that all new published information is accessible for everybody. Thirdly, textbooks, training manuals and examinations that are conducted by the government will be made accessible. Those are achievable targets with measurable outcomes in relatively short terms with relatively light budgets. This knowledge-based approach would encourage participation of persons with disabilities to improve their position in the society.

Kapka Panayotova: Fortunately, I'm not in charge of big money, but if I were I would have tried to allocate funds to opening up the mainstream public systems – education, transport, built environment, employment – and make them friendly for disabled people. It would not require much more money than is spent now on funding parallel systems, meaning special education, special transport, or special enterprises. Current budget allocations need reshuffling along with radical changes in the regulatory framework. Secondly, I would push for gradual but decisive reform of the welfare system: inclusion allowances should be separated from welfare payments. Can you believe that a disabled person in Bulgaria today is entitled to a monthly integration allowance amounting to between €15 and €17? The rate is linked to the government-defined "subsistence living income", which is €33 per month and which has not changed for the last three years. This is ridiculous, isn't it? Given the total lack of accessibility in the country, what disabled person could manage to get "included" by means of such "support"? This amount is but a minute contribution to the family budget made by the disabled family member. I can give you dozens of similar examples that prove the need for radical policy reform. But going

back to the budget discussion, I would put enough money (whatever is enough!) into proper training of support professionals – occupational therapists, social workers, etc. Given their crucial role in the process of inclusion, these persons need to be well aware of the social and human rights model of disability, to learn about “support” vs. “care”, to be familiar with the technological solutions that may help disabled people to become more independent, and with the personal assistance mechanism. And last but not least, I would make sure that peer support is well provided for so that experienced and self-confident disabled people can form support networks for their less confident brothers and sisters and help them by sharing experience and building their self-esteem, and by providing guidance through the systems and encouragement when things get rough. A tenth of the overall disability budget should go for monitoring and evaluation performed by mixed teams of disabled and non-disabled consultants. All these things can happen through pilot projects which should later on become a long-term policy with prospects for improvement.

If that happened, a whole new establishment would emerge. Disabled people would become and behave as clients, as citizens – demanding choices and quality because they would be given access to resources under their control. As things stand today, it would be pathetic to report on how you spend your €15 for integration, but if you had a thousand Euro for personal assistance or other services, you would have to report on spending them – with evidence of the expenditures. The current disability industry that brings benefits mostly to the business managers and experts would have to operate in a competitive environment depending on the clients who would be in control of the support provided to them with public money, and not on the government directly financing service providers. I wouldn't say that this would cost society less – though it might – but it would certainly result in better effectiveness and efficiency of public investment, and higher value-added for society as a whole. The world would become a different and better place to live. But most people are scared of change and powerful vested interests are a barrier to change. Therefore, at this time, I am sceptical.

Interviewer on behalf of ERT:
Dimitrina Petrova

1 Economic and Social Commission for Asia and the Pacific.

2 World Summit on the Information Society.

3 According to Article 2 (Definitions) of the CRPD: “‘Universal design’ means the design of products, environments, programmes and services to be usable by all people, to the greatest extent possible, without the need for adaptation or specialized design. ‘Universal design’ shall not exclude assistive devices for particular groups of persons with disabilities where this is needed.” See also Article 4(f), obliging state parties to “undertake or promote research and development of universally designed goods, services, equipment and facilities, as defined in article 2 of the present Convention, which should require the minimum possible adaptation and the least cost to meet the specific needs of a person with disabilities, to promote their availability and use, and to promote universal design in the development of standards and guidelines”.

4 Cerebral palsy.

ACTIVITIES

- **The Equal Rights Trust Advocacy**
- **Update on Current ERT Projects**
- **ERT Work Itinerary: January-June 2012**

The Equal Rights Trust Advocacy

In the period since the publication of ERR Volume 8 (March 2012), ERT has continued with its work to expose patterns of discrimination globally and to combat inequality and discrimination both nationally and internationally. A major component of ERT's advocacy work has been using the Declaration of Principles on Equality as a basis for advocacy aimed at the improvement, amendment or introduction of equality laws and policies. Below is a brief summary of some of the most important ERT advocacy actions.

ERT Publishes *In the Spirit of Harambee: Addressing Discrimination and Inequality in Kenya*

On 27 February 2012, ERT, in partnership with the Kenya Human Rights Commission (KHRC), published *In the Spirit of Harambee: Addressing Discrimination and Inequality in Kenya*. The country report, which was the result of ERT's three year long partnership with KHRC and was based on extensive field research, provided the first ever comprehensive account of discrimination and inequalities on all grounds and in all areas of life in Kenya. The report found that while Kenya has made great progress, discrimination exists across a range of grounds and areas of life, and that major substantive inequalities remain.

The report made a series of recommendations to the Government of Kenya. Some of the key recommendations include that Kenya:

1. Review all legislation and policy in order to (i) assess compatibility with the rights to equality and non-discrimination, as defined under the international instruments to which Kenya is party and the Constitution of Kenya 2010; and (ii) amend, and where necessary, abolish existing laws, regulations

and policies that conflict or are incompatible with the right to equality;

2. Adopt comprehensive anti-discrimination legislation which prohibits all forms of discrimination and which: a) includes a comprehensive legal definition of discrimination, including a non-exhaustive ("open") list of prohibited grounds 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;

3. Introduce mechanisms for victims of discrimination to have effective access to judicial and/or administrative procedures, including through the provision of legal aid;

4. Make effective and accessible mechanisms for individuals to bring complaints about discrimination by state actors; and

5. Collect and publicise information, including relevant statistical data, in order to identify inequalities, discriminatory practices and patterns of disadvantage, and to analyse the effectiveness of measures to promote equality.

ERT has used the report in its advocacy. It formed the basis of a parallel report to the UN Human Rights Committee's 105th session (9-27 July 2012) at which the state report of Kenya was considered. The Committee included a number of ERT's recommendations in its Concluding Observations.

UN Human Rights Council Makes Use of ERT Recommendations on Moldova as New Report on Discriminatory Ill-treatment is Published

In March 2012, as a reflection of ERT's increasing impact on current debates about discrimination and discriminatory violence in Moldova, states participating in the Universal Periodic Review (UPR) endorsed a number of ERT's recommendations, while government representatives at an event in Chişinău responded positively to calls from ERT and Moldovan NGOs for improved protection from discriminatory violence.

On 16 March, the UN Human Rights Council adopted the Working Group Report from the UPR of Moldova. ERT had made a stakeholder submission to this UPR which raised concerns about Moldova fulfilling its obligation to prevent discrimination and discriminatory violence against women and recommended that the State should take steps to adopt comprehensive anti-discrimination legislation and policies, amend existing legislation in order to guarantee adequate means of legal redress, develop and support an information campaign on gender equality and ensure more effective enforcement of existing legislation intended to protect women from domestic violence.

A number of states involved in the review of Moldova made recommendations on matters

of concern highlighted in the ERT's submission, including notably those recommending that Moldova:

1. Strengthen efforts in the prevention, punishment and eradication of all forms of violence against women (Argentina, Brazil, Hungary, Sweden, Uruguay); and
2. Adopt the draft law on preventing and combating discrimination (Argentina, Canada, Estonia, France, Mexico, Norway, Romania, Slovakia, UK, USA).

In a separate development, on 19 March, ERT participated in an event to mark the launch of the report *Discriminatory Ill-treatment in Moldova*, published by the Moldovan organisation Promo-LEX in partnership with ERT, with support from the European Union Delegation to Moldova and the United Nations Development Programme. The report, which examined evidence of discriminatory ill-treatment on grounds of gender, disability, sexual orientation, ethnicity and religion, made 20 recommendations for the improvement of law, policy and enforcement on discriminatory ill-treatment and discrimination more widely.

In its presentation at the event, ERT discussed Moldova's international legal obligations in respect of discriminatory ill-treatment. Referring to the report's recommendations, ERT called for parliament to adopt comprehensive anti-discrimination legislation and for the authorities to take steps to effectively implement the domestic legal framework on discriminatory ill-treatment. Government officials at the event, including the Director of Public Prosecutions, responded positively to the report and its recommendations, though the extent to which this will translate into action remains unclear.

ERT Recommendations on Thailand's Treatment of Rohingya Echoed by State Delegations

At its nineteenth session (27 February to 23 March 2012) the UN Human Rights Council adopted the Working Group Reports for states which had undergone review in the twelfth session of the UPR. In 2011, ERT made a stakeholder submission to the review of Thailand, raising concerns about its treatment of stateless Rohingya. The submission recommended that the state review its past actions of arbitrary arrest, detention and pushing back Rohingya into the sea in light of its human rights obligations, rectify past violations, amend its immigration policy, introduce comprehensive equality legislation and ratify relevant international treaties.

A number of states made recommendations on matters of concern highlighted in ERT's submission. These included recommendations that Thailand:

1. Accede to the 1954 Convention Relating to the Status of Stateless Persons (France);
2. Address, as a matter of priority, the conditions in Thai prisons and detention centres, including the expansion of the necessary infrastructure and prison personnel, as well as the improvement of inmates' access to medical care and legal counsel; repeal all relevant legal provisions with a view to eliminating excessive or unjustified detention; and reverse current practices regarding the rights of refugees, asylum-seekers and migrant workers (Slovakia);
3. Ensure migrants found at sea are afforded the full measures of protection they are entitled to under international law (New Zealand);

4. Facilitate access to asylum procedures in order to guarantee international protection to asylum-seekers (Switzerland);

5. Continue to strengthen cooperation with the High Commissioner for Refugees (UNHCR) as well as with donors and non-governmental organisations in order to provide necessary humanitarian aid and fundamental rights protection to displaced people (Qatar);

6. Take measures with a view to preventing and combating arbitrary arrest, violence, abuse and exploitation of migrants; and refrain from the *refoulement* of asylum-seekers (Brazil);

7. Continue to address remaining social inequalities and unequal access to opportunities and services by the poor and the marginalised (Bhutan); and

8. Consider withdrawing its reservations to various human rights instruments (South Africa).

ERT Urges Moldova to Re-instate Sexual Orientation and Other Grounds in Draft Equality Law

In May 2012, ERT urged the government of the Republic of Moldova to call a halt to the process of adopting a draft Law on Equal Opportunities (the Draft Law). In a letter to Moldovan Prime Minister, Vlad Filat, of 17 May, ERT recommended critical amendments to the Draft Law in order to ensure that it is consistent with Moldova's obligations under international law.

In particular, ERT's letter expressed grave concerns over three changes made to the Draft Law since publication of the previous version, entitled the *Law on Preventing and*

Combating Discrimination, in October 2011. In particular, the letter explained that ERT's concerns related to:

1. The removal of four protected characteristics – sexual orientation, health status, wealth and social origin – from Article 1(1) of the Draft Law, thereby excluding them from the list of grounds on which discrimination is prohibited under Article 2. ERT's letter stated that, while none of these characteristics, except social origin, enjoys explicit mention under international instruments, each is a protected ground through authoritative interpretation and merits the same protection as other grounds in the Draft Law. Relying on the consistent practice of the UN Human Rights Committee, the Committee on Economic, Social and Cultural Rights and the European Court of Human Rights, the letter stated that sexual orientation and health status are protected under the International Covenant on Civil and Political Rights, the International Covenant on Economic, Social and Cultural Rights and the European Convention on Human Rights;

2. The inclusion, in Article 1(2), of language stating that marriage is a union between a man and a woman. ERT argued that this provision was discriminatory on grounds of sexual orientation, in that it clearly disbars gay men, lesbians and bi-sexuals from entering into same-sex marriages. ERT noted that while there is no obligation on states to legislate to provide for same-sex marriage, Moldova is obligated to refrain from discriminating in law and action on grounds including sexual orientation; and

3. The inclusion, in Article 1(2), of a number of exceptions to the right to non-discrimination in respect of family life, adoption, and the activities of religious bodies and institutions.

ERT argued that these exceptions were too broad to be consistent with the Declaration of Principles on Equality, which states that the right to equality, and therefore the right to non-discrimination which is subsumed within the right to equality, "applies in all areas of activity regulated by law". The letter also noted that these exceptions were likely to be inconsistent with the interpretations of UN Treaty Bodies such as the Committee on the Elimination of Discrimination Against Women which had explicitly criticised laws which exclude areas of personal laws such as marriage and adoption from the prohibition on discrimination.

Based on these concerns, ERT's letter recommended that the government reverse these changes or withdraw the Draft Law completely, reverting instead to the previous draft. However, the letter also recommended that, should the government decide to revert to the previous draft, certain amendments based on ERT's recommendations on earlier drafts of the law be retained: the inclusion of a provision on reasonable accommodation, the inclusion of a provision on compensation for material and moral damage and the extension of standing in discrimination cases to associations, trade unions and non-governmental organisations. The letter also urged the government to consider further amendments based on previous ERT recommendations, in order that the final law reflected current international law and best practice on equality.

Joint Initiative to Address Statelessness in Europe Launched

On 8 June 2012 the European Network on Statelessness (ENS) was launched. ERT is a founding member of ENS – a network of non-governmental organisations, academic

initiatives, and individual experts committed to address statelessness in Europe. The Network is open to non-governmental organisations, research centres, academics and other individuals. ERT's Head of Statelessness and Nationality Projects, Amal de Chickera, is a steering committee member and focal point for law and policy activities of the ENS.

ERT Calls on Myanmar and Bangladesh to Protect Stateless Rohingya

In June 2012 ERT wrote to the President of Myanmar, Ambassador of Myanmar to the UK, Foreign Minister of Bangladesh, Foreign Secretary of Bangladesh, and High Commissioner of Bangladesh in the UK to express its deep concern about the on-going sectarian and ethnically motivated violence that resulted in an unknown number of deaths, serious injuries and extensive damage to property in the North Rakhine State in Western Myanmar. ERT also urged the governments of Myanmar and Bangladesh, along with the international community, to take action.

ERT urged the Government of Myanmar to:

1. Urgently take all necessary steps to end the violence and protect all individuals within their territory and subject to their jurisdiction;
2. Fully cooperate with UN agencies and the international community, to enable monitoring and documentation of the situation and the provision of humanitarian support to affected communities;
3. Bring martial law in the region to an end as soon as possible;
4. Conduct an impartial and transparent inquiry into the causes of the violence, with the

objective of identifying and bringing the perpetrators to justice, compensating the victims and restoring damaged property; and

5. Take all necessary steps to ensure equal access to justice, repealing discriminatory laws, restoring the rights of the Rohingya and establishing a clear path towards their citizenship and effective nationality.

ERT urged the Government of Bangladesh to prevent further escalation of this humanitarian disaster by opening its borders to Rohingya refugees fleeing violence and persecution in Myanmar and refraining from the involuntary repatriation of all refugees and persons of concern. It emphasised that it was essential that full cooperation be given to the international community in providing humanitarian support and protection to displaced communities.

ERT urged the UN, and in particular the UN-HCR to continue to engage with the governments of Myanmar and Bangladesh to ensure that their mandate to protect stateless persons and refugees is fulfilled. ERT stated that it hoped that they would resume their presence on the ground in affected areas of North Rakhine State as soon as possible to monitor and document the situation and enable their officers to function to their fullest potential in their mandate to protect during this time of crisis.

ERT also urged the international community to:

1. Engage with the Government of Myanmar to take immediate steps to end this unnecessary violence, and long-term steps towards the reduction of statelessness, building the rule of law and integrating equality and respect for human rights into their reform processes;

2. Engage with the Government of Myanmar to ensure that this conflict does not result in increased military control and extended periods of martial law during this period of reform;
3. Engage with the Government of Bangladesh to open its borders to refugees fleeing the violence; and
4. Consider concrete ways to support the Government of Bangladesh in providing protection to Rohingya refugees both in the short and long-term.

ERT Launches Situation Report on Rohingya Crisis in Myanmar and Bangladesh

On 2 July 2012, ERT launched its report *Burning Homes, Sinking Lives: A Situation Report on Violence against Stateless Rohingya in Myanmar and their Refoulement from Bangladesh*. The report, which included testimony collected from over 50 interviews with Rohingya in the period 13-29 June 2012, presented the findings and observations of ERT researchers and painted an extremely bleak picture, which demanded urgent action to prevent further human rights violations including loss of life, suffering, forced displacement and damage to property. In addition to the testimony of victims, the report reviewed the legal obligations of the parties to this crisis and made recommendations to the governments of Myanmar and Bangladesh, the UNHCR and the international community. The report made a series of findings and recommendations:

Main Findings

1. In Myanmar, what began as sectarian violence, evolved into large-scale state sponsored violence against the Rohingya. The

violence, including killings, rape and burning of houses, began on 3 June 2012 and had mainly occurred in Sittwe and Maungdaw. On 10 June, a state of military emergency was declared, after which the UN pulled its staff out of the area, leaving no international observers on the ground. On 29 June, it was announced that UNHCR staff had returned to Rakhine State. From 16 June onwards, the military became more actively involved in committing acts of violence and other human rights abuses against the Rohingya including killings and mass scale arrests of Rohingya men and boys in North Rakhine State.

2. Bangladesh, in contravention of its international legal obligations, closed its border and pushed back (*refouled*) into dangerous waters many Rohingya fleeing the violence and persecution in Myanmar. The first boat with Rohingya refugees arrived in Bangladesh and was *refouled* on 11 June 2012. On 18 June, 139 persons in eight boats were *refouled* from Teknaf. However, more refugees continued to arrive. No visible steps had been taken by the Government of Bangladesh to provide humanitarian aid for the refugees, thus shifting this burden onto local residents.

3. The legal obligations of both Myanmar and Bangladesh require them to protect all persons within their territories or subject to their jurisdictions, regardless of whether they are citizens, stateless persons or refugees. In their treatment of the Rohingya, both countries appeared to have violated the right to life, the right to be free from torture or cruel, inhuman or degrading treatment or punishment, the right to liberty and freedom from arbitrary detention, the right to food and shelter including the fundamental right to be free from hunger and the right to the highest attainable standard of health. Bangladesh

had also acted in violation of the rights to seek and to enjoy asylum and not to be subjected to *refoulement*. The severity of the treatment of the Rohingya and the widespread, systematic nature of the violence additionally raised a concern that crimes against humanity were being committed by Myanmar.

Key Recommendations

In addition to making recommendations to the UN member states and the international community, ERT's report made a series of recommendations to the governments of Myanmar and Bangladesh.

ERT's recommendations to the Government of Myanmar included that it:

1. Urgently take all necessary steps to end the violence and protect all individuals in Myanmar;
2. Fully cooperate with UN agencies to enable independent monitoring of the situation and the provision of humanitarian assistance and support to affected communities;
3. Bring martial law in the region to an end as soon as possible;
4. Conduct an impartial and transparent enquiry into the causes of the violence; and
5. Reduce statelessness in Myanmar by establishing clear paths towards the acquisition of citizenship and effective nationality for all stateless persons including the Rohingya.

ERT's recommendations to the Government of Bangladesh included that it:

1. Open its borders to Rohingya refugees fleeing violence and persecution in Myan-

mar and refrain from *refoulement* or forcible return of refugees, asylum-seekers and persons of concern;

2. Fully cooperate with UN agencies and international NGOs to enable the provision of humanitarian assistance and support to all refugees; and
3. Fully cooperate with the international community in providing humanitarian support and protection in a fair and non-discriminatory manner to all long-term Rohingya refugees and persons of concern within Bangladesh.

Civil Society Coalition Calls for Protection of Rohingya and End to Violence

On 16 July 2012, a coalition of 58 civil society groups led by ERT, the Arakan Project (AP) and Refugees International (RI) condemned the abuse and violence carried out during the Rohingya Crisis.

This joint civil society action was initiated by ERT, AP and RI during the annual UNHCR NGO Consultations, 3-5 July 2012, at which the three organisations briefed a group of NGOs on the Rohingya Crisis.

The joint statement included a series of recommendations to both governments, which were delivered to the governments of Myanmar and Bangladesh and to their embassies in 28 countries. The statement also included recommendations to the international community.

Since the drafting of the statement, Thein Sein, president of Myanmar, declared to the UNHCR that the Rohingya are illegal immigrants who should be moved to refugee camps or resettled to third countries – a proposal rejected by the Refugee

Agency. This statement of the president is emblematic of the exclusion, discrimination and abuse that stateless Rohingya have faced for many decades at the hands of the state, and a dangerous indication of Myanmar's preferred solution to this human rights crisis.

Launch of ERT Guidelines to Protect Stateless Persons from Arbitrary Detention

On 18 July ERT launched its Guidelines to Protect Stateless Persons from Arbitrary Detention (the Guidelines) at Garden Court Chambers, London. The launch event was chaired by Sir Bob Hepple (Chair of the ERT Board of Trustees). Speakers at the event were the Rt. Hon. Lord Justice Sedley (former Judge of the Court of Appeal of England and Wales and Trustee of ERT), Roland Schilling (UNHCR Representative to the UK), Stefanie Grant (Senior Advisor to ERT's statelessness work), and Amal de Chickera (ERT Head of Statelessness and Nationality Projects).

The Guidelines provide detailed guidance on how states should treat stateless persons in the context of immigration detention in order to comply with their obligations under international human rights law, in particular, the rights to equality and non-discrimination and the right to be free from arbitrary detention. They were drafted through a consultation process which sought to be comprehensive and inclusive and have been reviewed by experts in the complementary fields of human rights, equality, immigration, detention, refugees and statelessness.

Specific Guidelines address different aspects of the protection gap that exists in relation to stateless persons. For example:

1. Guideline 14 sets out the rights to equality and non-discrimination in relation to stateless persons;
2. Guidelines 19-22 focus on identification;
3. Guidelines 23-52 deal with arbitrary detention and related concerns around ongoing detention and vulnerable groups; and
4. Guidelines 55-60 address the stay rights that should be provided to stateless persons in order to respect, protect and fulfil their human rights.

Guidelines 23-52 form the very core of the Guidelines and articulate well-known and universally accepted standards which must be adhered to when depriving an individual of his or her liberty. Of particular importance, Guidelines 38-40 collectively articulate that there must be a reasonable and fair maximum time limit for all immigration detention and Guidelines 31-36 focus on alternatives to detention. International law clearly articulates that it is detention that should be the last resort and not alternatives.

The Guidelines have been welcomed by many key individuals and organisations. For example, Colm O'Conneide, Vice-President of the European Committee on Social Rights has said:

“These Guidelines fill a significant gap in international law standards, and reflect the weight of expert opinion of how some of the most vulnerable people on earth should be treated under international human rights law.”

ERT intends to use the Guidelines both as a practical protection tool to assist those representing stateless persons in detention and as an advocacy tool to influence policy and legislative change.

Update on Current ERT Projects

Greater Human Rights Protection for Stateless Persons in Detention

The purpose of this project, which started in 2008 with funding from the Oak Foundation, was to contribute to strengthening the protection of the equal rights of stateless persons, particularly in the context of immigration, security and criminal detention. ERT has continued its advocacy through participation in working groups and discussion forums relating to the issue of statelessness. The European Network on Statelessness (ENS) was officially launched in early June 2012. ERT co-founded and has been an active Steering Committee member of the ENS. ENS is a network of non-governmental organisations, academic initiatives, and individual experts committed to addressing statelessness in Europe. ENS aims to reach its goals by conducting and supporting legal and policy development, awareness-raising and capacity building activities. Amal De Chickera, ERT's Head of Statelessness and

Nationality Projects, is the Chair of the "Law and Policy" pillar of ENS. ERT has also been involved in network and coalition building in other geographical areas, and is a member of both the Asia Pacific Refugee Rights Network (APRRN) and the International Detention Coalition (IDC).

Following the publication of ERT's Draft Guidelines on the Detention of Stateless Persons (the Draft Guidelines) and accompanying Commentary in Volume 7 of this journal, a consultation process took place in which the 7000+ recipients of the journal and over 100 experts in the complementary fields of human rights, equality, immigration, detention, refugees and statelessness were asked to provide their review and feedback. Additionally, the Draft Guidelines were disseminated through four specialist networks on refugees and asylum and detention, and through this process, they reached an additional 1000 persons working close to the



Amal De Chickera (far left) presenting the Guidelines

Photo credit: ERT

issue. The Draft Guidelines were widely acknowledged and welcomed as a timely and positive development, which could have a significant impact on existing law and policy. A further draft was then prepared, taking into account the feedback received during the consultation process, including from the UNHCR. This draft was circulated amongst a smaller group of experts and a roundtable discussion was held on 14 December.

The Guidelines to Protect Stateless Persons from Arbitrary Detention, and a Commentary to the Guidelines, authored by Amal De Chickera, were published in early July 2012. The Guidelines provide detailed guidance on how states should treat stateless persons in the context of immigration detention in order to comply with their obligations under international human rights law, in particular the rights to equality and non-discrimination and the right to be free from arbitrary deten-

tion. The Guidelines are intended both as an advocacy tool to influence policy change and as a practical tool to assist those representing stateless persons in detention. The Guidelines are now open for endorsement and have already been endorsed by key organisations and individuals.

ERT presented the Guidelines at the UNHCR NGO Consultations on 4 July 2012. They were well received and approximately 100 copies were distributed to participants at the Consultations. ERT received requests for large numbers of copies to be sent to organisations working in Africa, Asia, Australia and Europe. The Guidelines were formally launched on 18 July 2012 at an event at Garden Court Chambers in London. The launch event was chaired by Sir Bob Hepple (Chair of the ERT Board of Trustees). The speakers were the Rt. Hon. Lord Justice Sedley (former Judge of the Court of Appeal of England and



Photo credit: ERT

Stafanie Grant and Bob Hepple at the launch of the Guidelines

Wales and Trustee of ERT), Roland Schilling (UNHCR Representative to the UK), Stefanie Grant (Senior Advisor to ERT's statelessness work), and Amal de Chickera. The event was well attended, and the Guidelines well received by an audience including legal professionals, civil society activists, and stateless persons.

A Special Issue on Statelessness of the European Journal of Migration and Law was published in August 2012. The Special Issue, co-edited by Amal De Chickera, contains articles by leading academics, activists and experts on statelessness in Europe, an interview with Thomas Hammarberg and ERT's Guidelines to Protect Stateless Persons from Arbitrary Detention. The five articles in the Special were written by Laura van Waas (University of Tilburg), Rene de Groot and Olivier Vonk (University of Maastricht), Mark Manly (UNHCR Statelessness Unit), Gabor Gyulai (Hungarian Helsinki Committee) and Claude Cahn (UN).

The outcomes and impact of this project so far include: (1) integrating statelessness as a key issue of the international movement to end arbitrary detention – ERT has worked in close partnership with the International Detention Coalition, UNHCR, OHCHR and other key players to highlight statelessness as an important issue which must be addressed by immigration detention regimes; (2) developing standards relating to the identification and detention of stateless persons through ERT's Guidelines to Protect Stateless Persons from Arbitrary Detention; (3) changing attitudes of civil society towards statelessness through trainings, networking and capacity building, including through ERT's UK training workshops, the establishment of the ENS and ERT's active participation in key NGO

networks including the Asia Pacific Refugee Rights network, the International Detention Coalition and the UK Detention Forum; (4) filling a documentation and knowledge gap on statelessness – ERT's report *Unravelling Anomaly* has been widely acknowledged as a key text on statelessness which has filled a research gap and serves as a useful resource to academics, activists and policy makers. The focus on detention and the highlighting of the connection between statelessness and lengthy immigration detention has resulted in many organisations addressing immigration detention from a statelessness perspective; and (5) promoting statelessness as a human rights issue – ERT continues to raise human rights concerns with regard to the treatment of stateless persons at different international forums, including most recently, at the Universal Periodic Review of the United Kingdom.

The Unified Perspective on Equality, LGBTI Rights and Islam

In September 2009, ERT started work on a project funded by the Arcus Foundation on a study to show how the unified approach to equality benefits LGBTI rights. One aspect of this project is to explore the possibility for promoting LGBTI equality in countries with Islam. The work under this project will produce two published outputs: an article in a forthcoming book focusing on the use of equality and non-discrimination law in advancing LGBTI rights in countries of the Commonwealth, with a special reference to the decriminalisation of same sex conduct; and a study on LGBTI equality in countries with Islam, including secular states. The editorial process for both publications is ongoing.

The expected outcomes of this project include: (1) better understanding among civil

society and other actors of the potential of using equality law principles and concepts in efforts to decriminalise same sex sexual conduct; (2) better understanding of the strategic choices for enhancing LGBT equality in countries with Islam; and (3) improved dialogue between LGBT groups, faith-based actors and civil society, particularly human rights organisations.

Malaysia: Empowering Civil Society to Combat Discrimination through Collective Advocacy and Litigation

Launched in March 2010, this project involved the provision of training to civil society actors, lawyers and the judiciary on equality law, development of a report on discrimination in Malaysia, and the establishment of a Malaysian Equality Forum. ERT worked with Tenaganita, an NGO based in Kuala Lumpur. Under this project ERT pursued a number of activities including: research and publication, capacity building, training workshops and roundtable discussions.

Since December 2011, ERT has worked on the production of a country report on discrimination and inequality in Malaysia. The draft has been developed further with new research, reflecting fast-paced legislative and political developments of 2011-2012.

The impact of this project includes the successful establishment of a functioning national Equality Forum which provided an institutional framework for civil society dialogue on equality and discrimination issues in Malaysia; the increased understanding of 35 workshop participants of both international and domestic equality and non-discrimination law; an increased capacity to develop advocacy strategies through which their improved knowledge can be used to

seek improvements in domestic protections of the rights to equality and non-discrimination for all vulnerable groups within Malaysian society; and capturing the interest of key stakeholders and legal experts in Malaysia with regards to improving the protection and implementation of the rights to equality and non-discrimination in Malaysia.

Moldova: Strengthening Legal Protection from and Raising Awareness of Discriminatory Ill-Treatment in the Republic of Moldova, Including Transnistria

This project, which started in April 2010, and in which ERT has been a partner to a Moldovan NGO – Promo-Lex – had two general objectives: (1) to contribute to strengthening legal protection from discriminatory ill-treatment; and (2) to raise awareness of stakeholders on discriminatory ill-treatment. ERT was responsible for certain aspects of the project related to building the capacity of local stakeholders on equality law issues.

A bilingual (Romanian-English) report on discriminatory ill-treatment in Moldova, to which ERT contributed, was published by Promo-Lex in March 2012. The report analyses the main patterns of discriminatory ill-treatment prevailing in Moldova and the relevant law, and illustrates the main issues with testimony of specific cases. ERT's contribution was a chapter on relevant international and regional legal standards on discriminatory ill-treatment, examined from the perspective of a number of grounds. In March 2012, ERT participated in a roundtable meeting to launch the report. In its presentation at the event, ERT discussed Moldova's international legal obligations in respect of discriminatory ill-treatment. Referring to the report's recommendations, ERT called for parliament



Launch event in Moldova, Jim Fitzgerald and Olga Manole

to adopt comprehensive anti-discrimination legislation and for the authorities to take steps to effectively implement the domestic legal framework on discriminatory ill-treatment. Government officials at the event, including the Director of Public Prosecutions, responded positively to the report and its recommendations, though the extent to which this will translate into action remains unclear.

This project has had a strong impact in Moldova, including in particular on the ongoing debates about the adoption of comprehensive anti-discrimination law and effective responses to discriminatory violence and ill-treatment. Over 70 legal practitioners, judges and civil society representatives have been introduced to the unitary framework on equality and its relationship to discriminatory ill-treatment in Moldova. Advocacy submissions made by ERT under the project directly improved the content of the Law on

Preventing and Combating Discrimination, enacted in May 2012. The publication of the report to which ERT contributed has made an important contribution to the understanding of the problems of discriminatory ill-treatment on various different grounds, and the recommendations developed in the report provide a strong basis for further civil society advocacy on this issue.

Discrimination and Torture in Nigeria

This project, which started in the autumn of 2010, has as its objective to provide practical and legal assistance to victims of discriminatory torture in Nigeria. Since the start of the project, ERT and its partner in Nigeria, the Legal Defence and Assistance Project (LEDAP), have delivered direct legal assistance to dozens of victims of torture arising from discrimination. Where necessary, LEDAP has arranged for the provision of medical, psychological and social support to those victims receiving legal sup-

port. The project has seen a number of significant court victories, with victims of discrimination successfully obtaining compensation and orders for investigation of the perpetrators.

Since the beginning of 2012, ERT and LEDAP have sought to identify further cases which can be supported through the project, with a view to providing support to an additional 19 victims of torture. It is intended that the project will support 10 legal cases on behalf of disabled victims of torture and ill-treatment, thus developing and supporting the work which ERT is undertaking with LEDAP under its Torture and Disability project (see below). The remaining cases will focus on providing support for cases which commenced in 2011, and which require further legal support to reach their conclusion.

Through providing support to individual torture victims and enabling them to pursue legal claims for torture against the Nigerian authorities, this project has secured redress for the individual victims, and will contribute to efforts to reduce impunity for discriminatory torture in the target countries, and strengthen the capacity of the project partners in this regard.

Sudan 1: Empowering Civil Society in Sudan to Combat Discrimination

This project, which started on 4 October 2010, is aimed at developing civil society capacity to combat discrimination through training, development and publication of a country report on discrimination, and establishment of a civil society coalition to undertake advocacy. It is being implemented by ERT in partnership with the Sudanese Organisation for Research and Development (SORD). The project is being implemented in the context of a rapidly-changing and dif-

ficult political and security environment, which has consistently affected the ability of SORD to operate freely.

At the end of January and in early February, SORD held two training workshops in Kassala and Khartoum. The workshops were delivered by consultants appointed by SORD who had taken part in a joint ERT-SORD train-the-trainer workshop which ERT convened in October 2011. The Kassala workshop targeted participants from NGOs and CBOs and other human rights defenders. Twenty-five persons attended in total, including 16 women; four of the participants were persons with disabilities. The Khartoum workshop targeted a number of NGOs and CBOs working within Khartoum state. Thirty persons attended in total, including twenty-two women; the group included four persons with disabilities. The workshops were well received and have helped SORD to continue its efforts to build the network of NGOs working on equality and non-discrimination issues in Sudan.

In March 2012, field researchers contracted and guided by ERT completed research, including interviews, focus groups and documentation on patterns of discrimination and inequality in Sudan. SORD has worked to incorporate the findings of this research into the draft country report which they have been developing, with guidance and support from ERT.

Since March the implementation of this project has been affected by growing civil unrest and the government's repressive response. In late March, SORD organised a conference to discuss the Sudanese family law and propose reforms. Following the conference, SORD was attacked in the media by both pro-government newspapers and government spokespeople. SORD and its staff were

labelled as pursuing an anti-Muslim, western agenda. In a speech attacking international NGOs and UN agencies, Dr Nafi Ali Nafi, the deputy leader of Sudan's governing party, accused SORD of being unpatriotic, and singled out the organisation's Executive Director. Despite the threats made against them, SORD staff have been directly engaged in a more recent wave of demonstrations against the government, placing them at further risk. What began on 16 June as demonstrations against austerity measures announced by the government, have escalated into significant protests calling for the end of the rule of President Al-Bashir. The Sudanese government has responded to these protests with a wave of repression directed at protestors, including civil society organisations such as SORD. There have been a number of reports of violent dispersal tactics being used by security forces and large scale arrests. A member of SORD staff and a member of the board of trustees were recently detained, though they were subsequently released. SORD has also experienced other forms of interference from security forces, particularly in relation to communications. As a result of the difficulties faced by SORD, the completion of the project's remaining activities faces delays.

Despite the severe challenges which this project has faced, SORD reports that it is having a significant impact in developing civil society capacity. The train-the-trainer workshop delivered in October and the workshops delivered in January and February, have developed the technical capacity and knowledge of participants in the area of anti-discrimination law, and have helped to expand the nascent network of organisations interested in pursuing legal reform on discrimination. Those organisations involved in field research have benefited in terms of increased capacity to document discrimination, while

the research itself, once completed and published, is expected to make a significant contribution in terms of raised awareness of discrimination in Sudan. Finally, the project has enabled SORD to continue its work, both in the area of discrimination and other human rights abuses, in the context of an extremely challenging and hostile environment.

Sudan 2: Equality and Freedom of Opinion, Expression and Association

ERT launched this project in October 2010, with the objective of enhancing the ability of Sudanese human rights defenders and journalists to use equality and human rights law concepts in their work, and to be aware about the need to balance freedom of expression with the right to non-discrimination, including in the form of freedom from hate speech. ERT works with anonymous Sudanese consultants operating from outside and inside Sudan. With support from the project, journalists are continuing to write for Sudanese and international media on human rights issues. The journalists have launched campaigns and published statements on a number of cases and issues of concern, including the closure of newspapers, arrests of journalists and human rights defenders, and hate speech. Project staff have been able to provide practical help and support to individual journalists who have been detained or otherwise mistreated.

In the first quarter of 2012, two sets of two training workshops were held in an undisclosed location. Each week long event comprised two two-day training workshops and two days of strategy discussion. The first workshop, conducted by ERT staff, covered an introduction to human rights law, freedom of expression, and equality and non-

discrimination, and discussed in detail the interaction between the rights to equality and freedom of expression including in respect of hate speech. The second workshop, delivered by a number of Sudanese and international consultants, focussed on techniques and practices for journalists working in high-risk environments. On the days before, between and after the two workshops, the participants held roundtable meetings at which strategies for reporting on human rights in insecure environments and for improving the quality of human rights reporting were discussed. Both week-long events were successful, with participants providing feedback stating that they felt the training was very useful. Participants' knowledge of human rights and equality law, as evaluated before and after the workshops, improved as a result of the training provided.

As noted above, implementation of ERT's projects in Sudan has been affected by ongoing unrest in the country. Individual journalists and consultants working for ERT's project are directly involved in the protest movement. Despite the significant obstacles faced by ERT and its local consultants, this project has begun to evidence impact in two critical areas. First, by providing financial, practical and technical support, the project has enhanced the ability of journalists to report on human rights violations and provided a mechanism to protect those who put themselves at risk by doing so. The impacts of these changes include a modest increase in freedom of the press, greater awareness of the violations of freedom of expression and other human rights perpetrated by the Sudanese authorities, and, in a small number of cases, the protection of individuals who without intervention would have been detained or otherwise mistreated for challenging the regime's human rights record.

Second, through providing training to Sudanese journalists, the project has successfully increased the understanding of the importance of the rights to equality and non-discrimination among the members of this group. As a result of the training provided by ERT, Sudanese journalists are able to identify and document cases of discrimination and understand the role which the media can play in both combating discrimination and ensuring that speech inciting discrimination and violence is not perpetuated. At this critical juncture in Sudan's history, and in the context of inflammatory racist and nationalist speech in both Sudan and South Sudan, this is a major achievement.

Guyana 1: Empowering Civil Society to Challenge Homophobic Laws and Discrimination against LGBTI Persons

This project started in October 2010. Its objective is to build 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. ERT's project partner is the Society against Sexual Orientation Discrimination (SASOD) based in Georgetown.

From November 2011 onwards, having completed all other project activities, ERT and SASOD focussed on completing a report on discrimination and inequality in Guyana, a process which involved collating the field research, undertaking desk research and engaging in legal research and analysis. A first draft report, provisionally entitled *Addressing Discrimination and Inequality in Guyana*, was produced in February 2012. Given the focus of the project, the report

has a strong focus on the problems affecting the LGBTI community in Guyana, but also deals with complex patterns of ethnic tension and discrimination and of persistent gender-based violence and discrimination against women. The draft report's recommendations focus in large part on improved implementation of Guyana's existing anti-discrimination laws, but also includes the repeal of laws which criminalise same-sex intimacy between men and cross-dressing by both men and women. The second draft of the report – a consultation draft – was subjected to review and validation at a conference and a number of other meetings in Georgetown in late June 2012 (see below, Guyana 2 project, for more details). ERT is currently finalising the report for publication in autumn 2012.

This project's principal impacts have been on ERT's local partner SASOD, and its immediate network of groups working on behalf of communities exposed to serious discrimination, such as LGBTI persons, sex workers, persons living with HIV and AIDs and survivors of

domestic violence. This group has benefitted from improved networking and increased knowledge of key concepts in equality law which has enabled effective advocacy. SASOD successfully established a Forum bringing together disadvantaged groups and linking them with larger, better established NGOs, increasing their capacity to challenge discrimination. It also benefited from training, which provided 35 civil society actors with knowledge of the key concepts in equality law. This increased capacity was further developed in the case of consultants and organisations engaged in field research through a sub-granting scheme. Using the knowledge acquired through the training and working with detailed guidelines provided by ERT to document cases of discrimination on different grounds, these individuals enhanced their skills in documenting discrimination. In part as a result of the support provided by this project, SASOD has been undertaking increasingly effective advocacy, entering negotiations with senior government figures on the question of decriminalisation of same-sex intimacy between men.



Photo credit: ERT

Consultation in Georgetown, Guyana, June 2012

Guyana 2: Empowering Civil Society to Address Societal Prejudice and Undertake Advocacy on Discrimination against LG-BTI Persons

This second project in Guyana commenced on 18 October 2011, overlapping with the first Guyana project (see above). It is implemented again in partnership with the Society Against Sexual Orientation Discrimination (SASOD). The two projects are closely interconnected: the second, focusing on media, political and international advocacy, builds on the first, which focussed on the development of basic capacities and tools for advocacy.

In June 2012, ERT, SASOD, and Red Thread (a Guyanese NGO focussed on supporting poor women) co-hosted a conference entitled “Combating Discrimination and Promoting Equality: Legislative and Policy Priorities”. The conference brought together a diverse range of organisations representing women, children, disabled persons, LG-BTI persons, persons living with HIV and AIDS, the indigenous Amerindian population and other groups to discuss the findings and recommendations of the draft report produced by ERT and SASOD (see Guyana 1 project, above).

The two-day conference was presented both as an opportunity for civil society and other stakeholders to comment on the draft report developed under the first Guyana project and as an opportunity to discuss advocacy to give effect to the report’s recommendations. Speakers included Dimitrina Petrova (ERT), who spoke on current trends in international equality law, and Jim Fitzgerald (ERT), who spoke on the legal and policy framework on non-discrimination and equality in Guyana. Liz Deane-Hughes (ERT

Consultant) presented the findings of the section of the report dealing with patterns of discrimination and inequality. Following these presentations, representatives of a number of disadvantaged groups covered in the report commented on specific sections. These included Autry Haynes, Chief Executive of the Indigenous People’s Commission, Vanda Radzik, founder member of Red Thread and member of the Women and Gender Equality Commission, Ganesh Singh, Project Manager at the Guyana Society for the Blind and member of the National Commission on Disability, and Sherlina Nageer, researcher on the situation of persons of different sexual orientation and gender identity and member of SASOD. The reviewers and other participants at the conference welcomed the report and its recommendations, and agreed to engage in further advocacy to promote the recommendations following publication.

ERT and SASOD also undertook a number of smaller meetings with key stakeholders to discuss the draft report and its findings. The two organisations met with three national commissions: the Women and Gender Equality Commission, the Rights of the Child Commission and the Indigenous People’s Commission to discuss the report and its findings, and request feedback. ERT also met with the civil society organisations ChildLink and the Justice Institute of Guyana.

On 21 June 2012, ERT delivered a day-long training workshop for 25 civil society activists and students, providing an introduction to the rights to non-discrimination and equality and an overview of the protection of these rights in Guyanese law. This was the first of four mini-workshops envisaged under the project, which are intended to sensitise participants to the current state of anti-

discrimination law in Guyana, and build their capacity to advocate for reforms to address gaps, inconsistencies and failures of implementation and enforcement.

The trip also provided a number of opportunities to raise awareness of ERT's work in Guyana and of the key legal and policy reforms which will be recommended in the report, once it is published. ERT was interviewed by two national television networks and spoke at a public debate on the rights of LGBTI persons in Guyana. On 22 June, SASOD organised a media briefing which received further coverage in print and broadcast media.

This project has made substantial progress towards its ultimate objective. The week of intensive advocacy activities based on the report developed by ERT and SASOD successfully built on SASOD's work to develop a coalition of organisations interested in advocating improved protection from discrimination. These organisations have developed a shared advocacy agenda based on the recommendations of the report, with repeal of discriminatory laws affecting the LGBTI population, and inclusion of sexual orientation and gender identity as grounds of discrimination, as central concerns. The media has been successfully engaged in support of these advocacy priorities, as evidenced by the favourable coverage received both before and after the conference and the public meeting. While a significant challenge remains in securing the active support of the authorities for reforms, particularly on the protection of persons of different sexual orientation and gender identity, a process of engagement has begun, and should continue following finalisation of the advocacy and awareness-raising plan.

Indonesia: Empowering Civil Society to Use Non-discrimination Law to Combat Religious Discrimination and Promote Religious Freedom

This project, which started on 1 November 2010, aims to build the capacity of Indonesian civil society to use equality law to combat religious discrimination and promote religious freedom. It is implemented in partnership with two of Indonesia's leading human rights organisations, the Indonesian Legal Aid Foundation (YLBHI) and the Institute for Policy Research and Advocacy (ELSAM) and involves a range of activities including training, documentation, production of a country report on discrimination and inequality in Indonesia, and the development of advocacy strategies.

In the first half of 2012, ERT and its partners completed field research on patterns of discrimination in Indonesia, and produced a first draft of a report on addressing discrimination and inequality in Indonesia. At the same time, ERT undertook work on the third part of the report, supplementing the initial draft with additional analysis of Indonesia's legal and policy framework from an international and comparative perspective.

In March, ERT participated in an event hosted by UPR-Info in advance of the 13th session of the Universal Periodic Review (UPR) of Indonesia. The meeting was intended to provide an opportunity for non-governmental organisations which had made written submissions to the review process to make representations to states which would be involved in the UPR Working Groups for different countries under review. ERT presented the findings and recommendations from its November 2011 stakeholder submission focused on

discriminatory laws, religious discrimination and discriminatory violence affecting religious minorities. The presentation was well received by both NGOs and states in attendance, and draft recommendations of the UPR Working Group indicate that ERT's advocacy has influenced the outcome.

ERT and YLBHI, the partner with lead responsibility for civil society engagement, have begun planning for an Advocacy Conference, the project's final activity. This conference will review and discuss a consultation draft of the aforementioned report, providing civil society and other stakeholders with the opportunity to comment on its accuracy and balance, and to highlight important omissions. It will also present an opportunity to promote the proposed recommendations of the report, and begin engaging key decision-makers from politics, government and the major religious communities.

The main impact of this project so far has been to add a level of competence on the application of equality law principles among a group of civil society actors which is already highly capacitated and engaged in advocacy on other human rights issues. The project has also provided a platform for ERT to engage in advocacy on the protection of religious minorities, urging such concerns to be addressed through effective protection from discrimination, as well as protection of the rights to freedom of religion and other rights. As a result of these interventions, made both in Indonesia and through the UN system, there is an increasing level of awareness of the need to provide protection from discrimination and discriminatory violence on grounds of religion or belief. It is expected that the publication of the report on discrimination in Indonesia will make a major contribution to this debate.

Developing Resources and Civil Society Capacities for Preventing Torture and Cruel, Inhuman and Degrading Treatment of Persons with Disabilities: India and Nigeria

This project commenced on 26 November 2010 with partner organisations in India (Human Rights Law Network – HRLN) and Nigeria (Legal Defence and Assistance Project – LEDAP). Its objectives include the development of legal and policy guidelines on the prevention and remedy of torture and ill-treatment of persons with disabilities, based on documentation of abuses and test litigation, as well as capacity building related to the intersection of disability equality rights and non-torture rights.

The project envisages publication of a Resource Pack on Disability and Torture, which will describe patterns of torture and ill-treatment of people with disabilities in India and Nigerian identified in the course of field research, present legal research and analysis bringing together relevant international, regional and domestic law and jurisprudence on disability and torture, and make recommendations for change to address the problems identified in the baseline report. ERT has, in conjunction with HRLN and LEDAP, continued to work towards the finalisation of the Resource Pack for each of India and Nigeria.

A further aspect of the project requires the partners to support strategic litigation concerning the ill-treatment of persons with disability. ERT, HRLN and LEDAP continue to work on identifying potential cases in their respective jurisdictions. In India, following analysis of potential cases against the selection criteria developed by ERT, a total of 13 cases have been brought. These include,

amongst others, a number of cases concerning the ill-treatment of persons with mental disabilities in state health care institutions and prisons; a case concerning clinical trials on vulnerable subjects such as children, Dalits, and disabled persons in a government hospital, which seeks an inquiry into the exact number of affected persons and the development and implementation of stronger guidelines and legal regulations; and a demand for an inquiry into the police failure to investigate the gang-rape of a deaf and mute tribal woman by army officers. ERT is also preparing amicus curiae briefs in respect of these cases.

In Nigeria, a long-list of 23 cases has been identified following discussions between LEDAP and ERT. These include cases concerning: i) The care of detainees with mental health problems in jail: Research identified prisoners held in detention on remand who were suspected to have serious mental health problems. No action had been taken to assess the mental health status of these detainees and they were consequently not receiving appropriate medical care. Further, detention conditions in high-security prisons had a particularly detrimental impact on them, because of their particular vulnerabilities; ii) Sexual abuse of children with intellectual disabilities: Children abandoned by their parents, or otherwise without parental support, have been subjected to sexual abuse. The state has not taken action against the perpetrators, nor have they put in place appropriate systems to protect such children; iii) Destruction of aids: Persons with disabilities who rely upon aids, such as wheelchairs, walking sticks, etc., have found that when they come into contact with the authorities the aids upon which they rely have been destroyed, or, when destroyed by others, have not been replaced. This has,

for example, left people to crawl/drag themselves around detention facilities. Progress towards developing these cases for litigation is now underway.

The project also involves capacity-building training to equip CSOs and lawyers in India and Nigeria to tackle problems of ill-treatment of persons with disabilities. ERT has worked in collaboration with the two Senior Advisors and the in-country partners to design and deliver a capacity-building training for CSOs and lawyers working in the fields of equality, disability and/or torture in India and Nigeria. The first set of workshops, focussing on international and domestic law relevant to the discriminatory ill-treatment of persons with disabilities, took place in December 2011, with an additional workshop being run in India in June 2012 to reach a further 50 participants.

Belarus 1: Empowering Civil Society to Combat Discrimination and Promote Equality

This project, which started on 21 December 2010, is implemented in partnership with the Belarusian Helsinki Committee (BHC) in Minsk. Its objectives are to improve knowledge of anti-discrimination law among NGOs in Belarus in order to enable them to monitor and report on discrimination and to bring discrimination cases to court; and to create a coalition of NGOs with a joint advocacy platform on issues of discrimination.

In the first half of 2012 ERT and BHC produced a first draft of the report, which was circulated to civil society organisations in Belarus for consultation. A roundtable event took place in mid-June, at which participants were invited to give their thoughts and input on the draft report. Feedback from this event

has been collated by BHC, in order that it can feed into the final draft of the report. ERT and BHC are currently working on a redraft of the report.

Under this project, ERT and BHC identified, developed and provided support to a number of strategic litigation cases on discrimination on grounds such as political opinion, nationality and gender.

This project has had a major impact in highlighting the nexus between discrimination and the ongoing political repression in Belarus. Through providing training, expertise and material support, this project has enabled Belarusian human rights defenders to challenge state-sponsored abuses through the courts, and resist the victimisation of the political opposition and their supporters, including defence lawyers, following the disputed presidential election in December 2010, and the imposition of travel bans on prominent dissidents and human rights defenders, including the members of ERT's partner NGO. As importantly, this project has enabled civil society in Belarus to coalesce around a politically less controversial issue – the right to equality being nominally a priority of the State – providing a vital safe space for joint work and activism.

Belarus 2: Empowering Civil Society to Advocate Collaboratively the Adoption of Anti-discrimination Legislation

This project began in April 2012, and aims to build upon and complement the work undertaken in ERT's first project in Belarus. ERT works with a partner based in Minsk – the Belarus Helsinki Committee (BHC). This project aims to empower civil society in Belarus to advocate collaboratively for the adoption of anti-discrimination legislation. Its objectives

include: strengthening civil society capacity to advocate for improved human rights protection; increasing civil society cooperation on a common human rights agenda; and increasing human rights protection and political participation for vulnerable groups. This will be achieved through providing training on developing and implementing strategic advocacy campaigns; engaging in international advocacy on equality issues for civil society organisations; establishing a National Equality Forum; developing and implementing a strategic paper and action plan for the National Equality Forum; creating an online equality forum; supporting international advocacy actions by Forum members; and generating new evidence of discrimination.

Jordan: Addressing Discrimination and Violence against Women in Jordan

The objective of this project, which started in January 2011, is to contribute to the protection of women from all forms of discrimination in Jordan at the societal and legal level. ERT is implementing this project in Jordan as a partner to Mizan, a Jordanian organisation which is one of the most prominent and active human rights and legal defence NGOs in the Middle East.

In April-June 2012, ERT reviewed a draft report on inequality and discrimination in Jordan, and drafted a critical memo to Mizan with recommendation for revising the draft. In August, ERT drafted and sent two sections to be included in the report: a section on the status of equality legislation around the world and a section containing detailed recommendations on the development of comprehensive equality legislation and policies in Jordan. ERT continues to serve as an expert consultant to its Jordanian partner on an ongoing basis.

Strengthening Human Rights Protection of the Rohingya

In March 2011, ERT began to implement this 30-month project, the overall objective of which is to strengthen human rights protection of the Rohingya. Since the last edition of this journal, the project has moved from the planning and preparatory phase to the research phase.

The project Research Workshop was held on 13-14 January 2012 at Mahidol University in Bangkok, Thailand. The workshop was attended by representatives of ERT and Mahidol, and nine project research consultants and advisors. The workshop focussed on developing the detailed research questions and methodology for each country study and also covered the issues of research ethics, safety and security. At the workshop, the research plan and approach across all six research countries were finalised. Research has now begun in all countries.

All scheduled project activities were overshadowed by the eruption of violence against the Rohingya in Myanmar from 3 June onwards. ERT monitored the situation and on 14 June issued a public statement condemning the violence in Myanmar and the *refoulement* of refugees from Bangladesh. As the situation worsened, ERT's researchers and project staff produced an emergency situation report on the crisis, *Burning Homes, Sinking Lives: A Situation Report on Violence against Stateless Rohingya in Myanmar and their Refoulement from Bangladesh*. The report was published on 2 July and was up-to-date as of 30 June. It has been used both to raise awareness on the issue and to carry out advocacy, reaching

a wide range of actors around the world, and has been picked up by the media including Reuters Alert. ERT has held meetings in Geneva with UNHCR and OHCHR on the situation. ERT's report has also been sent to relevant special mandate holders. The report has been sent to the Bangladesh and Myanmar governments. It has also been sent to "friendly" Bangladeshi MPs, to raise the matter in Parliament, and to the Organisation of Islamic Cooperation. The report has also been sent to the other governments for their consideration.

ERT, Refugees International and the Arakan Project have also collaborated on advocacy on this issue. A joint briefing of Permanent Missions was organised in Geneva at which ERT briefed the representatives of key Missions on the situation, shared ERT's report with them and provided them with recommendations. The three organisations also organised an NGO briefing that was well attended. At the briefing it was decided that a joint statement would be issued and be delivered to Bangladesh and Myanmar Missions around the world. The statement, signed by 58 organisations, was issued on 16 July 2012.

This project's major impact so far has been in its swift and timely response to the recent violence in Myanmar and subsequent *refoulement* of refugees from Bangladesh. Thanks to the strong local networks and expert knowledge built up over the course of this project, ERT has been in a position to monitor the ongoing violations, collect powerful witness testimony, and advocate strongly on behalf of the Rohingya at the international level.



Photo credit: Saiful Huq Omi



On 11 June 2012, boats of Rohingya fleeing ethnic violence in Myanmar began arriving in Bangladesh. They were pushed back - *refouled* - into dangerous waters by Bangladeshi authorities, in contravention of principles of international law. As international criticism grew, the boat people were not pushed back immediately, but detained, provided with drinking water and then pushed back. For the refugees, re-entering Myanmar was not an option, so they would risk taking their boats out to high sea, with the hope of re-entering Bangladesh undetected. On 18 June, the largest push back of 139 persons in eight boats occurred in Teknaf, Bangladesh. These pictures tell their story. On 19 June, ERT learnt that only two boats carrying 33 persons had safely managed to re-enter Bangladesh. To-date, there is no information on the plight of the other six boats or their passengers.





Photo credit: Saiful Huq Omi

Despite the efforts of Bangladesh, many Rohingya were able to enter the country. The first refugees to flee were the elderly, women and young children. This picture is of such a group which managed to enter and find refuge in Bangladesh. After 16 June, the demographic of Rohingya refugees changed, as the Myanmar security forces began targeting Rohingya men and boys for arrests, disappearances and killing. As Rohingya men were forced to flee Myanmar and *refouled* from Bangladesh, increasing numbers of the women left behind were raped by Myanmar security forces.

Greater Protection for Stateless Persons in the UK

This project, which started in March 2011, aims to complement the project “Greater Human Rights Protection for Stateless Persons in Detention” through undertaking advocacy and capacity building actions within the UK. Under this project, ERT, in partnership with Asylum Aid and Detention Action, designed and implemented four workshops for civil society organisations and lawyers on statelessness in the UK. The workshops were delivered in London (January), Cardiff (March), Glasgow (May), and Birmingham (June). The workshops were well attended by a mix of lawyers, case-workers, academics, social workers and detainee visitors. The workshops were well received with all participants giving positive feedback and requesting further workshops to be carried out in future.

ERT has been invited to be part of the Working Group on Indefinite Detention of the UK Detention Forum. ERT attended meetings of the working group in March, May and July 2012, and will continue to work with other participants in joint advocacy to combat indefinite detention in the UK.

This project’s biggest impact so far has been in providing training to lawyers, case-workers, academics, social workers and detainee visitors from all over the UK on statelessness, enabling them to integrate a more nuanced understanding of this issue into their work with refugees, migrants and other disadvantaged groups, and capacitating them to undertake advocacy on statelessness and arbitrary detention.

Kenya 4: Improving Access to Justice for Victims of Gender Discrimination

This project, funded by Comic Relief, commenced on 1 April 2011. It aims to enable Kenyan women to secure legal remedies and enhanced protection from discrimination by adding an equality component to free community based legal services. The project is implemented with a partner organisation, the Federation of Women Lawyers Kenya (FIDA) and its planned duration is four-and-a-half years.

Under this project, ERT has undertaken a number of activities including producing a feasibility study, providing training and development of resources for legal assistance providers. Since the commencement of this project, a first cohort of five community based organisations (CBOs) have been trained and supported to establish legal services. These organisations have provided legal advice to more than 100 individual women at the community level and have launched a number of successful local advocacy campaigns on pressing gender discrimination issues in their communities. In its first year, the project successfully demonstrated that the model of capacitating CBOs to provide advice to victims of discrimination works. ERT and its partner evaluated their progress April 2012 and decided on strategies to improve the effectiveness of the project.

In March 2012, ERT visited FIDA for the purposes of contributing to an organisational development plan for FIDA to improve their capacity particularly in relation to the management of strategic litigation. A draft organisational development plan was prepared in April 2012. A revised monitoring and evaluation plan was agreed in June and ERT and FIDA are currently in the process of implementing the first actions required to give ef-

fect to this plan. This will involve conducting a series of focus groups at a total of 60 locations in five different regions of Kenya, alongside capacity assessment interviews with CBOs in each location. Following this research process, ERT and FIDA will select a larger cohort of CBOs to participate in the next stage of the project and revise the project's proposed outcomes, based on the findings of the focus groups.

The impact of this project includes assisting participating CBOs with enhancing their knowledge and understanding of equality laws and principles, and skills on how to offer legal guidance on arising legal issues in the community setting, ensuring that they are better able to provide useful advice to women who have suffered discrimination at the community level. CBOs have used the knowledge gained in ERT's training workshops to undertake local advocacy in their communities. This advocacy has empowered women and girls as rights holders in these communities by providing them with knowledge of their rights and also sensitised duty bearers to their obligations in relation to rights. For instance, a CBO in Meru has undertaken advocacy around female genital mutilation which has provoked community debate and led to less ostracisation of the girls who choose to not undergo this practice. The project has had a measurable positive impact on women and girls experiencing discrimination in the target communities. In particular, poor women who previously experienced serious difficulties accessing justice have been able to do so in their own community. In addition to these specific impacts, the project has provided a strong evidence base to support the basic model of CBO-provided legal advice on discrimination issues, which will be at the centre of the project as it is further developed.

Kenya 5: Promoting Equality Inclusive of Sexual Orientation and Gender Identity

This project, which started in April 2012 with continued support from the Arcus Foundation, builds on some of the work carried out under ERT's previous Arcus-funded project, in collaboration with local partners: the Kenya Human Rights Commission (KHRC) and the Gay and Lesbian Coalition of Kenya (GALCK). The project contains four activities: (1) Continued civil society campaigning for the introduction of comprehensive substantive equality legislation and policies inclusive of sexual orientation and gender identity; (2) Distribution and promotion of the country report on equality in Kenya – *In the Spirit of Harambee* – published by ERT in February 2012; (3) Organisation and convening of a central campaign event featuring a presentation and discussion of the recommendations of the above report; and (4) Establishing a pilot legal service for LGBTI persons who complain of discrimination. Since the project's commencement, copies of the country report on equality in Kenya have been shipped to Nairobi, where they are being distributed by ERT's local partners.

Croatia: Empowering Civil Society through Training and Establishing a Croatian Equality Forum

Work on this project began in May 2011. The project envisages the provision of training on equality and non-discrimination law, production of a toolkit on equality and non-discrimination law for Croatian CSOs and legal professionals, and the establishment of a Croatian Equality Forum bringing together a number of civil society organisations working on issues related to equality and non-discrimination law.

Photo credit: ERT



Small group discussion at training Zagreb, June 2012

An initial training workshop was held in Pula in March 2012, and a second workshop took place in Zagreb on 1-3 June 2012. This workshop was designed to build on the first and was focused on building participants' capacity and willingness to use litigation and advocacy as tools to promote the enforcement and implementation of anti-discrimination legislation. ERT made a presentation on the use of strategic litigation as a tool for advocacy and

awareness-raising, based on examples from jurisdictions around the world. Participants evaluated the workshop very positively, and there is now strong support for further joint work, to be organised through an Equality Forum which is soon to be inaugurated.

The primary impact of this project to date is that over 25 CSO representatives, lawyers and human rights activists from through-

Photo credit: ERT



Small group discussion at training Zagreb, June 2012

out Croatia have been trained in applying current international equality law and best practice in their work, greatly increasing their capacity to contribute to the implementation of Croatia's recently enacted anti-discrimination legislation.

Applying Equality and Non-discrimination Law to Advance Socio-Economic Rights

This thematic project started on 1 July 2011 and will contribute to building strategies of better enforcement of economic and social rights through drawing and communicating lessons from a global review of jurisprudence and policies which have used equality and non-discrimination law to advance the realisation of social and economic rights. The planning process for the project is complete. An Advisory Committee comprising Daniel M. Brinks, Brun-Otto Bryde, Sandra Fredman, Bob Hepple, Sandra Liebenberg, Kate O'Regan, Denise Réaume, and Kamala Sankaran has assisted in ERT's preparation of a concept paper, which has formed the basis of the ongoing research on which the final report shall be based. The project research is ongoing.

The final report, which is due to be completed in 2013, is the envisaged main output of this project. It shall contain practical advice as to how equality arguments can be used to advance the implementation of economic and social rights and a compendium of case law examples where this has been done successfully. The report will serve as a resource for human rights activists working to promote economic and social rights. It will provide additional and/or alternative arguments on which human rights activists can rely in seeking to further the enjoyment of economic and social rights in the courts. In doing so, the report will enhance the ability of such activists to achieve the notoriously difficult objective of advancing economic and social rights.

Azerbaijan: Developing Civil Society Capacity for Preventing Discriminatory Torture and Ill-treatment

This project began in November 2011 in partnership with Women's Organisation Tomris based in Ganja, Azerbaijan's second city. The focus of this project is on raising the capacity of Azerbaijani CSOs to challenge and prevent discriminatory torture and ill-treatment.



Hasan Huseynli, Head of the Kamil Citizen's Society, speaking at Equality Forum in Guba, Azerbaijan, May 2012

Photo credit: ERT



Photo credit: ERT

Participants in Equality Forum meeting in Guba, Azerbaijan, May 2012

A first civil society Equality Forum meeting under this project took place in April 2012 in Ganja. Twenty-two representatives from local CSOs from the western region of Azerbaijan working on issues surrounding discrimination and human rights attended a full day session in which they were briefed on the project and discussed priority areas for joint action, including women's rights, minority rights, LGBTI rights, and disability rights. Participants expressed enthusiasm about the project's aims and objectives, and were keen to continue joint working, proposing to establish an online forum in order to exchange news, projects, and partnership ideas in selecting and delivering projects.

A second CSO forum meeting took place in Guba in May, covering similar themes. It was attended by 19 participants from the central and northern regions of the country. A third regional CSO forum meeting took place in Baku in July, and was attended by participants from the east of the country

and the Absheron peninsula, in advance of training workshops scheduled to take place later in the year.

Bosnia and Herzegovina: Developing Civil Society Capacity to Combat Discrimination and Inequality in Bosnia and Herzegovina

This project began in December 2011. It includes a range of activities designed to increase the capacity of civil society organisations to secure improved implementation and enforcement of Bosnia and Herzegovina's recently adopted Law on Prevention of Discrimination: roundtable discussions on combating discrimination and inequality, training workshops on anti-discrimination law and policy, the publication of a report on discrimination in Bosnia and Herzegovina, the establishment of a civil society Equality Forum, direct assistance to victims of discrimination through legal advice, strategic litigation and advocacy.

ERT visited Bosnia and Herzegovina in January 2012 to hold planning meetings with the local partner organisations, Helsinki Committee for Human Rights in Bosnia and Herzegovina (HCHR) based in Sarajevo, and Centre for Informative and Legal Aid (CIPP) based in Zvornik.

In the first months of the project, activity focussed on establishing a civil society Equality Forum. HCHR and CIPP, with expert input from ERT, drafted a concept note and draft statute for the Equality Forum, which were circulated to prospective members prior to a first meeting. The first Equality Forum took place on 16 May 2012 in Zenica. Thirty representatives of 25 organisations were present at the meeting, together with two observer organisations. Twenty-three organisations signed the Statute of the Forum, with others needing to consult with their Boards prior to deciding whether to join. The Equality Forum meeting also included a brief workshop for participants on the fundamentals of international standards and domestic legislation on discrimination and inequality, and the role of CSOs in combating discrimination. Following this, the participants divided into smaller working groups to discuss collaboration in promoting equality and challenging discrimination. Following the meeting, the Forum released a public statement in the form of an open letter to the Ministry for Human Rights and Refugees, announcing its formation and calling upon the Ministry to establish a central database on cases of discrimination, and to adopt rules on the method of collecting data on cases of discrimination in Bosnia and Herzegovina, both of which are legal obligations of the Ministry arising out of the Law Against Discrimination.

This project's key impact to date has been in securing the participation of CSOs in the CSO Forum, representing a range of disadvantaged groups and areas of interest, from both entities (the Federation of Bosnia and Herzegovina and the Republika Srpska), thus strengthening relations between civil society organisations.

Turkey: Empowering Civil Society to Challenge Discrimination against LGBTI Persons in the Aegean and Marmara Regions of Turkey

This 18-month project began on 1 January 2012. The project seeks to increase capacity among local level CSOs in two of Turkey's regions to challenge discrimination against LGBTI persons and advocate for improved implementation of legal protection from discrimination, including on grounds of sexual orientation and gender identity. The action plan for the project includes training seminars on anti-discrimination law and policy in two cities, the establishment of a Regional Equality Forum and the publication of a report on discrimination in the Aegean and Marmara regions of Turkey. ERT is working with the local partner Siyah Pembe Üçgen (SPU), based in Izmir.

With support from ERT, SPU organised an initial roundtable event for civil society in the region. At the event, SPU presented the project's aims and objectives, provided an opportunity for dialogue between stakeholders working on different discrimination issues and problems, promoted the merits of establishing a regional Forum to coordinate work to combat discrimination, and discussed how discrimination on grounds of sexual orientation and gender identity can be incorporated into the work of members of the Forum.

Solomon Islands 2: Empowering Civil Society to Promote Gender Equality and Reduce the Incidence of Gender Discrimination in the Solomon Islands

This project, which started in April 2012, builds directly on ERT's previous project in the Solomon Islands. ERT is again one of two partners to the Secretariat of the Pacific Community Solomon Islands Country Office (SPC-SI), with the second partner being the Secretariat of the Pacific Community Regional Rights Resource Team (RRRT).

The project will run for 24 months and aims to strengthen the role of civil society in the Solomon Islands in promoting gender equality and combating gender discrimination. In particular it seeks to: (1) increase the capacity of human rights focal points to engage in awareness-raising on issues relating to gender discrimination; (2) improve civil society cooperation on actions relating to the promotion of gender equality and reduction of gender discrimination in the Solomon Islands; (3) increase awareness and understanding of the causes, effects and prevalence of gender discrimination in Solomon Islands society; (4) contribute to the development of legislation and policy promoting gender equality and combating gender discrimination through targeted advocacy; and (5) contribute to the development of relevant jurisprudence through strategic litigation. ERT is primarily responsible for training and report writing activities under this project.

Since the project's commencement, ERT's principal role has been in preparing for and delivering a training workshop, which was held on 12-15 June in Honiara. ERT staff provided training to 18 participants coming from a number of provinces, on an introduction to human rights, the rights to equality and non-

discrimination, advocacy techniques and the development of advocacy strategies. The training received positive feedback from participants and saw participants demonstrate motivation to advocate for the reform of the Solomon Islands Constitution's equality and non-discrimination provisions and to make submissions to the Committee on the Elimination of Discrimination Against Women (CEDAW) to this effect.

Following the training workshop, ERT prepared a submission to CEDAW. The submission contained a set of proposed questions for adoption by the Pre-session Working Group of the Committee, which focused in large part on proposed amendments to the Constitution of the Solomon Islands. ERT is currently preparing a submission to the Constitutional Reform Unit which will cover the same concerns as those outlined in the submission to CEDAW.

The key impact and outcome of this project achieved so far is in increasing the capacity of 18 training participants in understanding and applying anti-discrimination law, and undertaking advocacy. The participants' motivation and capacity to develop advocacy submissions regarding the reform of the Solomon Islands Constitution's equality and non-discrimination provision, and to undertake advocacy at the UN level, indicates a significant improvement in both capacity and interest. Moreover, these 18 persons have been trained to act as focal points within their communities, monitoring and documenting cases of discrimination and advocating for improvements to law and policies. Thus, the project has made an important contribution to developing the capacity of civil society to promote the need for improved anti-discrimination laws in the Solomon Islands.

ERT Work Itinerary: January – June 2012

January 6, 2012: Delivered training workshop on statelessness in the UK for civil society representatives, in London.

January 13, 2012: Attended UK Detention Forum Meeting, in London.

January 13-15, 2012: Organised research workshop at the Institute of Human Rights and Peace Studies, University of Mahidol, bringing together research consultants from six countries to develop multi-country research framework, communications and advocacy strategies, in Bangkok.

January 25-27, 2012: Held project development meeting with Bosnian partners (The Helsinki Committee for Human Rights in Bosnia and Herzegovina and the Centre for Informative and Legal Aid) to plan a joint project entitled “Developing Civil Society Capacity to Combat Discrimination and Inequality in Bosnia and Herzegovina”, in Sarajevo.

January 30, 2012: Submitted a parallel report to the Committee on the Elimination of Discrimination against Women, commenting on the state report by the Hashemite Kingdom of Jordan.

January 30, 2012: Made a submission to the UN Special Rapporteur on the Human Rights of Migrants concerning his report on the issue of immigration detention.

January 31–February 5, 2012: Provided training on human rights, particularly the rights to equality, non-discrimination and freedom of expression, to Sudanese journalists and human rights defenders.

February 1, 2012: Submitted a response to Australian *Consolidation of Anti-Discrimination Laws Discussion Paper* to the Attorney-General’s Department of Australia.

February 7-9, 2012: Held a project development meeting with Turkish partners Siyah Pembe Üçgen to plan a joint project entitled “Empowering Civil Society to Challenge Discrimination against LGBTI Persons in the Aegean and Marmara Regions of Turkey”, in Izmir, Turkey.

February 27, 2012: Published *In the Spirit of Harambee: Addressing Discrimination and Inequality in Kenya*, the first in ERT’s series of comprehensive country reports which combine an assessment of the lived experience of those exposed to discrimination and inequality and analysis of relevant laws, policies and practices.

March 2-4, 2012: Provided training on “Enforcement of Anti-Discrimination Law and on Influencing Anti-Discrimination Policies in Croatia” to CSO representatives, lawyers and human rights activists, in Pula, Croatia.

March 19, 2012: Made a presentation on international and regional law standards on discriminatory ill-treatment at an event to mark the launch of the report *Discriminatory Ill-treatment in Moldova*, published by the Moldovan organisation Promo-LEX in partnership with ERT, in Chişinău.

March 26-28, 2012: Provided training on the rights to equality, non-discrimination and freedom of expression to 20 journalists and human rights defenders from Sudan.

March 28, 2012: Delivered a training workshop on statelessness in the UK for civil society representatives, in Cardiff, UK.

March 30, 2012: Participated in a pre-session meeting with state delegations involved in the Universal Periodic Review (UPR) process, in advance of the 13th session of the UPR and presented ERT’s recommendations to state delegations involved in the reviews of India and Indonesia, in Geneva.

April 18-19, 2012: Attended European Network on Statelessness Steering Committee Meeting, in Tilburg, the Netherlands.

May 7, 2012: Participated in the UK Detention Forum, Working Group on Indefinite Detention meeting, in London.

May 10, 2012: Convened and co-hosted a panel discussion “Advancing Sexual Rights in the ‘Developing World’: The Politics of Human Rights Interventionism”, in partnership with the Human Rights Lawyers Association, in London.

May 15, 2012: Delivered training workshop on statelessness in the UK for civil society representatives, in Glasgow, UK.

May 21, 2012: Submitted a letter of concern to the government of the Republic of Moldova calling for a halt to the process of adopting a draft Law on Equal Opportunities and recommending critical amendments to the law to ensure consistency with Moldova’s obligations under international law.

May 22, 2012: Attended UK Detention Forum Meeting, in London.

June 1-3, 2012: Provided training on “Collective Advocacy in Support of Litigation on Equality” to Croatian CSO representatives, lawyers and human rights activists, in Zagreb.

June 12-15, 2012: Provided training on the basic principles of equality and non-discrimination law and an introduction to human rights law to 18 members of Solomon Islander NGOs and CBOs, in Honiara.

June 14, 2012: Issued a statement on the violence against the Rohingya minority in Rakhine State, Myanmar.

June 15, 2012: Made a stakeholder submission to the UN Human Rights Committee concerning Kenya, focused on the extent to which Kenya has met its obligations related to non-discrimination under the International Covenant on Civil and Political Rights (ICCPR).

June 19-20, 2012: Co-hosted a Conference entitled “Combating Discrimination and Promoting Equality: Legislative and Policy Priorities”, with the Guyanese NGO the Society Against Sexual Orientation Discrimination (SASOD) and Red Thread, in Georgetown.

June 25, 2012: Submitted reports to CEDAW concerning the adherence of Jamaica, Guyana and the Solomon Islands to their obligations under the Convention on the Elimination of Discrimination against Women.

June 25, 2012: Participated in the “Good Pitch Europe 2012” event and spoke about civil society activism to promote the film *Call me Kuchu* which examines discrimination against LGBTI persons in Uganda, in London.

June 27, 2012: Delivered a training workshop on statelessness in the UK for civil society representatives in Birmingham, UK.

Note to Contributors

The Equal Rights Trust invites original unpublished articles for 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

For further information regarding submissions, please email: Joanna.whiteman@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.

Established as an advocacy organisation, resource centre and think tank, ERT focuses on the complex relationship between different types of discrimination, developing strategies for translating the principles of equality into practice.

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