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## **Chapter 7: Disability, healthcare law and ethics**

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## 1. Introduction

Why devote a chapter to disability in a handbook on *medical* law and ethics? It is increasingly recognized that a disability, however defined, cannot automatically be equated with a medical condition, let alone a disease. Instead, a disability is an ‘infinitely but various feature of the universal condition’ (Bickenbach 1999, p. 112) that may arise from a health condition, age or an injury at a certain point in life and leads to long-term impairments. The United Nations *Convention on the Rights of Persons with Disabilities* [CRPD] 2006 embraces the latter approach, and serves as a comprehensive human rights instrument that establishes a wide array of rights for persons with disabilities that also impact medical law and ethics.

Nonetheless, people with disabilities are and remain victims of human rights violations, both within and outside the healthcare sector. Various studies demonstrate that the right not to be discriminated against, as well as the right

to (individual or personal) autonomy,<sup>627</sup> are often neglected (Sapey 2010; Bach & Kerzner 2010; Koch 2009). These and other human rights violations affect the health and access to healthcare of people with disabilities (Krahn, Hammond & Turner 2006; Department of Health and Human Services [HHS] Advisory Committee on Minority Health 2011). According to the World Health Organisation [WHO] (2012), '[p]eople with disabilities have less access to healthcare services and therefore experience unmet healthcare needs' (p. 1). They experience poorer levels of health than the general population, and they may 'experience greater vulnerability to preventable secondary conditions, co-morbidities, and age-related conditions' (WHO & The World Bank 2011, p. 10). They are also at higher risk of being victims of violence. As a result, the world is witnessing disability-related health disparities, leading to ill health, the denial of sexual and reproductive health (rights), substandard healthcare, unnecessary institutionalisation, violence and premature death (Yee 2011). Disability is thus also a medical law and ethical issue deserving attention in this book.

Before turning to the relevant legal and ethical theories, and exploring the rights, principles and issues most prominent in the interrelationship between disability on the one hand and medical law and ethics on the other, we will briefly discuss the various meanings of the term disability, and the way this concept was finally defined in the CRPD. In this chapter, we pay special attention to the human rights of persons with disabilities, as defined under the CRPD, within the context of healthcare, and the implications of these rights for medical professionals. Due to the fact that this book entails a separate chapter on mental health, we will not embark on the human rights of people with mental disabilities (see Chapter VII).

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<sup>627</sup> Instead of 'autonomy,' the term 'self-determination' is often used. These terms are mostly used interchangeably. To stay as close as possible to the CRPD and the case law of the European Court of Human Rights [ECtHR], we use the term (personal or individual) 'autonomy' in this chapter.

## 2. Definition of Disability

Disabilities have traditionally been defined in terms of physical, mental, intellectual or sensory deviations from normality caused by disease, trauma or other health conditions. This reflects the deep-rooted idea that people with disabilities are unhealthy and in need of medical aid. In other words, disability is seen as a problem, one that is inherent to an individual and that needs to be addressed by medical professionals. In the past, healthcare was thus seen as a means to enable people with disabilities to live a humane and dignified life. In addition, and of particular importance from a medical law and ethical perspective, healthcare decisions were made for, but not by, people with disabilities. The concept of ‘informed consent,’ a leading principle in medical law and ethics (Faden, Beauchamp & King 1986; Manson & O’Neill 2007), was thought not to be relevant for people deemed unable to make autonomous decisions. As a result of judgments by court, and more often informally, people with disabilities were treated as lacking the capacity to make decisions for themselves and as not entitled to autonomy.<sup>628</sup>

This medical model of disability - portraying people with disabilities as persons with problems, objects of care and recipients of welfare - has been harshly criticized over the last few decades (Percy 1989; Barnes 1991; Finkelstein 1990). According to the medical model, a disability essentially denotes an inability to function in the conventional way due to a defect. It was recognized that, although such an impairment can be inherent (such as a patient suffering from a neurodegenerative disease affecting his or her cognitive competences), this is not always the case. Impairments can also be the result of an external factor that has no relationship with medicine at all, like an accident that results in a leg amputation, which leads to impaired mobility. As such, not all disabilities are necessarily medical.

Proponents of the social model of disability argue that the problems of disability should not be centred on individuals, as medically inspired disability programmes are. Rather they should refer to the interaction between individuals and their environment. In fact, many obstacles faced by those with

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<sup>628</sup> See, for example, Lewis 2012.

disabilities are imposed and exacerbated by the physical and social environment, often designed by able-bodied persons who fail to take into account the needs of differently abled persons. Therefore, disability is not merely an individual characteristic, but a social construct that reflects the systematic denial of human rights to a group of individuals deemed less able to function in our society due to individual impairments. Disability and human rights scholars argue that healthcare is used as an instrument to negatively label people with disabilities, withholding them from participating in society as equals, and hindering efforts to bridge the gap between disabled and able-bodied persons (Krahn & Campbell 2011).

So-called social constructionists demand the breakdown of barriers inhibiting people with disabilities from participating equally in society - a demand clearly echoed in the 2001 'International Classification of Functioning, Disability and Health' [ICFDH] (Taket 2012). Despite these demands for equality, policymakers, legislators and the public at large still widely believe that preventive, curative and rehabilitative healthcare measures are the best remedies to reduce the adverse impact of impairments on differently-abled persons (Borg, Lindström & Larsson 2009). Much to the regret of disability and human rights scholars, disability continues to be perceived as a medical and healthcare issue (Shakespeare 2012). Furthermore, medicalization is feared to threaten the dignity of people with disabilities and justify the discrimination they experience on a daily basis, as opposed to offering a means to strengthen and ensure the equal enjoyment of human rights.

This fear is reflected in the CRPD. After long debates at the United Nations<sup>629</sup>, it was finally recognized that people with disabilities are entitled to full and equal human rights, despite much resistance amongst representatives of many States to introduce new 'disability specific' rights. The decision to include a definition of disability in the CRPD was also a point of contention amongst its drafters. Opponents argued that any definition would prevent the CRPD from adequately protecting the rights of disabled groups and persons who are most

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<sup>629</sup> See, for example, Quinn 2009 and Trömel 2009.

at risk.<sup>630</sup> For this reason, in combination with the express difficulty of establishing what precisely constitutes a disability, the law of the European Union does not include a definition. Moreover, there were also fears that the absence of a definition in the CRPD would allow States Parties to adopt strict definitions of disability, possibly denying many people with disabilities protection under the CRPD on a national level (Trömel 2009, p. 121). Others were concerned that the absence of a definition would impose costly obligations on States to accommodate differently-abled persons in education, housing, employment and healthcare, and therefore favoured its inclusion (Quinn 2009, p. 102). As a compromise, States agreed to an open-ended definition, stating, ‘persons with disabilities *include* those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others’ (CRPD, article 1). This refers to the group that should at least be protected under the CRPD on a national level. It is important that this definition does not build on a medical model, but rather embraces the social approach to disability. Although the nature of the impairment is not emphasized, the CRPD definition draws attention to problems that may occur ‘in interaction’ between impairments and environmental barriers.

It should be noted the CRPD definition purposefully states that impairments should be ‘long-term.’ Such delineation was included to allow States to confine entitlements, such as to social security, additional healthcare insurance, protection against dismissal and the right to personal assistance, to persons with particular impairments.

Prior to the adoption of the CRPD, the question of whether persons who were absent from work due to sickness were entitled to the same level of protection as people who were unable to work due to a disability emerged. According to the European Court of Justice [ECJ], this was not the case: ‘...by using the concept of ‘disability’ in Article 1 of that directive, the legislature deliberately chose a term which differs from ‘sickness’. The two concepts cannot therefore

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<sup>630</sup> On this issue see the judgment of the European Court of Justice in *Coleman v Attridge Law and Steve Law* [2008] Case 303/06, ECR I-5603.

simply be treated as being the same' (*Chacón Navas v Eurest Colectividades* [2006], ECR I-6467, paragraph 2). Building on the medical model of disability, the ECJ held that a disability was a medical condition more serious than a sickness. The ECJ thus did not pay attention to the fact the reactions of others to a condition, ranging from fear to hostility, can be as disabling as the condition itself. After the EU acceded to the CRPD in 2010, the ECJ adapted its case law, and embraced a combination of the medical and social model. Also the long-term nature of an impairment recognized by the ECJ is now sufficient to determine whether a person is entitled to the protection bestowed to persons with disabilities under the CRPD (joined cases C-335/11 and C-337/11 *HK Danmark (Ring and Skouboe Werge)* decided on 11 April 2013 and *European Commission v. Italy* (case C-312/11) decided on 4 July 2013).

To conclude, though disabilities are - at least from a human rights perspective - no longer defined in terms of mere individual or medical conditions, it is still often thought that 'the solution' to the obstacles encountered by people with disabilities in daily life lies in the medical domain, by treating the disabled individual. Like everyone else, people with disabilities have healthcare needs that may be related or unrelated to their impairments. The latter brings to the fore questions of access; how healthcare is guaranteed to persons with disabilities, and how medical professionals treat people with disabilities within the healthcare sector.

### **3. Legal and Ethical Theory**

#### **A. From Ethics to Law**

Medical law and ethics are both normative disciplines focused on human conduct in the field of healthcare. Different from evidence-based sciences, they do not analyze, describe, comprehend or predict human conduct, but seek to prescribe what individuals should do, based on what is considered a form of morally good treatment. The focus of medical law and ethics is on the conduct of medical professionals towards patients.

Since the times of Aristotle, it has been believed that medical professionals should abide by standards of ethical behaviour. These standards, or principles, were meant to inspire and regulate professional conduct. Compliance with these standards was deemed indispensable to guarantee professional behaviour and instil public confidence in the medical profession. Members of the profession themselves defined these standards and their contents. Medical ethics is thus a form of self-regulation, for and by members of the medical profession.

The dominant standards of medical ethics were later summarized into four principles: respect for autonomy, beneficence, non-maleficence and justice (Beauchamp & Childress 2013). These principles were referenced in many professional codes of conduct, both nationally and internationally, and equally applied to medical professionals when caring for ‘patients’ and ‘persons with disabilities,’ however defined (Blustein 2012).

However, these principles leave considerable room for interpretation, and make it difficult to determine a universally-ethical action for a medical professional in any specific case. Moreover, ethical principles cannot be enforced by (invoking the power of) the State. Rather, they are supposed to be morally binding on members of the professional group.

The atrocities committed in the Second World War, amongst others, against patients and research subjects with disabilities displayed the shortcomings of medical ethics (Wolfensberger 1981; Annas & Grodin 1995). In response, efforts to draft treaties and establish other legal standards for regulating the behaviour of medical professionals were introduced in the 1950s and 1960s. The focus of these laws and other legal instruments centred on protecting people with disabilities, the underlying assumption being they are unable to exercise their own autonomy.<sup>631</sup> The ethical principle of justice was thus equated with protection, inspired by non-maleficence (from the perspective of non-disabled persons) and denied people with disabilities the freedom of

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<sup>631</sup> See, for example, the *Declaration on the Rights of Mentally Retarded Persons* (UN General Assembly 1971, p. 93) and *Recommendation No. R(99)4 of the Committee of Ministers of the Council of Europe on Principles Concerning the Legal Protection of Incapable Adults* (Council of Europe 1999).

choice and other equal opportunities. The shift from non-enforceable medical ethics to legally binding medical law, in an effort to strengthen the ethical principles and make them enforceable, could not mask the fact that little attention was being paid to beneficence, from the perspective of disabled persons, self-determination by persons with disabilities and non-discrimination.

## **B. From Pity and Charity to Human Rights**

Medical law emerged in the 1950s and 1960s in response to the shortcomings of medical ethics and the lack of enforceable legal standards that would regulate the provision of healthcare compatible with human rights law. Like medical ethics, medical law was first primarily concerned with professional conduct and not with the rights of healthcare recipients, including persons with disabilities. This approach was akin to most of the laws applying to persons with disabilities, who were portrayed as unable to generate incomes and thus in need of welfare. The urge to assist people with disabilities often reflected pity, a self-defined form of beneficence, instead of respect for autonomy (Shapiro 1993). This was particularly true for war veterans (Anderson 2011). It was felt that these patriots, who became disabled while fighting to protect the rights and freedoms at home, were most deserving of compensation. Quota systems were introduced to ensure veterans gained access to employment and better treatment options (Waddington 1996). Introducing quota systems and other forms of segregated treatment for war veterans and other people with disabilities was not considered a breach of the right to equal treatment. It was simply argued that war veterans and other people with disabilities were not the same as others and therefore not always entitled to the same treatment. This notion of equality, where no attention is paid to the context and where in actual fact inequality is perpetuated, is known as formal equality (Ventegodt Liisberg 2011, p. 23; Hendriks 1995).

It was not until the late 1960s and 1970s that people with disabilities complained against these institutionalized forms of pity and charity, and asserted their human rights, notably the right to be treated as equals (Iezzoni

& Long-Bellil 2012, p. 137). Working in sheltered workplaces, enrolling in separate schools and living in institutions became increasingly seen as methods of exclusion and discrimination. It was also acknowledged that by treating people with disabilities like others, not protecting them against discrimination, and only providing them with segregated forms of different treatment, justified by the formal equality model, discouraged integration and inclusion in society. Instead of the formal equality model, a different approach to equality emerged – known as material or substantive equality – that would take into account the context of a person and historical disadvantages, and would be less concerned about the form of treatment but primarily look at its outcomes. As a result, it was acknowledged that treating disabled persons the same as others, not taking relevant factors into account, could constitute discrimination whereas forms of different treatment were not necessarily regarded as incompatible with the prohibition of discrimination (McLean & Williamson 2007). To the contrary, certain forms of different treatment were regarded as indispensable in efforts to contribute to more equality (Hendriks 1995, pp. 40-62).

It took many decades before the call for equal rights for people with disabilities was echoed at the international level, ultimately leading to the adoption of the CRPD in 2006 (Quinn 2009, pp. 93-99). This Convention is based on a number of general principles, including the principles of autonomy and free choice, equality, respect for difference and non-discrimination, participation, inclusion and accessibility (article 3, *CRPD*). Different from the four ethical principles mentioned above, the human rights principles underlying the CRPD stress the need to also take difference into account, as well as the need to break down barriers that prevent people from participating as equals in society.

As previously mentioned, the drafters of the CRPD did not intend to introduce ‘disability specific’ rights. At the same time, it becomes clear from reading the CRPD that its drafters were well-aware that free choice, participation, inclusion and accessibility remained unachievable for many persons with disabilities as long as their human rights were interpreted from the perspective of formal equality. A material equality approach to the rights of

people with disabilities is reflected in the general obligation to provide ‘accessible information’ (CRPD, article 3), to ensure the provision of ‘reasonable accommodation’ (CRPD, article 5), to raise awareness and combat stereotypes (CRPD, article 8) and to ensure access to the physical environment (including to ‘medical facilities’), to transportation, to information and communications (CRPD, article 9). It can therefore be argued that the main goals of the CRPD are to promote the autonomy and equal rights of people with disabilities, instead of confining the goal to protecting people with disabilities against themselves, and in this way, preventing these persons from participating in the life-world. Before examining the CRPD’s provisions with respect to medical law and ethics, we set out some of the CRPD’s foundational concepts, namely disability-based discrimination and autonomy.

## 4. Discrimination

### A. Definition

According to the CRPD, State Parties are obliged to prohibit all forms of discrimination on the basis of disability, and guarantee to persons with disabilities equal and effective legal protection against discrimination on all grounds (CRPD, article 5(2)). This material provision has been modelled after similarly-worded provisions in other human rights treaties. It is also seen as elaborating on the general principle of non-discrimination underlying the CRPD (CRPD, article 3(b)). But what is meant by discrimination?

Article 2 of the CRPD sets out that ‘discrimination on the basis of disability’ is a term covering:

*any distinction, exclusion or restriction on the basis of disability which has the purpose or effect of impairing or nullifying the recognition, enjoyment or exercise, on an equal basis with others, of all human rights and fundamental freedoms in the political, economic, social,*

*cultural, civil or any other field. It includes all forms of discrimination, including denial of reasonable accommodation.*

This description is almost identical to the one contained in article 1, paragraph 1 of the *International Convention on the Elimination of All Forms of Racial Discrimination* 1965. It is important to note here that discrimination neither requires the intent to discriminate nor confines itself to a specific addressee. That is, the prohibition to discriminate formulated in the CRPD equally applies to states and their agents (judges, public hospitals, public healthcare providers, etc.), as well as to private persons and organisations (private healthcare providers, churches, nongovernmental organizations, etc.).

However, the CRPD extends this definition so that the denial of a reasonable accommodation is also recognized as a form of discrimination (Waddington & Hendriks 2002), a concept that we return to below.

It follows from this definition that discrimination is generally understood to mean a form of detrimental or some other form of unfavourable treatment because of certain actual or perceived human features ('characteristics') or 'disability.' This allegedly-discriminatory treatment is usually worse, and therefore detrimental or unfavourable in comparison to the treatment received by people with a different type of disability, or without disabilities. Discrimination on the basis of disability is therefore the denial of equal treatment or rejection of equal worth of a person due to his or her disability. The harms that result from discrimination can manifest in the treatment itself (*e.g.*, intimidation) or as a consequence of the way a person is treated (*e.g.*, the denial of a job).

The prohibition of discrimination and, as a corollary, the obligation to treat people equally, are widely-recognized norms under international human rights law. Non-discrimination law emerged in response to forms of detrimental treatment deemed objectionable in a society built on human rights. Treating people less favourably because of particular features was considered unacceptable, because it was argued that they closely relate to

human dignity.<sup>632</sup> Thus, discrimination denies the principle that all human beings are equally worthy and merit equal respect and protection. Discrimination is therefore at odds with the core values and principles underlying human rights law, as well as the CRPD.

Discrimination, as prohibited by the CRPD needs to be distinguished from mere 'different' or 'arbitrary' detrimental treatment. Providing information on the effectiveness and side effects of medication in braille for someone who is blind is a form of differential treatment, but would not constitute discrimination. Likewise, providing a sign-language interpreter to a person with a hearing impairment is not a form of discrimination; rather, it can be an obligation within the context of healthcare to ensure the patient receives adequate information and can consent to treatment (*Eldridge v British Columbia* [1997] 3 S.C.R. 624). As previously stated, discrimination implies disadvantageous conduct due to characteristics intimately linked to human dignity, such as gender, race and sexual orientation and gender identity. A person cannot, at least not easily, change these characteristics without significantly changing his or her identity.

For a long time it was contested that the non-discrimination norm applied to people with disabilities. Some felt a disability reflects a human defect unrelated to someone's identity or dignity. Others were concerned that non-discrimination law would make it impossible to introduce measures and policies aimed at protecting people with disabilities, helping them to cope with their impairments and provide them with necessary care and assistance. Others feared that by adding disability as a prohibited ground, the strong protection generally offered through non-discrimination law, would water down protection for all covered groups due to this inflation of grounds. Regardless, these arguments reflect negative stereotypes of people with disabilities and were otherwise defeated (Rothstein 2000). Since the adoption of the CRPD, a human rights instrument with a very high number of ratifications,<sup>633</sup> it can no longer be contested that detrimental treatment or

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<sup>632</sup> Much has been written on the meaning of the concept human dignity. See, for example, McCrudden 2008; Thies 2009; and Aasen, Halvorsen & Barbosa da Silva 2009.

<sup>633</sup> As of 1 February 2014, the CRPD has had 141 ratifications and accessions (and 158 signatories).

other forms of less favourable treatment due to a disability constitutes discrimination, and should, as such, be prohibited and combatted around the world. This also has, as we will argue below, implications for medical professionals.

## **B. Discrimination and Healthcare**

At first glance, it is difficult to see why the prohibition of discrimination on grounds of disability should be concern medical law and ethics, let alone medical professionals. These disciplines, as mentioned above, are traditionally aimed at protecting and promoting justice, autonomy, beneficence and non-maleficence. In an effort to clarify why medical law and ethics should address discrimination and the lack of equal opportunities for persons with disabilities, we will briefly describe the various forms discrimination can take, using the designations outlined in the CRPD.

Direct disability discrimination has – according to the CRPD – ‘the purpose’ to discriminate. This occurs when a law, company policy or an individual, including a medical professional, treats someone less favourably than another similarly-situated person because of that person’s disability. For example, denying people with intellectual disabilities the right to procreate, or refusing to insure a person with a history of coronary disease are forms of direct disability discrimination (CRPD, article 25(e)). Direct discrimination is, from a legal perspective, always forbidden, unless there is an accepted justification for the differential treatment.

Indirect disability discrimination entails differential treatment on the basis of an apparently neutral criterion, with as a result (‘effect’) that (some) people with disabilities are disadvantaged compared to non-disabled persons. Such differentiation becomes discriminatory when no objective justification is provided. Denying dogs entrance to a hospital can lead to indirect discrimination towards people with a visual impairment with a service dog. Under non-discrimination law, not permitting access to dogs constitutes indirect discrimination towards a particular group of disabled persons, unless it can be demonstrated that the presence of dogs in hospitals poses, for

example, a threat to hygiene and that this threat cannot be appropriately alleviated without prohibiting service dogs.

Disability harassment, a third form of discrimination, occurs when unwanted conduct related to a disability (actual or perceived) takes place with the purpose or effect of ‘nullifying’ the dignity of a person and of creating an intimidating, hostile, degrading, humiliating or offensive environment (Weber 2007). One example is refusing children with severe disabilities any form of medical treatment because they pose a burden on society and the healthcare system.

In addition, the CRPD – like the so-called *Framework Employment Directive* (Directive 2000/78/EC) adopted by the European Union in 2000 – recognizes a fourth form of discrimination – or, more precisely, a form of treatment necessary to enable ‘the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities’ (CRPD, article 1). Reasonable accommodation discrimination takes place in situations where a party covered by non-discrimination law fails to take into account the impairments of a person with disabilities that – in the interrelationship with his or her environment – constitute a barrier for participation and integration on an equal basis. Such is the case where a physician refuses to consult the representative of a person with an intellectual disability, arguing that speaking to the patient’s representative would lead to an unjustified breach of the physician’s duty to maintain patient confidentiality. The obligation to provide reasonable accommodations (CRPD, article 2) requires the covered party to take reasonable and effective steps or adjustments to remove the barriers that hinder the equal opportunities of the disabled person, unless the covered party, in all reasonableness, cannot be expected to make the adaptations needed, given the disproportionate burden the adaptations impose on that party. It is for States Parties to ensure that this norm is correctly transposed and enforced under national law (*European Commission v Italy*).

## **C. Multiple Discrimination**

Before turning to the principle of autonomy, it is important to emphasise that discrimination not only occurs because of a sole ground, for example a disability, but that there is often a combination or intersection of grounds that cause or contribute to discriminatory reactions by others. This phenomenon is known as multiple discrimination (Fredman 2005). For example, where a person is denied health insurance due to a particular disability, together with his or her weight and age is multiple discrimination.

Non-discrimination case law demonstrates that the nature, type and intensity of discrimination a person experiences is often not merely dependent on a single ground ('disability'), but on a number of overlapping 'unfavourable' grounds, such as, obesity, age, ethnicity, or religious or sexual minority. Such a combination of 'unfavourable' grounds makes some people with disabilities more prone to discrimination than others.

In response, it was felt that non-discrimination law should also offer protection against multiple discrimination. The CRPD is the first - and so far the only - international human rights instrument expressly recognizing multiple discrimination (preamble) and also offering protection to two forms of multiple discrimination: against girls and women with disabilities (CRPD, article 6) and against children with disabilities (CRPD, article 7).

The difficulty in addressing multiple discrimination by law does not negate its significance (Hendriks 2010). We wish to shed light on this form of discrimination because of its ethical importance to medical professionals and others responsible for health and healthcare policies and legislation, and because of the unambiguous references in the CRPD.

## **D. Discrimination and Justice**

In conclusion, people with disabilities may face various forms of discrimination, both within and outside the healthcare sector. Medical law and ethics cannot abstain from this issue without undermining the principle of justice. Non-discrimination law, including the prohibition of multiple

discrimination, should therefore be an important aspect of medical law and ethics with respect to persons with disabilities, and the way these persons should be treated by medical professionals, including healthcare institutions (Silver, Wasserman & Mahowald 1998, p. 42).

## 5. Autonomy

### A. Definition

Respect for autonomy is both one of the four core bioethical principles (Beauchamp & Childress 2013), including the freedom to make one's own choices, and one of the general principles of the CRPD (article 3, *CRPD*). According to the CRPD, the autonomy of people with disabilities should also be respected in healthcare contexts, as set out in article 25. But what precisely does autonomy mean and how does it differ from the term discrimination (see section IV (A) of this chapter)? Like the term disability, the CRPD neither defines, nor describes autonomy.

The term autonomy is derived from 'auto' (self) and 'nomos' (government or law), thus literally meaning 'self-government'. Under international law, not only people or nations are entitled to autonomy, or self-determination, but individuals have the right to self-government, that is to say the right to determine their own course of life without external pressure. Thus, autonomy is above all a *negative* or non-interference right. It is therefore often associated with, according to Berlin, 'freedom from' interference by others (1958, p. 7). It has increasingly been recognized that autonomy cannot be equated with negative rights, but also requires positive 'freedom': the right to free choice and the right to fulfil one's own potential. Freedom of choice and the entitlement to evolve in a self-chosen way presuppose that choices can be made and are respected. Autonomy is therefore a complex concept, particularly with respect to health and healthcare. Often, choices must be made and individuals are not always in a position to make 'good' ones, due in part to insufficient information, their dependence on others, or a lack of intellectual capacity. Moreover, healthcare providers are bound by legal and

ethical standards as well as professional norms, which at times prohibit them from complying with patient's wishes. This sometimes leads to a dilemma between 'professional autonomy' (the freedom of the professional group to set its own norms) and the individual autonomy of the patient.

## **B. The CRPD and Autonomy**

As noted above, autonomy is a foundational concept of medical law and ethics and is examined in more detail in Chapter III on consent. For people with disabilities, autonomous decision-making often boils down to whether the medical professional is willing to respect the person's decision, including the wish not to be treated, as medical professionals tend to associate 'unwise wishes' with symptoms of incompetence. The latter is not self-evident and disrespectful to people with disabilities who may have views different from those of medical professionals. At the same time, many laws allow medical professionals to override a person's consent or rejection of treatment in case of demonstrated 'incompetence' (as decided by that medical professional). Surrogate decisions are, in these cases, traditionally seen as compatible with the principles of justice, beneficence and non-maleficence, provided that they are as much as possible in line with the previously-expressed wishes of the patient and not infringing his or her best interests. Thus, these laws are seen as protecting the health and wellbeing of the patient and doing justice to individual autonomy. As said, however, proxy or surrogate consent (which the CRPD Committee calls 'substituted decision-making') is easily applied to patients with (mental) disabilities for whom particular forms of treatment are deemed necessary. It can be argued that this situation is discriminatory towards persons with (mental) disabilities, as their autonomous will is not respected. This also raises concerns for medical law and ethics, and for the practice and standards of medical professionals, which should conform to international human rights law.

Consent, at the heart of the principle of autonomy, in the context of healthcare is referenced twice in the CRPD. First, there is a prohibition on medical or scientific experimentation without consent (CRPD, article 15). This provision

targets the horrific experiments carried out on people with disabilities during the Nazi regime (Wolfensberger 1981; Annas & Grodin 1995), or more recently, feeding radioactive material to mentally disabled children in the late 1940s (Welsome 1999). However, the absolute prohibition on experimentation without consent raises a dilemma about research with individuals that are unable to consent, but for whom gaining scientific insights may be essential to enhance treatment options. The second place where consent is mentioned in the CRPD is article 25(d), in providing equal quality in healthcare, which we will explain in more detail below.

If autonomy is to be understood as making one's own choices and having those choices respected, how is this to be applied in the context of healthcare decisions for people with disabilities? A simple answer is that decisions should be made in exactly the same way as for people without disabilities: all persons should be properly informed about treatment options, and the repercussions of refusing treatment. This solution would alleviate many of the discriminatory elements of unwanted treatments, especially but not limited to, the mental health field. This would provide formal equality, but it would leave many people with disabilities vulnerable to exploitation by others if they did not receive any decision-making assistance. Article 12 of the CRPD tackles this issue by setting out two normative premises aimed at strengthening the autonomy of persons with disabilities.

First, everyone has legal capacity, in all domains of life. Legal capacity is the law's recognition of both holding and exercising a right. For example, in certain jurisdictions the law recognizes adults as having the capacity and right to get married, but denies this right to an adult with an intellectual disability by placing him or her under guardianship with restrictions on his or her legal capacity. In the context of healthcare decisions, people with disabilities are similarly denied the right to provide consent or reject a proposed medical intervention.<sup>634</sup> In response, the CRPD sets out the fundamental principle in article 12(2) that people should have legal capacity.

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<sup>634</sup> See, for example, Hammarberg's *Who Gets to Decide?* (2012); and Lewis' *Advancing Legal Capacity Jurisprudence* (2011).

Second, article 12(3) of the CRPD maintains that States must ‘take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity’. If a dentist, for example, does not understand a person’s will and preferences, then a patient is entitled to the support necessary in order to make his or her treatment decisions and preferences understood by the dentist.

In doing so, the CRPD aims to ensure that people with disabilities meaningfully participate in society and truly exercise their autonomy. The Committee on the Rights of Persons with Disabilities [CRPD Committee] states that substituted decision-making systems must be *replaced* by systems of supported decision-making, a system recognising that persons with disabilities should be involved in the decision-making process even though they may need assistance, for example to assess the consequences of various treatment options. According to the Committee, States must repeal legislation allowing for systems of guardianship that are incompatible with human rights law and introduce laws ‘which recognize the rights of persons with disabilities to make their own decisions and to have their autonomy, will and preferences respected’ (CRPD Committee 2012a, paragraph 21). Rights including ‘the right to free and informed consent to medical treatment, the right of access to justice, and the rights to vote, to marry and to choose their place of residence’ (CRPD Committee 2013a, paragraph 30) are also mentioned as being at risk under substituted decision-making regimes. In September 2013, the CRPD Committee issued a draft general comment on article 12 of the CRPD. The draft document declared ‘mental health laws that permit forced treatment ... need to be abolished to ensure that full legal capacity is restored to persons with disabilities on an equal basis with others’ (CRPD Committee 2013b, paragraph 7). Healthcare is clearly a domain that needs to bring its practices in line with human rights norms.

## **6. The CRPD and Healthcare**

The CRPD emphasizes that people with disabilities have ‘the right to the enjoyment of the highest attainable standard of health without discrimination’

(CRPD, article 25), reiterating the classic formulation of the right to health set out in the 1966 *International Covenant on Economic, Social and Cultural Rights* [ICESCR]. The focus of the CRPD, however, is not on health and healthcare. Instead, the CRPD is based on a number of general principles – as outlined above – including the principles of autonomy and free choice, equality, respect for difference and non-discrimination, participation, inclusion and accessibility (CRPD, article 3). This is not to suggest that the CRPD is irrelevant for medical law and ethics, or that health and healthcare have no importance in achieving these general principles. On the contrary, we argue that the CRPD requires an adjustment of these principles and the approach of medical law and ethics in order to do justice to the human rights of people with disabilities in the healthcare sector.

Different from medical ethics and, to a lesser extent, medical law, the CRPD is not so much focused on regulating the performance of medical professionals, but rather on guaranteeing that people with disabilities, irrespective of the cause, nature or severity of their impairments, and no matter their needs for medical care, actually get the healthcare they need and want. The CRPD thus also emphasizes the importance of autonomy in cases where disabilities may impair the capacity of individuals to make healthcare decisions. We will illustrate this by examining the relevant CRPD provisions.

Article 25 of the CRPD is the longest and most programmatic explanation of the right to health of any of the human rights treaties. It sets out the obligation of States to ‘take all appropriate measures to ensure access for persons with disabilities to health services that are gender-sensitive, including health-related rehabilitation’ (CRPD, article 25). The drafters of the CRPD (namely the UN Member States) then established six priorities, ensuring that people with disabilities get ‘the same range, quality and standard of free or affordable healthcare and programmes as provided to other persons’ (CRPD, article 25(a)). This includes access to sexual and reproductive healthcare (this is the first time that this has been articulated in international human rights law) and public health programmes. States need to provide healthcare to alleviate, insofar as is possible, someone’s disability. Early identification and intervention, and ‘services designed to minimize and prevent further

disabilities, including among children and older persons' are among the actions which fall under this mandate (CRPD, article 25(b)). The Convention emphasizes the provision of healthcare 'as close as possible to people's own communities, including in rural areas' (CRPD, article 25(c)). Articles 25(d) to (f) of the CRPD then set out overarching principles, reiterating the principles contained in article 3. They require the State to ensure that its medical professionals provide equal quality care, which is given 'on the basis of free and informed consent,' an issue to which we return, below. Equal quality should be achieved, according to the Convention, by pursuing actions that may include raising awareness of human rights 'through training and the promulgation of ethical standards' for medical professionals (CRPD, article 25(c)).

Article 25(e) of the CRPD reiterates the right to non-discrimination, this time with respect to health and life insurance. Article 25(f) of the CRPD establishes non-discrimination in providing a patient with disabilities healthcare, food and fluids. This is of particular concern, for example, when a person with Down syndrome needs a kidney transplant, given the reported cases where this has been denied based on the person's disability.<sup>635</sup> It is also a concern for end of life decisions and the management of people in conditions such as persistent vegetative state.

The CRPD recognizes health in parallel with the broader notion of independence, a concept that implies autonomy and the obligation to provide support to exercise autonomy. The drafters of the Convention were keenly aware that health can play an important part in reversing the invisibility of people with disabilities. Healthcare systems are unable to do this alone as many determinants of health are not within the realm of control of healthcare. It is widely known that income and other socio-economic determinants have, on a population basis, a greater effect on health than the quality of healthcare. That is not to ignore the importance of essential healthcare at times

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<sup>635</sup> For a review of outcomes, see Martens, Jones & Reiss 2006. For a case that permeated the public consciousness and resulted in a global campaign to provide an intellectually disabled girl with a much-needed kidney transplant, see Change.org 2012.

(Wilkinson 1997). One socio-economic determinant is adequate housing.<sup>636</sup> There is now abundant evidence that poor housing can lead to poor health, and people with disabilities are particularly vulnerable.<sup>637</sup> The right to adequate housing is set out in article 28 of the CRPD on social protection, and appears alongside other essentials of health, such as water, food, clothing, social protection, poverty alleviation and so on. Housing is a prominent issue in human rights literature. It does not mean simply having a roof over one's head, but is framed in terms of access to, and participation in the community. Central to this right is the obligation of States to provide 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' (CRPD, article 19). This provision speaks to the right to habilitation and rehabilitation, whereby health services should be directed towards enabling people with disabilities 'to attain and maintain maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life' (CRPD, article 26(1)).

## A. When Treatment Becomes Ill-Treatment

Despite the normative clarity of the CRPD on the right to live in the community, some people with disabilities are forced to live in institutions, often for their entire lives, without their consent, and they are unable to challenge the underlying decision. These institutions are often healthcare establishments such as psychiatric hospitals, or social care institutions where people are forced to take psychiatric medication,<sup>638</sup> while being deprived of basic human needs, such as food, heating, water and sanitation (*Nencheva and others v Bulgaria* [2013] appl. no. 48609/06). It should be added that

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<sup>636</sup> 'The Committee encourages States parties to comprehensively apply the Health Principles of Housing prepared by WHO which view housing as the environmental factor most frequently associated with conditions for disease in epidemiological analyses; i.e. inadequate and deficient housing and living conditions are invariably associated with higher mortality and morbidity rates' (Committee on Economic, Social and Cultural Rights 1991, paragraph 8(d)).

<sup>637</sup> See, for example, Tually, Beer & McLoughlin 2011; CRESA, Public Policy & Research & Auckland Disability Resource Centre 2007.

<sup>638</sup> See many of the reports of the European Committee for the Prevention of Torture, Inhuman and Degrading Treatment and Punishment 2013.

this also raises legal and ethical dilemmas for the responsible healthcare providers: what to do when laws prescribe forms of forced treatment, ignoring the consent of the patient, while the conditions under which the patient will be treated amount to inhuman and degrading treatment.

Prior to the adoption of the CRPD, international law on psychiatric treatment was mainly extrapolated from other human rights treaties, such as a 1994 General Comment by the UN Committee on Economic, Social and Cultural Rights [CESCR] on disability (General Comment No. 5). As progressive as this General Comment was in many respects, it is, in retrospect, disappointing that it did not address forced psychiatric treatment. Six years later, the same Committee published a General Comment on the right to health (General Comment No. 14 2000). This document did not examine mental health in any depth, stating that mental health treatment without consent is allowed on an 'exceptional basis', without explaining why it is allowed at all, or explaining this exceptional bases (CESCR 2000, paragraph 34). Both of these general comments referred to a non-binding document adopted in 1991 by the UN General Assembly called the 'Principles for the Protection of Persons with Mental Illness and the Improvement of Mental Healthcare' [MI Principles]. The MI Principles set 'the right to be treated in the least restrictive environment, with the least restrictive or intrusive treatment appropriate to the patient's health needs and the need to protect the physical safety of others' (principle 9(1)). Also, '[n]o treatment shall be given to a patient without his or her informed consent' (MI Principles, principle 11). The MI Principles then clearly set out five exceptions to this principle, including a scenario where a doctor thinks that that it is 'urgently necessary in order to prevent immediate or imminent harm to the patient or to other persons' (principle 11(8)). This watering down of normative standards led Paul Hunt, the then UN Special Rapporteur on the Right to Health, to observe in his 2005 report on disability and the right to health that while informed consent is necessary to provide treatment and 'is consistent with fundamental tenets of international human rights law', the combined effect of the 'extensive exceptions and qualifications' 'tends to render the right of informed consent almost meaningless' (UN Economic and Social Council 2005, paragraph 88).

Paul Hunt's report marked a turn for the mainstream human rights movement, because it pointed out the discriminatory element of diluted standards for treatment concerning mental health. Reiterating that the right to health is subject to progressive realisation (CRPD, article 4(2)), the Special Rapporteur highlighted that 'the international right to health also imposes some obligations of immediate effect' (UN Economic and Social Council 2005, paragraph 34), which includes freedom from non-consensual medical treatment, or as the CRPD puts it, the obligation of States to ensure that medical professionals provide healthcare to people with disabilities on the basis of free and informed consent (CRPD, article 25(d)).

Though clear on informed consent, the CRPD is silent on forced treatment.<sup>639</sup> That is to say, the Convention neither explicitly permits force when someone lacks the capacity to consent to treatment (as most mental health laws around the world currently around permit force), nor does it ban forced psychiatric treatment (Dhanda 2008). The Convention does not define 'informed consent' nor does it offer guidance as to the actions medical professionals should take when, for whatever reason, it is not possible to seek patient consent.

Despite this, others have stepped up to the challenge of filling the void with human rights content. In 2008, Manfred Nowak, the (then) UN Special Rapporteur on Torture, issued a report on torture and disability in which he notes that people with disabilities are subject to treatment without their consent (UN General Assembly 2008). He highlights in particular the effects of 'electroshock treatment and mind-altering drugs including neuroleptics' (UN General Assembly 2008, paragraph 40). Noting that these treatments are often justified against people with disabilities when they would be unacceptable if performed on others, Nowak calls for a review of the anti-torture framework in relation to disability (UN General Assembly 2008, paragraph 40). In 2013, Nowak's successor as special rapporteur, Juan Méndez, presented his report to the UN Human Rights Council on torture in healthcare (UN General Assembly 2013). He goes further than Nowak in observing how ill-treatment is justified by rhetorical devices such as 'best

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<sup>639</sup> See the 'Special Issue: Torture Prevention and Disability' in the *International Journal of Human Rights* (2012).

interests' which are masked as 'good intentions' of medical professionals (UN General Assembly 2013). Méndez's argues:

*[States should] impose an absolute ban on all forced and non-consensual medical interventions against persons with disabilities, including the non-consensual administration of psychosurgery, electroshock and mind-altering drugs, for both long- and short- term application. The obligation to end forced psychiatric interventions based on grounds of disability is of immediate application and scarce financial resources cannot justify postponement of its implementation. (UN General Assembly 2013, paragraph 89(b))*

Méndez notes that States should boost community-based mental health which meets the needs of people with disabilities and which respects 'autonomy, choices, dignity and privacy.' He advises States to revise laws 'that allow detention on mental health grounds or in mental health facilities and any coercive interventions or treatments in the mental health setting without the free and informed consent by the person concerned' (UN General Assembly 2013, paragraph 89(d)). Moreover, he cites Anand Grover's 2009 report, the 'Right of everyone to the enjoyment of the highest attainable standard of physical and mental health', which discusses various international and domestic laws that enshrine informed consent as a fundamental principle, before observing that it is, 'frequently compromised in the health-care setting' (UN General Assembly 2013, paragraph 29).

The CRPD Committee shares this view in its 'Draft General Comment on Article 12' (2013b). The Committee reiterates the wording of article 25 on the right to health, and points out that:

*[States are obliged] to require all health and medical professionals (including psychiatric professionals) to obtain free and informed consent from persons with disabilities. In conjunction with the right to legal capacity on an equal basis with others, this also obligates States to refrain from permitting substitute decision-makers to provide consent on behalf of persons with disabilities. (2013b, paragraph 37)*

It makes a further point about patient-doctor communications by suggesting that ‘health and medical personnel should ensure the use of appropriate consultation skills that directly engage the person with disabilities and ensure, to the best of their abilities, that assistants or support persons do not substitute or have undue influence over the decisions of persons with disabilities’ (CRPD Committee 2013b, paragraph 37).

Thus the CRPD outlines some specific operational standards for governments which should be translated into law, and standards for medical professionals as well as others assisting people with disabilities.

## **B. A Framework for Policy Discussion**

The CRPD offers no guidance as to the actions medical professionals must take beyond a non-discrimination approach. It does, however, make a process point about how these issues are to be discussed and decided upon. Article 4(3) of the CRPD imposes on States a general obligation when laws and policies are developed and implemented. In other decision-making processes relating to persons with disabilities, governments need to ‘closely consult with and actively involve persons with disabilities, including children with disabilities through their representative organizations’ (Mental Disability Advocacy Center 2011, p. 19).

## **7. Conclusions**

Medical ethics is traditionally centered on the principles of autonomy, beneficence, non-maleficence and justice. Doctors and other medical professionals ultimately decide how these principles are to be applied in individual cases. These foundational principles are also at the heart of medical law, even though other branches of law also influence medical law, including human rights law. This has, or at least should have, an impact on the way these principles are to be applied in cases of persons with disabilities, how they regulate the behavior of healthcare providers and how they bestow rights on healthcare recipients.

These observations do not deny the fact that many medical professionals care very deeply for their patients, have a profoundly humane approach, and deliver excellent quality care and treatment for people with disabilities. At the same time, it is uncontroversial to state that the human rights of people with disabilities have frequently been disregarded or devalued within the healthcare system. This can be explained by a lack of understanding and cooperation between the human rights and healthcare domains; by discriminatory laws which result in poor practices; and by a lack of inclusion of people with disability in public health and other development programmes.

The fact that people with disabilities have been treated differently for many decades by healthcare laws and medical professionals does not necessarily constitute a form of disability discrimination. Differential treatment can be a good thing, and the CRPD encourages this by obliging States and medical professionals to adjust their practices when they are seen as ‘reasonable accommodations’ benefitting people with disabilities. However, differential treatment can result in negative consequences, constituting unlawful, direct or indirect discrimination. The advent of the CRPD in 2006 provides an opportunity for people occupying various domains in society, notably in the field of healthcare, to critically assess their engagement with people with disabilities. This is exactly what the current and previous UN Special Rapporteurs on Torture have tried to do by reassessing the international torture framework. They together pointed out how what the international human rights mainstream almost unanimously viewed as acting in someone’s best interests, can be challenged as an invasion of autonomy, trivializing the notion of informed consent, and perpetuating inhumane and degrading treatment that sometimes constitutes torture.

A shift in the conceptualization of healthcare for people with disabilities through a human rights lens should be a clarion call to medical professionals, and those who teach and train medical law and ethics, to alter care practices in the name of justice, beneficence and non-maleficence. Such a shift also requires the political will to address some very challenging dilemmas about how to move from a model of proxy consent to one which truly respects the will and preferences of the person with disabilities when accessing healthcare;

how to ensure that support in decision making is not usurped by substitution; how to prevent supporters exercising undue influence; and how to ensure a person with disabilities does not lose out on their right to health because of the (in)actions of their support network.

Medical professionals must abide by their national laws. They are in a difficult position when their national law does not comply with international human rights standards. If this is the case, medical professionals can capitalize on the power and authority of their professional organizations and liaise with patients' rights organizations about how to instigate legal reform that better meets the healthcare needs of people with disabilities – their patients.

It is also incumbent on medical professionals to become acquainted with the current international human rights standards in more depth than is possible to include in this chapter. Training should feature in medical school curricula and continue post-qualification (Iezzoni & Long-Bellil 2012, p. 137). This coincides with recommendations made by the CRPD Committee that training and legislative reforms should be done 'in consultation and cooperation with persons with disabilities and their representative organizations, at the national, regional and local levels for all actors.'<sup>640</sup>

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<sup>640</sup> See the CRPD Committee's concluding observations with respect to Hungary (2012b, paragraph 26). The same recommendations were made by the CRPD Committee for Spain (2011a, paragraph 34); Austria (2013c, paragraph 28); and Tunisia, where the Committee also stated that training should be provided to 'relevant public officials and other stakeholders' (2011b, paragraph 23).

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