



# Disability rights in Higher Education Programs: The case of medical schools and other health-related disciplines



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## ABSTRACT

Recognising and respecting the human rights of persons with disabilities constitutes an integral element of a democratic society. This caveat has been long articulated in health professionals' rhetoric on the importance of embedding a human rights discourse in the protection and promotion of individual and global health. Having signed and ratified the International Convention on the Rights of Persons with Disabilities (UNCRPD), state parties are expected to educate doctors and other health professionals to understand the human rights dimension of disability. This article is concerned with exploring the extent to which the programmes and curriculum outlines in medical schools and other health-related academic disciplines are informed by concerns about promoting disability rights education. Further, it discusses some future directions for monitoring the implementation of a disability rights discourse and suggests some ways in which a rights-based approach to disability can be incorporated in higher education programmes and curricula for health-related disciplines.

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## 1. Introduction

A large percentage of people, currently estimated around 1 billion people or 15% of the global population (WHO, 2011), have been identified with a number of congenital or acquired disabilities. Thus, placing a pronounced emphasis on the promotion of disability rights across all academic disciplines is an ethical, as well as a legal imperative. This is especially true in disciplinary fields of study in which graduates are expected to be in direct contact with people with disabilities; this is a prospect for the vast majority of, if not all, professionals who are in daily contact with an increasing number of individuals with disabilities (United Nations, 2008).

Disability should no longer be seen through a 'deficit-oriented' lens and as conferring a subordinated ontological status but should be re-conceptualised as an endemic and valuable aspect of the human experience and diversification (Corker and Shakespeare, 2002). Disability has been re-conceptualised as a multifaceted form of social oppression on par with racism, sexism and other

sources of social disadvantage that call for socio-politically informed interventions (Oliver, 1990; Barnes et al., 1999).

This ideological paradigm shift is necessary, not only because of the legal recognition of disabled individuals' human rights and entitlements, but also because of the omnipresent nature of the disability experience, which can potentially become a 'lived' reality for everyone (Goodley, 2011; WHO, 2011). Notably, it is anticipated that in the future, there will be a greater percentage of people with disabilities due to the prolonged life expectancy of the general population, as well as of people with chronic conditions. This is especially true if we bear in mind that 97% of impairments are acquired (Symons et al., 2009).

A very important international legislative development is the United Nation's Convention on the Rights of People with Disabilities (UNCRPD), which defines disability as an 'evolving concept' (United Nations (UN) 2008:1) that is largely contingent on social conditions and exigencies, thereby subscribing to a social relational, or what has been termed a 'bio-psychosocial approach', toward disability (Norwich, 2010; Thomas, 1999, 2004). Given the social dimension of the disability experience and the contextually mediated conditions through which disability is conceptualised and 'lived', the Convention highlights the necessity of promoting a disability rights discourse in the education of doctors and other health professionals.

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The UNCRPD is considered the first international treaty to embrace a human rights model of disability that goes a step further from the social model of disability. This is because it recognizes disabled people as rights-bearing subjects without pre-empting the absence of impairment. Acknowledgement of the latter as a potential ontological denominator, presupposes that individuals with disabilities need more than the civic and political rights envisaged by the social model of disability. As rights-bearing subjects they also require social, economic and cultural rights in order to experience dignified living on par with their non-disabled peers (Degener, 2016). This perspective recognizes ‘impairment’ as an integral aspect of human experience across a continuum of ontological variations and experiential embodiments of ‘impairment effects’ such as pain, fatigue, compromised quality of life and early death (Degener, 2016).

In light of the UNCRPD and its human rights and social justice orientations the state parties should:

Require health professionals to provide care of the same quality to persons with disabilities as to others, including on the basis of free and informed consent by, inter alia, raising awareness of the human rights, dignity, autonomy and needs of persons with disabilities through training and the promulgation of ethical standards for public and private health care (UNCRPD:Article 25d).

Along similar lines, the ‘European Disability Strategy 2010–2020: A Renewed Commitment to a Barrier-Free Europe’ is explicit on the necessity to ‘promote awareness of disabilities in medical schools and in curricula for healthcare professionals’ (p.9).

Cotter et al. (2009) pointed to another highly relevant dimension of the human rights discourse by focusing on the ways in which the neglect or violation of human rights may adversely affect health and subsequently cause disabilities. For instance, even though people with disabilities, in particular, learning difficulties in the UK, have been under the auspices of the NHS (National Health Service) for over 60 years, they are, paradoxically, by far more likely to have health problems in comparison with other segments of the population. For instance, research evidence from the Medical Expenditure Panel Survey documented that disabled people were more likely, in comparison with their non-disabled peers, to hold the view that their doctors ‘had not listened to them, treated them with respect, taken enough time, involved them in treatment decisions or explained treatments properly’ (Shakespeare and Kleine, 2013:21). These phenomena can be largely attributed to the inaccessibility of health services due to ignorance, prejudice and negative attitudes related to longstanding misconceptions held by health professionals, who might perceive disability as a form of ‘illness’ and individual pathology (Cotter et al., 2009; Goble, 2008; Minihan et al., 2011; Shakespeare and Kleine, 2013; Symons et al., 2009; WHO, 2011).

Historically, health care professionals have been positioned in negative terms because they have routinely treated people with disabilities in paternalistic and oppressive ways (Goble, 2008; Sullivan, 2005). The ‘discourse of professionalism’ (Fulcher, 1999) manifested in health, educational, social work and other domains, has played a dominant role in contributing to institutional forms of oppression experienced by people with disabilities owing to longstanding ‘institutionalization or other involuntary treatment, abuse, neglect and persistent devaluation’ (WHO, 2011:77).

Sadly, notwithstanding ostensible progress in introducing legal mandates to safeguard disability rights, a number of recent scandals in the UK have brought to the surface the ways in which people with disabilities have been abysmally neglected and abused while being under the care of the NHS and social care (Parliamentary and

Health Service Ombudsman and Parliamentary and Health Service Ombudsman, 2016). Similarly, the Pancyprrian Alliance for Disability (2016:77) – a disability advocacy consortium that consists of twenty organizations representing persons with disabilities and their families in Cyprus-categorically document that the health system has failed to ‘take into consideration the disability dimension under the CRPD or that otherwise secures respect of the dignity and difference of persons with disabilities’. As a result, a plethora of structural and ideological barriers to accessing quality healthcare have been reported with a notable example ‘the rejection that persons with disabilities are confronted with by other patients, the personnel of the public clinics and partly of the medical staff and their focus on the “deficiencies” of severely disabled persons’ (Pancyprrian Alliance for Disability, 2016:80).

Parallel to the ascendancy of international legal mandates that advance a human rights approach to disability, a human rights and medical ethics discourse has been at the epicentre of the rhetoric of the World Medical Association. As early as 1999, it declared that medical ethics and human rights are an ‘integral part of the work and culture of the medical profession’, and therefore, the ‘teaching of Medical Ethics and Human Rights [should] be included as an obligatory course in their curricula’ (cited in Cotter et al., 2009:2). A number of other medical bodies, such as the Surgeon General, the Institute of Medicine and the Association of American Medical Colleges, have also alluded to the necessity of educating physicians in more effective and comprehensive ways so as to better address the needs of persons with disabilities (Shapiro, 2011).

Even though it is not the primary focus of this article to discuss the ways in which Disability Rights can inform Higher Education Programs, an important dimension of this endeavor should focus on enabling healthcare professionals to reflect upon their own role in creating and perpetuating disabling barriers. Considerable research evidence suggests that accessibility to health care services is still significantly undermined by negative attitudes towards disability (Minihan et al., 2011; Shakespeare and Kleine, 2013; Symons et al., 2009; WHO, 2011), as well as a deficit-oriented perspective that positions people with disabilities as ‘abnormal’ and ‘deficient’ (e.g Cotter et al., 2009). This perspective is linked to the individual model of disability that is associated with the medicalization and pathologization of disability experience and considers disability ‘to be logically separate from and inferior to “normalcy”’ (Corker and Shakespeare, 2002: 2).

The discussion in the previous paragraph provides evidence that higher education programmes and curricula should primarily concentrate on changing negative and discriminatory attitudes by enabling health professionals to problematise their own assumptions and misconceptions about disability. This can be achieved by acquiring an informed understanding of the human rights model of disability and the ways in which this is enshrined in international legal mandates (Degener, 2016; WHO, 2011) and informs/should inform their professional roles (British Medical Association, 2007). The human rights model of disability valorizes impairment as an indispensable aspect of human experience that does not undermine human dignity or corrodes disabled people’s rights-bearing identities (Degener, 2016). The ‘abled-bodied order’ (Campbell, 2009) needs to be challenged by adopting a critical, reflective and reflexive understanding of the precarious ontological status of the ‘abled bodied’ ideal (Goodley, 2011).

This article is concerned with exploring the extent to which the programmes and curriculum outlines in medical schools and other health-related academic disciplines in Cyprus are informed by a disability rights discourse in view of the legal obligations of the country to implement the UNCRPD. The establishment of medical schools and health-related academic schools is a recent phenomenon in Cypriot universities. Therefore, it is important to identify

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